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| Complete List of Authors: | Liu, Zhijian; Second Military Medical University School of Nursing,<br>wenjing, sun; Shanghai Changzheng Hospital, neurology<br>Chen, Honglin; Fudan University<br>Zhuang, Jianhua; Shanghai Changzheng Hospital, Department of Neurology<br>Wu, Bei; New York University, Rory Meyers College of Nursing<br>Xu, Hanzhang; Duke University School of Nursing; Duke University School of Medicine,<br>Li, Peng; Shanghai Changzheng Hospital, Department of Neurology<br>Chen, Xiaohan; Shanghai Changzheng Hospital, Department of Neurology<br>Li, Juan; Second Military Medical University School of Nursing<br>Yin, You; Shanghai Changzheng Hospital, Department of Neurology |
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# A Study on the Family Caregivers' Burden of Dementia Patients in Chinese Community

Zhijian Liu[#a,b], Wenjing Sun[#b,c], Honglin Chen[#d], Jianhua Zhuang[b], Bei Wu[e]， Hanzhang Xu[f,g], Peng Li[b], Xiaohan Chen[b], Juan Li**[a], You Yin*[b]

a Navy Medical University School of Nursing, Shanghai, China

b Department of Neurology, Changzheng Hospital, Navy Medical University, Shanghai, 200003, China

c Department of Neurology, Third Affiliated Hospital of the Naval Medical University, Shanghai, 200003, China

d Department of Social Work School of Social Development and Public Policy, Fudan University, Shanghai, China

e New York University Rory Meyers College of Nursing, New York, NY, United States,

f Duke University School of Nursing, Durham, NC, United States

g Duke University School of Medicine, Durham, NC, United States

# Wenjing Sun[#b,c], Honglin Chen equal to Zhijian Liu.

*Corresponding author: You Yin, yinyou179@163.com;

**Corresponding author: Juan Li, lijuanjr@126.com

**Key Words:** Dementia, Caregiver burden, Family caregivers, Community

## ABSTRACT

**Objective** To explore the level and related factors of caregiver burden of people with dementia (PWD) in Shanghai. **Methods** A cross-sectional survey was conducted. 109 PWDs with family caregivers were recruited. We collected socio-demographic information, tested caregivers' caregiver burden inventory (CBI), positive aspects of caregiving (PAC), community service needs, social support, cope strategy of, and PWDs' cognitive function, sleep quality, Activities of daily living, and neuropsychiatric symptoms. Multiple linear regression and moderate effect was tested. **Result** The average score of CBI was 65.92±16.74. The results showed that the MoCA, PAC, and social support were negatively associated ( $\beta=-0.84$, $p<0.001$, $\beta=-3.61$, $p=0.03$, $\beta=-1.22$, $p=0.001$, respectively) while the community service needs were positively associated ( $\beta=3.46$, $p<0.001$) with caregivers burden. Besides, social support moderated the relationship between the caregiver burden and caregiver's depression. **Conclusion** Caregiver burden was associated with various factors. Strengthening social support, providing efficient community service, relieving depression may reduce caregiver burden.

### Strengths and limitations of this study

The study explored the level and related factors of caregiver burden of people with dementia (PWD) in Shanghai which is the most aging city in China.

The conclusion of our study may provide strategy of reducing the caregiver burden of PWDs' caregivers.

Participants were recruited from Hongkou district in Shanghai. Hongkou district is one of the central urban areas in Shanghai and Shanghai has advanced healthcare system. Due to the disparities of economic and social developmental levels in China, the participants in this study may not be representative of PWDs and caregivers in China.

The sample size was relatively small. Large sample multi-center studies are needed to confirm the result.

The study was a cross-sectional study and cause-and-effect relationships cannot be established. Besides, this cross-sectional study is not able to explore the trajectory of caregiver burden across different disease stages. Longitudinal studies are needed in future.

## INTRODUCTION

With the rapid development of society, population aging is becoming a prominent problem. With the increasing age, numerous underlying physiological changes occur, and the risk of the chronic disease rises[1]. Dementia is one of the striking diseases followed by the aging of the population. The age standardized prevalence of dementia for old adults aged≥60 varies from 5% to 7% in the most regions around the world[Error! Reference source not found.]. According to the report of global population in 2017, there are nearly 25% old adults aged over 60 in China. The number of old adults aged over 60 is expected to increase to 478.8 million (35.1%) in 2050 according to the Department of Economic and Social Affairs of the United Nations[3]. The age standardized prevalence of dementia in China is 6%. There are almost 7.4 million PWDs in China. The number will grow to 18 million by 2030 if no effective preventions are implemented[Error! Reference source not found.].

Dementia is characterized by the deterioration of intellectual functions, dysfunction with executive function, sleeping disorders, emotional problem, and behavioral and psychological symptoms[5]. Due to the negative impact on persons' abilities of daily life (ADL) and quality of life by these symptoms, the PWDs relies on their caregivers' support for daily activities. Caregivers will have to confront increasing dementia-related symptoms over time, which will cause increasing burden. The caregiver burden is defined as the extent to which caregivers perceived their emotional or physical health, social life, and financial status as a result of caring for their relatives[6]. Due to negative consequences of dementia, the caregiver burden had been found to be high among population without dementia[Error! Reference source not found.]. To reduce caregiver burden of PWDs, it is essential to identify factors affecting caregiver burden. Previous study from Ireland, Turkey, Korea, Japan and France had reported significant caregiver burden of informal caregivers of PWD and the caregiver burden was associated with age of PWD, level of cognitive function, neuropsychiatric symptoms, frontal lobe dysfunction, antidepressant drugs and ADLs[Error! Reference source not found.].

Previous studies also have been explored in northern cities in China[9]. However, the level and related factors of caregiver burden of PWD in communities of China was not consistent. This study aimed to explore the level and related factors of caregiver burden of PWD who were resident in communities in Shanghai.

Depression of caregivers was significantly associated with higher level of caregiver burden among caregivers of PWD s[10]. Social support refers individual or collective resources that can provide emotional and mental assistance according to Ross et al's study[11] Cohen and Thoits proposed and verified the buffing hypothesis in their study and confirmed that social support was a buffer against life stress and protect physical and mental health[12,13]. Greater social support can help people to cope with change in life better [14]. Ruisoto reported that social support and resilience were protective factors against caregiver burden among caregivers of PWDs[15]. Therefore, we tested the moderating effect of social support on caregiver burden and depression of caregivers.

In China, most old persons living with dementia live in communities and depend on their family members' caregiving. China pilot long-term care (LTC) insurance policy has been implemented in 15 cities in 2016. However, the supply and demand of LTC services are unmatched and unbalanced[16]. Formal care service is difficult to access at home and support to family caregivers of PWDs is limited in most area in China[17], which is not enough to reduce the caregiver burden. Furthermore, due to different socio-cultural background, a cultural sense of caregiving obligation may lead to different level of burden felt by caregivers[18]. Besides, the caregivers were experiencing sense of stigma in China[19]. Therefore, we conducted this study to explore the level and related factors of caregiver' burden of PWDs in Chinese communities, to provide healthcare professionals useful information of reducing caregiver burden.

## PARTICIPANTS AND METHODS

### Participants

This was a cross-sectional study conducted from March 2017 to March, 2018. A total of 8800 old adults aged over 60 were selected randomly from seven community healthcare centers in Hongkou District, Shanghai, China. The healthcare providers in community centers screened 8549 old adults' cognitive function used self-rating scale Alzheimer's disease-8 (AD8), which score$\geqslant$2 meant cognitive impairment . A total of 2272 old adults with AD8$\geqslant$2. Among these 2272 old adults, 500 old adults were selected randomly to receive Mini-Mental State Examination (MMSE). A total of 456 old adults with cognitive impairment(MMSE$<$26 ). Then these older adults and their primary family caregivers were invited to the Neurology Clinic of Changzheng Hospital affiliated to Navy Medical University for further comprehensive neuropsychological assessment by neurologists. The primary family caregivers were defined as an unpaid family member who took care of the persons most of the time with greatest responsibility for their care and know the condition and environment mostly[20]. A total of 116 old adults were diagnosed with dementia according to the National Institute of Aging-Alzheimer's Association (NIA-AA) criteria in the Neurology Clinic after the clinical examination and neuropsychological assessment. The exclusion criteria of PWDs included: (1) visual and auditory impairment (2) severe aphasia, (3) the acute stage of chronic disease, (4) unable to be seated for more than 40minutes, (5) the presence of other nervous system diseases. Seven dyads of PWDs and their primary family caregivers refused the study. There were 109 dyads of PWDs and their primary family caregivers were recruited in the study finally. The study was approved by the ethics committees of Changzheng Hospital, and all the participants signed the informed consent.

### Patients and Public Involvement

Patients and the public were not involved in this study, including the recruitment, data collection, analysis, interpretation and dissemination of the results.

### Variables

### Outcome Variable

The caregiver burden of the caregivers was measured by the Caregiver Burden Inventory (CBI). It was developed by Novak in 1989 to measure the caregivers burden of PWDs and was wildly used in disabled stroke patients, spinal cord injuries, chronic-acquired brain injury, and neurologic Wilson disease in previous studies[21].CBI including five domains including time-dependence burden (20 points), development burden(20 points), physical burden (16 points), social burden(16 points), and emotional burden(20 points). The total score of CBI was 96. The higher score means the heavier caregiver burden. Chou tested the reliability and validity of the Chinese version of CBI, which showed adequate internal consistency reliability, appropriate content validity and concurrent validity[22]. The score of CBI＞36 indicated that the caregivers' "risk of burning out" [23].

### Independent Variables

*Caregivers' Variables*

The socio-demographic characteristics included age, gender, education, employment, and relationship with dementia patients.

The caregivers' depression was measured by the Self-rating Depression Scale (SDS) which was developed by Zung in 1965 to measure the level of depression of adults[24]. We used a simplified Chinese vision which including 12 items, the vision has been used in the previous study[25].

The community service utilization was measured by the Community Service Utilization Measurement. The measurement included 10 items: nursing assistant, housekeeper, doctor, psychologist, day care center, food delivered, ambulance, hospitalization, nursing home and other services. Each item had two options: used or not, the 10 items were developed according to the existing services in communities of Shanghai. The measurement has been used in the previous study[25].

The social support perceived by the caregivers was measured by three questions: (1) How many people can be relied on when the situation is urgent; (2) How do people care about the recent situations; (3) How easy help from neighbor or colleagues can be reached when needed. Sum score range from 3 to 14, with higher scores indicating a stronger social support. The measurement has been used in the previous study[25].

The positive aspects of caregivers were measured by Positive Aspects of Caregiving (PAC). The scale was developed by the Tarlow to evaluate the positive aspects of the caregiving in 2004 and was translated and tested by Zhang, the Cronbach's α coefficient of PAC and two domains were 0.89, 0.86, 0.80, respectively [26]. The scale is a self-rating scale which included nine items with two domains: self-affirmation and outlook on life. The items used a 5-point Likert-type scale. The higher score indicated more positive aspects of caregiving. The content validity and structure validity of the scale were acceptable [26].

*Participants variables*

The socio-demographic characteristics included age, gender and education. The disease characteristics included types of dementia (Alzheimer's disease (AD), vascular dementia, frontotemporal dementia, mixed dementia, and dementia with Lewy bodies), cognitive function, subjective sleep quality, the behavioral and psychological symptoms, and activities of daily living.

The cognitive function of the dementia patients was assessed by MoCA. MoCA was developed by Nasreddine in Canada in 2004. It included 8 domains of cognitive function: attention, executive function, memory, language, visual spatial, abstract thinking, calculation, and orientation. MoCA score ranged from 0 to 30, with lower score indicating poorer cognition. MoCA has been widely used in the assessment of cognitive function among patients with stroke, Parkinson's disease and other diseases. It had stable sensitivity and specificity. MoCA has been translated into 30 different versions. Wang translated the MoCA-Beijing version and the assessment can is available from *www.mocatest.org*. Chen tested the reliability and validity of the MoCA-BJ in people with obstructive sleep apnea hypopnea syndrome, the Cronbach's α of the MoCA-BJ was 0.73[27].

The sleep quality of the dementia patients was assessed by the Pittsburgh Sleep Quality Index (PSQI), the index was answered by the PWDs and their caregivers. PSQI was developed by Buysse in 1989 and was translated by Liu [28]. The sensitivity and specificity of Chinese version of PSQI were 98.3% and 90.3%[28].The PSQI is a self-report questionnaire that access seven dimensions of sleep over a one-month time period. The seven dimensions included subject sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medicine and daytime dysfunction. PSQI score ranged from 0 to 21 with higher scores representing poorer subjective sleep quality[28].

The abilities of daily life was assessed by the Activities of daily living Scale (ADL), the scale was answered by the caregivers of PWDs. The scale was modified by Mingyuan Zhang[29]. It included 20 items with stable reliability and validity[29]. Each item score ranged from 1 (completely independent ) to 4 (completely dependent ). The total score ranged from 20 to 80, with lower score indicating higher level of ADL.

The behavioral and psychological symptoms of dementia patients was assessed by the Neuropsychiatric Inventory (NPI), the inventory was answered by the caregivers of the PWDs. The inventory was used to evaluate the severity and frequency of 10 common abnormal behaviors in dementia patients[29]. Tao translated the inventory and tested the reliability and validity of the Chinese version among patients with Alzheimer's disease. The Chinese version of NPI was a reliable and valid tool for measuring neuropsychiatric disturbances in patients with AD[29].

## DATA ANALYSIS

Descriptive statistics were used to summarize socio-demographic status and clinical characteristics. Characteristics of participants were reported as mean and standard deviation (SD) for continuous variables and as numbers and proportion for categorical variables. The univariate linear regression was run to test the association between demographic, PWDs' disease-related, and caregivers' caregiving-related variables and caregiver burden. Then only the statistically significant variables were entered into the multivariate linear regression. Categorical variables were transferred to dummy variables. The coding of the variables was shown in Table 1. The Statistical package for social science (SPSS) 26.0 was used to analysis the data. The statistically significant value was set as $p < 0.05$.

Multiple regression analysis was performed to examine the moderating effect of social support on the relationship between caregiver burden and caregivers' depression. Caregiver burden was regressed on social support and caregiver's depression.

## RESULT

In total, 109 dyads of PWDS and their caregivers were recruited in the study. Of these PWDs, 37(33.3%) were diagnosed with AD, 15(13.5%) with frontotemporal dementia, 22(19.8%) with mixed dementia, 12(10.8%) with Lewy bodies-associated dementia, and 23(20.7%) with vascular dementia. The average age of the PWDs was 76.02±8.78. The percentage of female was 57.8%. Among 109 PWDs, 83 (76.1%) with high school education or above, 12(11.0%) middle school, 7(6.4%) primary school, and 7(6.4%) illiteracy. The average MoCA was 12.50±5.84. The average

PSQI was 5.57±5.00. Eighty (72.1%) patients had poor sleep quality. Socio-demographic and disease characteristics of the dementia patients are shown in Table 2.

The mean age of the caregivers was 65.18±12.03. The percentage of female were 57.8%. Among the 109 caregivers, 66 (50.6%) were spouses and 42 (36.7%) were children. 86 (77.0%) caregivers had taken care of the PWDs for one to four years. 53 (47.7%) caregivers spent 21 to 40 hours per week on caregiving. The mean score of CBI was 65.92±16.74, which indicated a high level of caregiver burden. The average score of five domains of CBI were shown in Figure 1. The socio-demographic characteristics of the caregivers and caregiver burden was shown in Table 3.

Table 4 presents the results from univariate and multivariate linear regression. Age of PWDs, MoCA, PAC, community service needs, and social support were significantly associated with caregiver burden. MoCA, PAC and social support of caregivers were negatively associated with caregiver burden ($\beta$=-0.84, $p<0.001$, $\beta$=-3.61, p=0.03, $\beta$=-1.22, p=0.001,respectively), which indicated better PWDs' cognitive function, more PAC and higher level of social support were related to less caregiver burden. The community service needs were positively associated with caregivers burden ($\beta$=3.46, $p<0.001$), which indicated more community service needs were related to more caregiver burden.

The moderation effect of social support on the relationship between caregiver burden and caregivers' depression was tested. Social support independently contributed to caregivers' depression. Specifically, higher level of caregiver burden displayed high level of depression ($b = 0.1235$, $p<0.001$). Moreover, the two-way interaction between social support and caregiver burden significantly contributed to caregivers' depression (unstandardized $B = -0.027$, $p = 0.011$), as reflected in Figure 2.

## DISCUSSION

This was a cross-sectional study to explore the level and related factors of caregiver burden of PWDs in communities of Shanghai. The level of caregiver burden was relatively high. After multivariate analyses, PWDs' cognitive function (MoCA), PAC, social support and community service needs were significantly associated with caregiver burden. The social support had a moderate effect on the relationship between caregiver burden and caregivers' depression.

The level of caregiver burden (65.92±16.74) was relatively higher than those reported in previous studies[23,30]. *TORRISI et al* and *Iavarone et al* reported that the average CBI scores of dementia patients' caregivers and Alzheimer's Disease patients' caregivers by convenient sampling in Italy were 31.9±19.5 and 37.05±20.37, respectively[23,30].

Firstly, present study has shown that worse cognitive function of PWDs and older age of PWDs was related to more caregiver burden, which was consistent with previous study[20,30]. Dementia always accompanies with neuropsychiatric behaviors and decreased ADL[31]. With progressing of disease, dementia patients' dependence on the caregivers keeping getting serious. The participants were with moderate to severe cognitive function impairment in our study and the age of the caregivers(65.18 ± 12.03) in our study is older than previous studies(57.5±12.3) [30].

Secondly, The differences of caregiver burden from similar samples between previous studies and present study may be due to different social environments, cultures, healthcare policies, ethnicity and age of caregivers[33, 16, **Error! Reference source not found.**]. Caregiver burden was defined as "a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience" [32]. Caregiver burden derived from the perceived stressors which was influenced by many psychosocial factors like social environment and culture[33]. A cultural sense of caregiving obligation may overlap the distress and burden felt by the caregivers[18]. Among Chinese cultures, a greater sense of responsibility to care for elderly family members and a reluctance to discuss family problems leads to less social and emotional support for caregivers[34].

Thirdly, although Long-term care insurance policy has been introduced since 2016 in 15 cities of China, many PWDs were not included in the LTC insurance policy in the pilot phase in China[17]. The participants in our study who were from Hongkou District were not covered during the interviewing period of Shanghai. Informal care from family members is primary source of care for dementia patients in China. However, as a result of the rapid socioeconomic shifts and changing demographic structure, reliance on the care provided by family has become untenable[16]. The formal care in most high-income countries were gradually evolved into home-and community- based care[16]. All the situation may cause more caregiver burden in our study compare to other countries.

Previous studies also reported that the PAC was associated with the higher level of caregiver burden[35]. The positive aspects of caregiving were generally interpreted as the satisfaction and reward stemming from the caregiving relationship[36]. PAC was associated with higher level of well-being and better health condition of caregiver[36]. Furthermore, PAC can help caregivers coping with challenges associated with role of caregivers[36]. Therefore, higher level of PAC was associated with lower level of caregiver burden.

Present study has shown that more community service needs were associated with higher level of caregiver burden. Previous study has reported that dementia cause social stigma to dementia caregivers in China and stigma were associated with caregiver burden significantly[19,37]. Utilization of community service may make caregivers experience more stigmatic feelings from their neighbors, friends or colleagues and further increase the level of caregiver burden. Furthermore, previous study reported that informal dementia patients' caregivers seldom used respite services[37]. The gap between needs of supportive community service among dementia patients' caregivers and provision of community service in real environment is supposed to be explored in the future study.

This study found that caregiver burden with low level social support had stronger effect on depression of caregivers compared to those with high level social support. Caregiver burden and depression were complex clinical and social problems[38]. Depression of caregivers was associated with stress from providing care, social isolation, limited money, and decreased leisure time[39]. Previous study reported that higher level of social support was associated with lower level of caregiver burden[40]. In our study, caregivers of dementia patients perceived social support from family members, relatives, neighbors, and colleagues. Previous study reported that emotional support in the form of reassurance from supporters was important in reducing depressive symptoms[41]. Secondly, social support positively influenced resilience, especially caregivers with high family support had the highest probability of elevated resilience[42]. Besides, our study tested the support of actual caregiving, effective sharing on caregiving can reduce the caregiver burden of caregivers in some way[41]. Therefore, strengthening social support for caregivers can buffer the negative effects of depression on the caregiver burden and reduce the depression of caregivers.

The present results showed that the caregiver burden of PWDs was relatively high and it was related to both patients' and caregivers' factors. Some of the factors were unmodifiable such as dementia patients' cognitive function. However, depression symptom of caregivers, social support and community service were modifiable. The communities can provide more convenient and supportive services for caregivers of dementia patients to relieve caregiver burden. According to China pilot long-term care (LTC) insurance policy, the level of disability of old adults were assessed to decide whether the old adult accord with the criterion of long-term care insurance. However, the assessment in European countries and American were more in-depth and comprehensive, and more detailed regarding the specific diseases such as dementia [44,45]. The assessment is supposed to be further refined in the future. Chinese government is now continuously improving the policy of the LTC insurance and the covering area is extending to more cities. LTC insurance can provide more specific services that are urgently needed by PWDs and caregivers in home care to alleviate the depression of caregivers and reduce caregiver burden. LTC insurance may also effectively reduce financial burden of PWDs in the future[43].

## CONCLUSION

This study highlighted the growing issues of dementia and the heavy burden from which family caregivers were suffering in Shanghai and explored the associated factors with caregiver burden. The result suggests that caregiver burden is at a relatively high level and it was associated with dementia patients' cognitive function (MoCA), caregivers' depressive symptoms, perceived social support and community service utilization. Providing more social support and community service and relieving depressive symptoms of caregivers may help to reduce the caregiver burden.

## ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Institutional Review Board (IRB) of Changzheng Hospital, Second Military Medical University. The patients/participants provided their written informed consent of participating. The IRB approval number was 2019SL026.

## CONFLICT OF INTEREST

Authors have no conflict of interest to declare.

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## CONTRIBUTORSHIP STATEMENT

Zhijian Liu designed concept, analyzed data, interpreted data and prepared manuscript.

Wenjing Sun designed concept, analyzed data, interpreted data and prepared manuscript.

Honglin Chen designed concept, analyzed data, interpreted data and prepared manuscript.

Jianhua Zhuang interpreted outcome and reviewed manuscript.

Bei Wu, interpreted outcome and reviewed manuscript.

Hanzhang Xu, interpreted outcome and reviewed manuscript.

Peng Li, collected the data.

Xiaohan Chen, collected the data.

You Yin, designed concept, interpreted outcome and reviewed manuscript.

Juan Li, designed concept, interpreted outcome and reviewed manuscript

All authors have read and approved the submission, and ensure that this is the case.

## DATA AVAILABILITY STATEMENT

Data are available upon reasonable request.

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Table1: The list of the associated variables

| Associated variables | Variables | | Coding |
|---|---|---|---|
| Socio-demographic characteristics | Age | Continuous variable | |
| | Gender | Categorical variable | Male=1,female=0 |
| | Education level | Categorical variable | Illiteracy=1<br>Primary school=2<br>Middle school=3<br>High school or above=4 |
| | Status of work | Categorical variable | |
| | Relationship | Categorical variable | Spouse=1<br>Children=2<br>Relatives=3 |
| Characteristics of disease | Type of dementia | Categorical variable | AD=1, FTD=2, MD=3, Lewy=4, VD=5 |
| | MoCA | Continuous variable | |
| | PISQ | Continuous variable | |
| | NPI | Continuous variable | |
| | ADL | Continuous variable | |
| Characteristics of caregivers | Caregiving years | Categorical variable | No caring=1<br><0.5years=2<br>0.5years-1year=3<br>1years-4years=4<br>5years-9years=5<br>More than 9years=6 |
| | Education | | |
| | Caring hours/week | Categorical variable | 0hour-8hours=1<br>9hours-20hours =2<br>21hours-40hours =3<br>More than 40hours=4 |
| | Depressive symptoms | Continuous variable | |
| | Coping Style Questionnaire | Continuous variable | |
| | PAC | Continuous variable | |
| | Social support | Continuous variable | |
| | Community Service Utilization | Continuous variable | Used=1<br>Not used=0 |

**AD=Alzheimer's Disease ;FTD=frontotemporal dementia ;MD= mixed dementia ;Lewy= Lewy body associated; VD=vascular dementia; PAC=positive aspects of caregivers.**

Table2: Social-demographic and disease characteristics of the dementia patients

| Characteristics | | Mean±SD | N(%) |
|---|---|---|---|
| Socio-demographic characteristics | Age(year) | 76.02±8.78 | |
| | Gender | | |
| | *Female* | | 63(57.8%) |
| | Education level | | |

| | | | |
|---|---|---|---|
| | *Below primary* school | | 14(12.8%) |
| | *Middle* school | | 12(11.0%) |
| | *High school or above* | | 83(76.1) |
| Disease characteristics | Type of dementia | | |
| | *Alzheimer's* | | 37(33.3%) |
| | *Frontotemporal* | | 15(13.5%) |
| | *Mixed* | | 22(19.8%) |
| | *Lewy bodies-associated* | | 12(10.8%) |
| | *Vascular dementia* | | 23(20.7%) |
| | MoCA total score | 12.50±5.84 | |
| | NPI total symptom scale | 21.50±14.94 | |
| | *Caregiver distress subscale* | 0.28±0.45 | |
| | *Delusion* | 1.5±2.77 | |
| | *Hallucination* | 1.3±2.99 | |
| | *Agitation* | 1.22±2.17 | |
| | *Depression* | 1.22±2.17 | |
| | *Anxiety* | 2.18±2.81 | |
| | *Euphoria* | 0.37±1.60 | |
| | *Apathy* | 4.17±3.76 | |
| | *Disinhibition* | 0.28±0.87 | |
| | *Irritability* | 2.51±3.52 | |
| | *Aberration* | 1.11±2.33 | |
| | *Sleep* | 1.11±2.33 | |
| | ADL total score | 42.94±14.17 | |
| | Poor Sleep quality | | 80(72.1%) |
| | Score of PSQI | 5.57±5.00 | |
| | *Subjective Sleep Quality* | 0.85±1.02 | |
| | *Sleep Latency* | 1.23±2.01 | |
| | *Sleep Duration* | 0.58±0.83 | |
| | *Habitual Sleep Efficiency* | 0.64±1.00 | |
| | *Sleep Disturbances* | 0.64±1.00 | |
| | *Use of Sleep Medications* | 1.34±1.49 | |
| | *Daytime Dysfunction* | 1.34±1.49 | |

**NPI= the Neuropsychiatric Inventory；PSQI= Pittsburgh Sleep Quality Index；ADL=activities of daily life**

Table3: Social-demographic characteristics and caregiver burden of caregivers

| Characteristics | Mean±SD | n(%) |
|---|---|---|
| Age(year) | 65.18±12.03 | |
| Gender | | |
| *Female* | | 64(58.7%) |
| Education level | | |
| *Below primary* school or | | 12(11.0%) |

| | | |
|---|---|---|
| *Middle* school | | 12(11.0%) |
| *High school or above* | | 85(78.0%) |
| Relationship with dementia patients | | |
| *Spouse* | | 66(59.5%) |
| *Children* | | 42(38.5%) |
| *Relatives* | | 3(2.7%) |
| Caregiving hours/week(h) | | |
| *20* | | 12(10.8%) |
| *21-40* | | 53(47.7%) |
| *40* | | 44(39.6%) |
| Caregiving year (years) | | |
| *≤1* | | 12(11%) |
| *1-5* | | 86(77.5%) |
| *5* | | 11(10.1%) |
| Score of SDS | 25.53±3.84 | |
| Positive Feeling of Caregivers | 29.49±3.86 | |
| Coping strategy | 92.90±5.78 | |
| Social Support | 8.61±1.32 | |
| Community Service Utilization | 2.46±1.74 | |
| Score of CBI | 65.92±16.74 | |
| *Time-Dependence Burden* | 16.03±5.59 | |
| *Development Burden* | 13.72±3.93 | |
| *Physical Burden* | 9.79±3.48 | |
| *Social Burden* | 7.09±3.07 | |
| *Emotional Burden* | 10.28±3.50 | |

**CBI=caregiver burden inventory；SDS= Self-rating Depression Scale**

Table4: Linear regression of CBI

| Variables | Univariate analyses | | | | | Multivariate analyses | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | b | p | SE | 95%CI | | b | p | SE | 95%CI | |
| | | | | Lower | Upper | | | | Lower | Upper |
| Age of patients | 0.48 | 0.008 | 0.18 | 0.126 | 0.835 | 0.11 | 0.19 | | | |
| Gender of patients | 0.41 | 0.90 | 3.26 | -6.06 | 6.87 | | | | | |
| Education level of patients | | | | | | | | | | |
| *Primary school* | -10.43 | 0.25 | 9.00 | -28.28 | 7.42 | | | | | |
| *Middle school* | -1.79 | 0.82 | 8.01 | -17.67 | 14.09 | | | | | |
| *Highschool or above* | -4.60 | 0.49 | 6.63 | -17.74 | 8.54 | | | | | |

|  |  |  |  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|---|---|---|
| Type of dementia |  |  |  |  |  |  |  |  |  |  |
| *FTD* | -3.65 | 0.48 | 5.11 | -13.78 | 6.49 |  |  |  |  |  |
| *MD* | 2.624 | 0.56 | 4.96 | -6.29 | 11.54 |  |  |  |  |  |
| *Lewy* | -1.65 | 0.77 | 5.55 | -12.65 | 9.35 |  |  |  |  |  |
| *VD* | 6.74 | 0.13 | 4.43 | -2.05 | 15.54 |  |  |  |  |  |
| Score of MoCA | -0.80 | 0.003 | 0.10 | -1.33 | -0.27 | -0.84 | ＜0.001 | 0.22 | -1.29 | -0.40 |
| Total score of NPI | 0.30 | 0.005 | 0.06 | 0.09 | 0.50 | 0.16 | 0.05 |  |  |  |
| Score of ADL | 0.41 | ＜0.001 | 0.11 | 0.20 | 0.63 | 0.14 | 0.13 |  |  |  |
| Score of PSQI | 0.33 | 0.60 | 0.001 | -0.304 | 0.973 |  |  |  |  |  |
| Caregivers' age | 0.14 | 0.30 | 0.32 | -0.13 | 0.40 |  |  |  |  |  |
| Education level of caregivers |  |  |  |  |  |  |  |  |  |  |
| *Primary school* | 14.75 | 0.15 | 10.28 | -5.66 | 35.13 |  |  |  |  |  |
| *Middle school* | 5.75 | 0.55 | 9.69 | -13.46 | 24.96 |  |  |  |  |  |
| *High school or above* | 7.31 | 0.40 | 8.59 | -9.71 | 24.34 |  |  |  |  |  |
| Relationship |  |  |  |  |  |  |  |  |  |  |
| *Children* | 3.71 | 0.27 | 3.31 | -2.85 | 10.26 |  |  |  |  |  |
| *Relatives* | -17.71 | 0.07 | 9.74 | -37.02 | 1059 |  |  |  |  |  |
| Caregiving time for each week |  |  |  |  |  |  |  |  |  |  |
| *9-20* | -5.00 | 0.65 | 10.94 | -26.67 | 16.70 |  |  |  |  |  |
| *21-40* | -0.93 | 0.93 | 9.74 | -20.24 | 18.39 |  |  |  |  |  |
| *40* | 6.89 | 0.48 | 9.80 | -12.54 | 26.31 |  |  |  |  |  |
| caregiving years |  |  |  |  |  |  |  |  |  |  |
| *0.5* | -17.00 | 0.36 | 18.28 | -53.45 | 19.45 |  |  |  |  |  |
| *0.5-1* | -15.78 | 0.32 | 15.82 | -47.15 | 15.59 |  |  |  |  |  |
| *1-4* | -12.44 | 0.41 | 15.09 | -42.37 | 17.49 |  |  |  |  |  |
| *5-9* | 11.86 | 0.46 | 16.04 | -19.95 | 43.67 |  |  |  |  |  |
| *9* | 16.00 | 0.34 | 16.78 | -17.27 | 49.27 |  |  |  |  |  |
| PAC | -1.33 | 0.001 | 0.40 | -2.12 | -0.54 | -1.22 | 0.001 | 0.34 | -1.90 | -0.55 |
| Coping strategy | -0.25 | 0.38 | 0.28 | -0.80 | 0.31 |  |  |  |  |  |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| Social Support | -3.32 | 0.006 | 1.18 | -5.667 | -0.972 | -3.61 | ＜0.001 | 0.99 | -5.58 | -1.64 |
| Community Service Utilization | 3.54 | ＜0.001 | 0.87 | 1.82 | 5.26 | 3.46 | ＜0.001 | 0.76 | 1.96 | 4.96 |

**AD=Alzheimer's Disease ;FTD=frontotemporal dementia ;MD= mixed dementia ;Lewy= Lewy body associated; VD=vascular dementia; PAC=positive aspects of caregivers；NPI= the Neuropsychiatric Inventory；PSQI= Pittsburgh Sleep Quality Index；ADL=activities of daily life.**

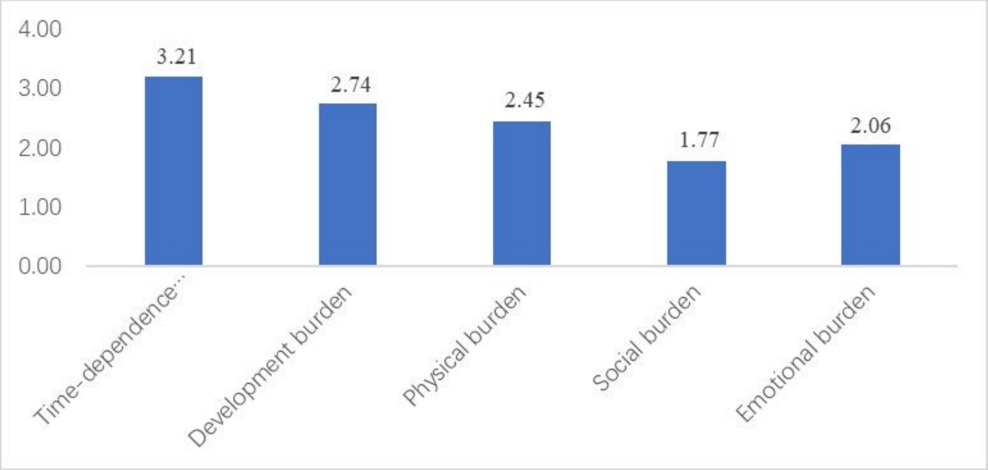

**Figure 1: The average score of five domains of Caregiver burden index**

**Figure 2 The association between caregivers' depression and caregivers' depression.**

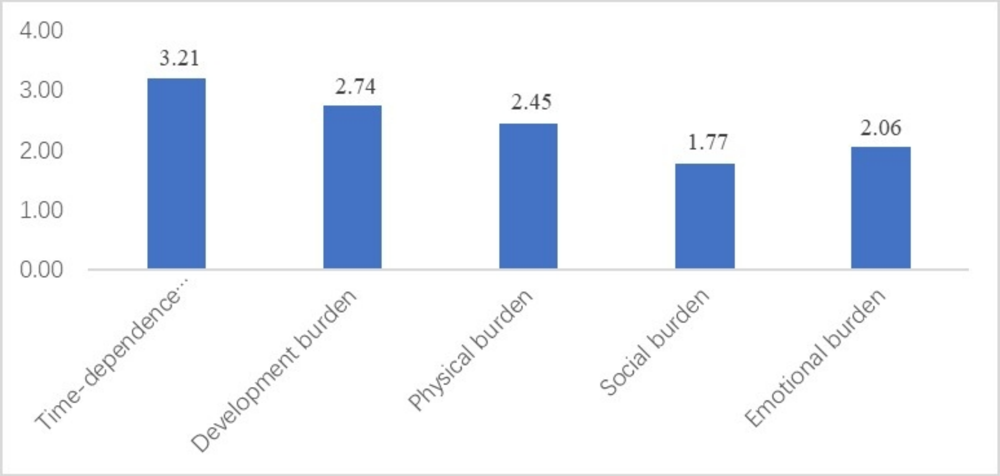

Figure 1 The average score of five domains of Caregiver burden index

130x62mm (150 x 150 DPI)

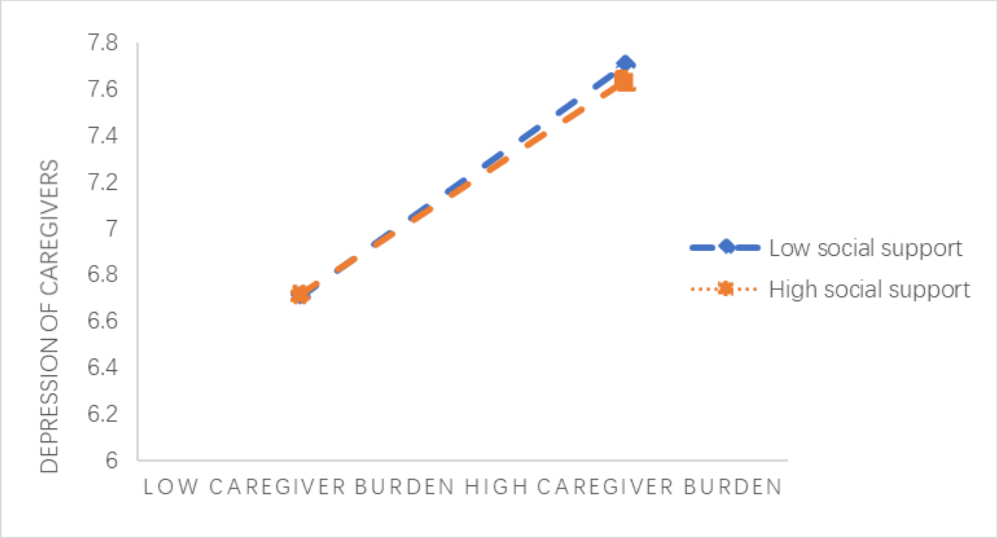

Figure 2 The association between caregivers' depression and caregivers' depression.

332x179mm (59 x 59 DPI)

STROBE Statement—Checklist of items that should be included in reports of ***cross-sectional studies***

|  | Item No | Recommendation | Page No |
|---|---|---|---|
| **Title and abstract** | 1 | (*a*) Indicate the study's design with a commonly used term in the title or the abstract | 1 |
|  |  | (*b*) Provide in the abstract an informative and balanced summary of what was done and what was found | 1 |
| **Introduction** |  |  |  |
| Background/rationale | 2 | Explain the scientific background and rationale for the investigation being reported | 1-2 |
| Objectives | 3 | State specific objectives, including any prespecified hypotheses | 3 |
| **Methods** |  |  |  |
| Study design | 4 | Present key elements of study design early in the paper | 3 |
| Setting | 5 | Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection | 3 |
| Participants | 6 | (*a*) Give the eligibility criteria, and the sources and methods of selection of participants | 3 |
| Variables | 7 | Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable | 4 |
| Data sources/ measurement | 8* | For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group | *3* |
| Bias | 9 | Describe any efforts to address potential sources of bias |  |
| Study size | 10 | Explain how the study size was arrived at | 3 |
| Quantitative variables | 11 | Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why |  |
| Statistical methods | 12 | (*a*) Describe all statistical methods, including those used to control for confounding | 6 |
|  |  | (*b*) Describe any methods used to examine subgroups and interactions | 6 |
|  |  | (*c*) Explain how missing data were addressed |  |
|  |  | (*d*) If applicable, describe analytical methods taking account of sampling strategy |  |
|  |  | (*e*) Describe any sensitivity analyses |  |
| **Results** |  |  |  |
| Participants | 13* | (a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed | 6 |
|  |  | (b) Give reasons for non-participation at each stage | 3 |
|  |  | (c) Consider use of a flow diagram |  |
| Descriptive data | 14* | (a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders | 6 |
|  |  | (b) Indicate number of participants with missing data for each variable of interest |  |
| Outcome data | 15* | Report numbers of outcome events or summary measures | 7 |
| Main results | 16 | (*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included | 7 |

| | | | |
|---|---|---|---|
| | | (*b*) Report category boundaries when continuous variables were categorized | |
| | | (*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period | |
| Other analyses | 17 | Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses | 7 |
| **Discussion** | | | |
| Key results | 18 | Summarise key results with reference to study objectives | 7 |
| Limitations | 19 | Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias | 10 |
| Interpretation | 20 | Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence | 9 |
| Generalisability | 21 | Discuss the generalisability (external validity) of the study results | 8 |
| **Other information** | | | |
| Funding | 22 | Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based | 10 |

*Give information separately for exposed and unexposed groups.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

BMJ Open

# Caregiver Burden and Its Associated Factors among Family Caregivers of Persons with Dementia in Shanghai, China: A Cross-Sectional Study

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| | |

# Caregiver Burden and Its Associated Factors among Family Caregivers of Persons with Dementia in Shanghai, China: A Cross-Sectional Study

Zhijian Liu$^{\#a,b}$, Wenjing Sun$^{\#b,c}$, Honglin Chen$^{\#d}$, Jianhua Zhuang$^{b}$, Bei Wu$^{e}$， Hanzhang Xu$^{f,g}$, Peng Li$^{b}$, Xiaohan Chen$^{b}$, Juan Li$^{**h,a}$, You Yin$^{*b}$

a Navy Medical University School of Nursing, Shanghai, China

b Department of Neurology, Changzheng Hospital, Navy Medical University, Shanghai, 200003, China

c Department of Neurology, Third Affiliated Hospital of the Naval Medical University, Shanghai, 200003, China

d Department of Social Work School of Social Development and Public Policy, Fudan University, Shanghai, China

e New York University Rory Meyers College of Nursing, New York, NY, United States,

f Duke University School of Nursing, Durham, NC, United States

g Duke University School of Medicine, Durham, NC, United States

h Huashan Hospital affiliated to Fudan University, Shanghai, China

\# Wenjing Sun$^{\#b,c}$, Honglin Chen equal to Zhijian Liu.

*Corresponding author: You Yin, yinyou179@163.com;

**Corresponding author: Juan Li, lijuanjr@126.com

**Keywords:** Dementia, Caregiver burden, Family caregivers, Community

## ABSTRACT

**Objective** To assess the level of caregiver burden and factors associated with it among family caregivers of persons with dementia (PWD) living in communities of Shanghai, China.

**Design** Cross-sectional study

**Setting** Communities in Hongkou District of Shanghai, China.

**Participants** A random sample of 109 older adults with dementia and their primary family caregivers.

**Main outcome measure** Caregiver burden measured by the Caregiver Burden Inventory (CBI) and the Caregivers' depressive symptom measured by the simplified Chinese version of Self-rating Depression Scale (SDS) was the outcome variable of the study. The independent variables, including the cognitive function (measured by Montreal Cognitive Assessment (MoCA), sleep quality assessed by the Pittsburgh Sleep Quality Index (PSQI), abilities of daily life assessed by the Activities of Daily Living Scale (ADL), and behavioral and psychological symptoms assessed by the Neuropsychiatric Inventory (NPI) of PWDs, the community service utilization (measured by the Community Service Utilization Measurement), perceived social support (assessed by three questions), positive aspects of caregiving (assessed by the Positive Aspects of Caregiving, PAC) of dementia caregivers were analyzed. Multivariate linear regression was employed to determine the factors related to caregiver burden.

**Results** The average level of CBI was 65.92 ±16.74. The score of MoCA, PAC, and perceived social support of caregivers were negatively associated with caregiver burden ( $\beta$ =-0.84, $p<0.001$, $\beta$ =-3.61, p = 0.03, and $\beta$ =-1.22, p = 0.001, respectively). Community service utilization was positively associated ( $\beta$ = 3.46, $p<0.001$) with caregiver burden. Perceived social support by the caregiver moderated the relationship between caregiver burden and caregivers' depression symptom.

**Conclusion** Dementia caregivers experienced a high level of caregiver burden. The cognitive function of PWD, PAC, social support, and community service utilization were factors associated with caregiver burden. Strengthening social support, providing more high-quality home care services, promoting positive aspects of caregiving are imperative to reduce caregiver burden.

**Strengths and limitations of this study**

- The study was conducted in Shanghai, which is the most aging city in China.
- The participants were randomly sampled from a convenient sample of 8,800 older adults in seven different communities.
- Factors related to PWDs as well as their family caregivers were included in the study.
- The conclusion of the present study needs to be interpreted with caution since the socioeconomic status, healthcare services, and cultural behavior vary between different regions of China.

## INTRODUCTION

With the advancement of society, the prevalence of the aging population has increased. With the increasing age, numerous underlying physiological changes occur, and the risk of the chronic disease rises[1]. Dementia is one of the predominant diseases occurring in the aging population. The age-standardized prevalence of dementia in older adults (age⩾60 years) varies from 5% to 7% in most regions worldwide[2]. According to the global population report in 2017, there were nearly 25% of older adults in China and their number is expected to increase to 478.8 million (35.1%) in 2050, according to the Department of Economic and Social Affairs of the United Nations[3]. The age-standardized prevalence of dementia in China is 6%. There are approximately 7.4 million PWDs in China. The number is expected to reach 18 million by 2030 if effective measures are not undertaken[4].

Dementia is characterized by the deterioration of intellectual functions, executive dysfunction, sleeping disorders, emotional problem, and behavioral and psychological symptoms[5]. PWD rely on their family caregivers' support for daily activities. Family caregivers have to handle deteriorative function and progressive dementia-related symptoms of

PWD, thereby increasing the burden. Dementia also has a financial impact on society. The estimated total annual cost of dementia in China is predicted to increase from 0.9 billion US dollars (US$) in 1990 to 114.2 billion US$ in 2030. The costs of informal care accounted for 81.3% of the total estimated cost in 2010[6]. Caregiver burden is defined as the extent to which caregivers perceive their emotional or physical health, social life, and financial status due to caring for their relatives[7]. Due to the negative consequences of dementia, caregiver burden is higher among them compared to the population without dementia[8]. To reduce the dementia caregiver burden of PWDs, it is essential to identify factors that influence caregiver burden. Previous studies from Ireland, America, Korea, and Spain have reported significant caregiver burden in family caregivers of PWD, and it was associated with age, the severity of dementia, duration of the illness, level of neuropsychiatric symptoms, frontal lobe dysfunction, antidepressant drugs, and functional status of PWD [9,10,11,12]. A cross-section study in Hong Kong revealed that the prevalence of caregiver burnout was 15.5%. Caregiver burnout was associated with PWDs' ADL dependence and history of falls in the previous 90 days. Factors such as primary caregivers being adult children and the utilization of allied health services were found to be protective to caregiver burnout[13]. As the social services and healthcare systems are different between Hong Kong and mainland China, factors contributing to caregiver burden may also differ between the two settings. Studies on caregiver burden of dementia caregivers conducted in northern cities of China showed that the average score of caregiver burden measured by the Zarit Burden Interview(ZBI) was 12.2 ±13.2, which lies in the mild range. Moreover, caregiver burden was associated with the functional status of PWDs, physical status, life satisfaction, depression, and anxiety of caregivers[14]. The study conducted by Wang et al. in central China showed that the mean score of caregiver burden measured by the caregiver burden inventory was 44.56 ±10.18. Caregiver burden was associated with the risk of caregiver's committed abuse. However, caregiver burden was not found to be associated with social support[15]. Liu et al. reported that severity of dementia, daily caregiving time, depressive symptom, and anxiety of caregivers were associated with caregiver burden in Beijing [16]. The novelty of our study is that the earlier studies did not include some key factors, such as positive aspects of caregiving, social support, and community service utilization, that could impact caregiver burden. Further, as prior studies were conducted in the northern and central parts of China, information regarding caregiver burden among family caregivers of persons with dementia in Shanghai, which is one of the most developed cities in China, is limited. Data available for factors such as positive aspects of caregiving, perceived social support, and utilization of community services associated with the level of caregiver burden is sparse. To address the knowledge gap, this study is aimed to explore the level and factors associated with dementia caregivers' burden in communities in Shanghai. We hypothesize that the factors associated with caregiver burden are community service utilization, social support, and positive aspects of caregivers as well as the cognitive function, sleep quality, ability of daily life, the behavioral and psychological symptoms of PWDs.

Psychological health deterioration is one of the consequences of caregiver burden[17]. Caregivers experience psychological issues like depression and anxiety after caring for persons with dementia for a long period of time[14]. Social support refers to an individual or a collective resource that can provide emotional and mental assistance[18]. The study conducted by Cohen and Thoits proposed and verified the buffering hypothesis and confirmed that social support is a buffer against life stress and protects physical and mental health[19,20]. As for dementia caregivers, the antecedents of caregiver burden consist of insufficient financial resources, multiple responsibilities, and lack of social activities[17]. Adequate social support from family and community can release stress and burden of caregivers and allow them to participate in social activities. We propose that with different levels of social support, the impact of caregiver burden on depressive symptom vary.

In China, most PWD lives in communities and depend on their family members for caregiving. China's pilot long-term care (LTC) insurance policy is implemented in 15 cities since 2016. However, the supply and demand of LTC services are unmatched and unbalanced[21]. Formal care service is difficult to access at home. Support to family dementia caregivers is limited in most areas of China[22], which is insufficient to reduce the caregiver burden. Furthermore, the Chinese are influenced by Confucianism, which promotes the value of filial piety and family responsibility[23]. Especially, in traditional Chinese culture, family secrets should be confined to family members and not be revealed to those outside the family[23]. The cultural sense of caregiving obligation may be a barrier for caregivers to seek help outside of the household, which leads to a high level of caregiver burden[24]. Therefore, we aim to conduct this study to examine the level of dementia caregiving burden in Chinese communities and explore the factors related to caregiver burden. Besides, we also explored the relationship between social support, depression of caregivers, and caregiver burden. The results of the study may provide insight into the development of programs and services to reduce caregiver burden.

## PARTICIPANTS AND METHODS

### Participants

This was a cross-sectional study conducted from March 2017 to March 2018. A total of 8800 older adults were randomly selected from seven community healthcare centers in Hongkou District, Shanghai, China. The healthcare providers in these community centers screened the cognitive function of 8549 older adults using the measure of Alzheimer's disease-8 (AD8), A score of 2+ was considered as cognitive impairment. A total of 2272 of the screened persons were designated as cognitively impaired out of which 500 persons were randomly selected using random seed generated by SAS. These selected individuals underwent further cognitive testing using the Mini-Mental State Examination (MMSE). A total of 456 older adults with cognitive impairment (MMSE＜26 ) were identified, and they were invited along with their primary family caregivers to the Neurology Clinic of Changzheng Hospital for further comprehensive neuropsychological assessment by neurologists. The primary family caregivers were defined as unpaid family members who were primarily taking care of the older adults and were well aware of their condition and environment[25]. A total of 116 older adults were diagnosed with dementia. All the PWDs met the NIA-AA criteria(2011) for probable Alzheimer's Disease(AD), the NINDS-AIREN criteria for vascular dementia (VaD), the Gorno-Tempini criteria (2011) for frontotemporal dementia, and dementia with Lewy body (DLB) clinical diagnostic criteria(2005) for DLB, and underwent thorough clinical examinations, medical history taking and assessment of the physical, neurological and psychiatric status, including the Hamilton Anxiety Scale; psychological test; laboratory screening test; electrocardiography (ECG); chest radiography; electroencephalography (EEG); magnetic resonance imaging (MRI) of the brain; neuropsychological assessment with the use of the mini-mental state examination (MMSE); functional autonomy evaluation using Activities of Daily Living Scale. The exclusion criteria of PWDs included: (1) visual and auditory impairment (2) severe aphasia, (3) the acute stage of chronic disease, (4) unable to sit for more than 40 min, (5) the presence of other nervous system diseases. Seven dyads of PWDs and their family caregivers refused to participate in the study. A total of 109 dyads of PWDs and their primary family caregivers consented to participate in the study. The flow chart of the sampling is shown in Figure 1. The study was approved by the ethics committees of Changzheng Hospital, and all the participants signed the informed consent.

The power of the sample size was calculated by the *G*power* 3.1; we chose Linear multiple regression: Fixed model, single regression coefficient. The effect size $f^2$ was set as a large of 0.35[38], the number of predictors was 7, the results showed that the power of the sample was 99.81%, indicating a sound power of the test.

**Patients and Public Involvement**

Patients and the public were not involved in this study, including the recruitment, data collection, analysis, interpretation and dissemination of the results.

**Variables**

**Outcome Variable**

The caregiver burden of the caregivers was measured by the CBI developed by Novak in 1989 to measure the caregiver burden of PWDs. CBI was widely used in disabled stroke patients, spinal cord injuries, chronic-acquired brain injury, and neurologic Wilson disease in the previous studies[26]. CBI included 24-items, which were divided into five domains. Each item was evaluated from "never" (0 points) to "always" (4 points) 5 levels. The five domains were: time-dependence (Items 1 to 5, with 20 points), developmental (Items 6 to 10, with 20 points), physical (Items 11 to 14, with 16 points), social (Items 15 to 18, with 16 points), and emotional (Items 19 to 24, with 24 points) [26]. The total score of CBI was 96. A higher score correlates with increased caregiver burden. Chou tested the reliability and validity of the Chinese version of CBI, which showed adequate internal consistency reliability, appropriate content validity, and concurrent validity[27]. The Cronbach α coefficients of the five domains ranged from 0.79 to 0.93. The content of validity index (CVI) of the Chinese version was 95.8%. The exploratory factor analysis showed that there were five common factors for the original scale. The accumulative variance contribution of the five common factors was 62.78%[27]. The inventory was used to measure the caregiver burden of dementia caregivers in central China, with a Cronbach α coefficient of 0.92[15]. The score of CBI＞36 indicated the caregivers' "risk of burning out"[28].

### Independent Variables

*Caregivers' Variables*

The socio-demographic characteristics included age, gender, education, employment, and relationship of caregiver with PWDs.

The caregivers' depressive symptom was measured by the Self-rating Depression Scale (SDS) developed by Zung in 1965 to measure the level of depression of adults[29]. We used a simplified Chinese version that includes 12 items and has been used in the previous study[30].

The community service utilization was measured by the Community Service Utilization Measurement included 10 items: nursing assistant, housekeeper, doctor, psychologist, daycare center, food delivered, ambulance, hospitalization, nursing home, and other services. Each item had two options: used or not. These items were developed according to the existing services in the communities of Shanghai.

Caregivers were asked to choose the community service they had used in the past three months. The measurement has been used in the previous study[30].

Three questions measured social support perceived by caregivers: (1) How many people can be relied on when the situation is urgent; (2) How do people care about the current situations; (3) How easy it is to receive help from neighbors or colleagues when needed—total score ranges from 3 to 14, with higher scores indicating stronger social support. The measurement has been used in the previous study[30].

The positive aspects of caregivers were measured by PAC. This scale was developed by Tarlow to evaluate the positive aspects of caregiving in 2004 and was translated and tested by Zhang. Cronbach's α coefficient of PAC and two domains were 0.89, 0.86, and 0.80, respectively[31]. The scale is a self-rating scale that includes nine items with two domains, namely self-affirmation and outlook of life. The items used a 5-point Likert-type scale. The higher score indicated more positive aspects of caregiving. The content validity and structural validity of the scale were acceptable[31].

*Participants variables*

The socio-demographic characteristics were age, gender, and education. The disease characteristics included types of dementia (Alzheimer's disease (AD), vascular dementia, frontotemporal dementia, mixed dementia, and dementia with Lewy bodies), cognitive function, subjective sleep quality, behavioral and psychological symptoms, and activities of daily living.

The cognitive function of the PWDs was assessed by MoCA developed by Nasreddine in Canada in 2004[32]. It incorporates 8 domains of cognitive function, including attention, executive function, memory, language, visuospatial skills, abstract thinking, calculation, and orientation. MoCA score ranges from 0 to 30, with a lower score indicating poorer cognition. MoCA has been widely used in assessing cognitive function among patients with stroke, Parkinson's disease, and other diseases. It has stable sensitivity and specificity. MoCA has been translated into 30 different versions. Wang translated the MoCA-Beijing (BJ) version, and the assessment is available from *www.mocatest.org*. Chen tested the reliability and validity of the MoCA-BJ in people with obstructive sleep apnea-hypopnea syndrome. The Cronbach's $\alpha$ of the MoCA-BJ was 0.73[33].

The sleep quality of the PWDs was assessed by the PSQI where the PWDs and their caregivers answered the index. PSQI was developed by Buysse in 1989 and was translated by Liu[34]. The sensitivity and specificity of the Chinese version of PSQI were 98.3% and 90.3%, respectively[34]. The PSQI is a self-report questionnaire that accesses seven dimensions of sleep during the past month. The seven dimensions included subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medication, and daytime dysfunction. PSQI score ranged from 0 to 21, with higher scores representing poorer subjective sleep quality[34].

The abilities of daily life were assessed by the ADL scale. The response was recorded from the dementia caregivers. The scale was modified by Mingyuan Zhang[35]. It included 20 items with stable reliability and validity[35]. Each item score ranged from 1 (completely independent) to 4 (completely dependent). The total score ranged from 20 to 80, with a lower score indicating a higher level of ADL.

The behavioral and psychological symptoms of PWDs were assessed by the NPI answered by the dementia caregivers. The inventory was used to evaluate the severity and frequency of 10 common abnormal behaviors in PWDs[37]. Tao[37] translated the inventory and tested the reliability and validity of the Chinese version among persons with Alzheimer's disease. The Chinese version of NPI is a reliable and valid tool for measuring neuropsychiatric disturbances in people with AD.

## DATA ANALYSIS

To summarize the socio-demographic status and clinical characteristics, descriptive statistics were used. For continuous variables, mean and standard deviation (SD) were reported, and for categorical variables, numbers and proportions were reported. The univariate linear regression was used to test the association between demographic, PWDs' disease-related, and caregivers' caregiving-related variables and caregiver burden. Then only the statistically significant variables were entered into the multivariate linear regression. The statistically significant value of the univariate linear regression was set as $p < 0.1$[36]. Categorical variables were transferred to dummy variables. The coding of the variables is shown in Table 1. The Statistical package for social science (SPSS) 26.0 was used to analyze the data. The statistically significant value was $p < 0.05$.

Multiple regression analysis was performed to examine the moderating effect of social support on the relationship between caregiver burden and caregivers' depressive symptom. Caregiver burden and depressive symptom reduced on receiving social support.

## RESULT

In total, 109 dyads of PWDS and their caregivers were included in the study. Of these PWDs, 37(33.3%) were diagnosed with AD, 15(13.5%) with frontotemporal dementia, 22(19.8%) with mixed dementia, 12(10.8%) with DLB, and 23(20.7%) with VaD. The average age of the PWDs was 76.02 ±8.78 years. The percentage of females was 57.8%. Among 109 PWDs, 83 (76.1%) have received education till high school education or above, 12(11.0%) studied till middle school, 7(6.4%) till primary school, and 7(6.4%) were illiterate. The average MoCA was 12.50 ±5.84. The average PSQI was 5.57 ±5.00. Eighty (72.1%) PWDs reported poor sleep quality. Socio-demographic and disease characteristics of the PWDs are shown in Table 2.

The mean age of the caregivers was 65.18 ±12.03 years. The percentage of females was 58.7%. Among the 109 caregivers, 66 (50.6%) were spouses, and 42 (36.7%) were children of the PWD. 86 (77.0%) caregivers cared for the PWDs for one to four years. 53 (47.7%) caregivers spent 21 to 40 h per week on caregiving. The mean score of CBI was 65.92 ±16.74, which indicated a high level of caregiver burden. The average score of five domains of CBI is shown in Figure 2. The socio-demographic characteristics of the caregivers and caregiver burden are shown in Table 3.

The results of univariate and multivariate linear regression are shown in Table 4. PWD age, MoCA, PAC, community service needs, and social support all had a significant impact on caregiver burden. MoCA, PAC, and social support of caregivers were negatively associated with caregiver burden ( $\beta$ =-0.84, $p<0.001$, $\beta$ =-3.61, $p = 0.03$, and $\beta$ =-1.22, $p = 0.001$, respectively), which indicated better PWDs' cognitive function, more PAC and a higher level of social support were related to less caregiver burden. The community service needs were positively associated with caregiver burden ( $\beta = 3.46$, $p < 0.001$), which indicated more community service needs were related to more caregiver burden.

The moderation effect of social support on the relationship between caregiver burden and caregivers' depressive symptom was tested. Social support independently contributed to caregivers' depressive symptom. Specifically, a higher level of caregiver burden displayed a high level of depressive symptom ($b = 0.1235$, $p < 0.001$). Moreover, the two-way interaction between social support and caregiver burden significantly contributed to caregivers' depressive symptom (unstandardized $B = -0.027$, $p = 0.011$), as reflected in Figure 3.

## DISCUSSION

The level of caregiver burden in the present study was relatively higher than that in previous studies[15,16]. The study conducted by Wang et al. in central China demonstrated that the average CBI score of dementia caregivers was 44.6 ±10.2[15]. Liu et al. reported that the average CBI scores for caregivers with mild dementia, moderate dementia, and severe dementia were 19.63 ±10.75, 36.48 ±14.20, and 45.29 ±10.71, respectively in Beijing[16]. This was a cross-sectional study to explore the level of caregiver burden and factors related to it in PWDs in communities of Shanghai. After controlling for covariates, PWDs' cognitive function, PAC, social support, and community service needs were significantly associated with caregiver burden. Social support was a moderator for the relationship between caregiver burden and caregivers' depressive symptoms.

Firstly, the present study has shown that worse cognitive function and older age of PWDs are related to higher caregiver burden, which is consistent with the previous studies in Beijing and Taiyuan of China.[39,16]. Dementia is always accompanied by neuropsychiatric behaviors and decreased ADL[41]. With disease progression, PWD's dependence on their caregiver increases. The participants suffered from moderate to severe cognitive dysfunction in our study, and the age of the caregivers (65.18 ±12.03 years) in our research is more than in previous studies(57.5 ±12.3)[16].

Secondly, the level of caregiver burden in our study was relatively high compared to western countries, which can be attributed to the different social environments, cultures, healthcare policies, ethnicity, and age of caregivers[21,41,42]. , Caregiver burden is defined as "a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience"[43]. Caregiver burden derived from the perceived stressors is influenced by psychosocial factors like social, environmental, and cultural[41]. A cultural sense of caregiving obligation may augment the distress and burden felt by the caregivers[24]. Sharing family affairs with outsiders is not acceptable in Chinese culture[23]. A strong sense of family responsibility may prevent caregivers from sharing their caregiving burnout with others. These aspects are not conducive to releasing the burden of caregiving.

Thirdly, although an LTC insurance policy has been introduced since 2016 in 15 cities of China, many PWDs were not included in the policy in the pilot phase[22]. The participants in our study who were from Hongkou District were not covered by the policy during the interview period. Informal care from family members is the primary source of care for PWDs in China. However, due to the rapid socioeconomic shifts and changing demographic structure, reliance on the care provided by families has become untenable[21]. Formal care in most high-income countries has evolved into the home-and community-based care[21]. The situation might be responsible for more caregiver burden in our study compared to other countries. Community service is delivered at community healthcare centers, and caregivers need to bring PWD to use such service. The traffic between home and healthcare centers may increase caregiver burden. The reimbursement of community service by China's healthcare insurance is limited. Without the support of insurance, community service utilization may cause an additional financial burden to dementia caregivers. It has been reported that informal dementia caregivers seldom used respite services[44]. The gap between the needs of supportive community service and community service, especially home visiting service in a real environment is needed to be explored in the future.

PAC is known to be associated with a lower level of caregiver burden[45]. The positive aspects of caregiving refer to the satisfaction and reward stemming from the caregiving relationship[46]. PAC is associated with a higher level of well-being and better health condition of caregiver[46]. Furthermore, PAC can help caregivers cope with challenges related to caregiving[46]. Therefore, we found that a higher level of PAC was associated with a lower level of caregiver burden.

We found that caregivers with low-level social support had more depressive symptoms than those with high-level social support. Caregiver burden and depression are complex clinical and social problems[47]. Depression of caregivers was associated with providing care, social isolation, limited money, and decreased leisure time[48]. It has been reported that a higher level of social support is associated with a lower level of caregiver burden[49]. In our study, dementia caregivers received social support from family members, relatives, neighbors, and colleagues. An earlier study has confirmed that emotional support like reassurance from supporters is critical in reducing depressive symptoms[50]. Social support positively influences resilience, and caregivers with strong family support depict elevated resilience[51]. Besides, it has been found that sharing in the caregiving role can reduce the caregiver burden effectively[50]. Therefore, strengthening social support for caregivers may diminish the adverse effects of depressive symptoms in them.

The results of this study confirmed that the caregiver burden of PWDs was relatively high, and it was dependent on the factors associated with both PWD and the caregiver. Some of these factors could not be altered, such as PWDs' cognitive function. However, social support and community service are modifiable. Supportive services can be made readily available for dementia caregivers to relieve the caregiver burden. According to the China pilot, LTC insurance policy, the level of disability of older adults is assessed to determine whether the individual met the criterion of long-term care insurance. However, the assessment in European and American countries is more in-depth and comprehensive and more detailed regarding specific diseases such as dementia[52,53]. The evaluation in China is required to be refined in the future. The Chinese government is now continuously improving the LTC insurance policy, and the coverage is extending to more cities. LTC insurance can provide more specific services to PWDs and caregivers to alleviate depression and reduce their burden. LTC insurance may also effectively reduce the financial burden of PWDs in the future[54].

This study had a few limitations also. The participants were recruited from the Hongkou district, part of the center of Shanghai with high socioeconomic status, advanced community services, and improved healthcare resources. Therefore, findings from this study may be restricted as caregiver burden is expected to be higher among family caregivers living in more disadvantaged areas. A large multi-site study is needed to confirm the conclusions of this study. Moreover, the study was cross-sectional; thus, the cause-and-effect relationships were not established, and it was not possible to explore the trajectory of caregiver burden of PWD across different stages of the disease. Longitudinal studies are required to overcome these limitations in the future.

## CONCLUSION

This study highlights the emerging issues of dementia and the burden perceived by their family caregivers living in Shanghai communities. Furthermore, the factors associated with caregiver burden were explored. The result verified that caregiver burden is substantial among the family caregivers of PWDs. The cognitive function of PWD, caregivers' perceived social support, and community service utilization were found to be associated with caregiver burden. Providing adequate social support and home-visit service may alleviate the caregiver burden.

## ETHICS STATEMENT

The study was reviewed and approved by the Institutional Review Board (IRB) of Changzheng Hospital, Second Military Medical University. Written informed consent was taken from PWDs/participants for this study. The IRB approval number was 2019SL026.

## CONFLICT OF INTEREST

Authors have no conflict of interest to declare.

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## CONTRIBUTORSHIP STATEMENT

Zhijian Liu designed the concept, analyzed data, interpreted data, and prepared the manuscript.

Wenjing Sun designed the concept, analyzed data, interpreted data, and prepared the manuscript.

Honglin Chen designed the concept, analyzed data, interpreted data, and prepared the manuscript.

Jianhua Zhuang interpreted the outcome and reviewed the manuscript.

Bei Wu, interpreted the outcome and reviewed the manuscript.

Hanzhang Xu, interpreted the outcome and reviewed the manuscript.

Peng Li, collected the data.

Xiaohan Chen, collected the data.

You Yin, designed the concept, interpreted the outcome, and reviewed the manuscript.

Juan Li, designed the concept, interpreted the outcome, and reviewed manuscript

All authors have read and approved the submission and ensure that this is the case.

## DATA AVAILABILITY STATEMENT

Data are available upon reasonable request.

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Table 1: List of the associated variables

| Associated variables | Variables | | Coding |
|---|---|---|---|
| Socio-demographic characteristics | Age | Continuous variable | |
| | Gender | Categorical variable | Male = 1, female = 0 |
| | Education level | Categorical variable | Illiteracy = 1<br>Primary school = 2<br>Middle school = 3<br>High school or above = 4 |
| | Status of work | Categorical variable | |
| | Relationship | Categorical variable | Spouse = 1<br>Children = 2<br>Relatives = 3 |
| Characteristics of disease | Type of dementia | Categorical variable | AD = 1, FTD = 2, MD = 3, Lewy = 4, VD = 5 |
| | MoCA | Continuous variable | |
| | PISQ | Continuous variable | |
| | NPI | Continuous variable | |
| | ADL | Continuous variable | |
| Characteristics of caregivers | Caregiving years | Categorical variable | No caring = 1<br><0.5years = 2<br>0.5years-1year = 3<br>1years-4years = 4<br>5years-9years = 5<br>More than 9years = 6 |
| | Education | | |
| | Caring hours/week | Categorical variable | 0 hour-8 hours = 1 |

| | | | |
|---|---|---|---|
| | | | 9 hours-20 hours = 2 |
| | | | 21 hours-40 hours = 3 |
| | | | More than 40 hours = 4 |
| | Depressive symptoms | Continuous variable | |
| | Coping Style Questionnaire | Continuous variable | |
| | PAC | Continuous variable | |
| | Social support | Continuous variable | |
| | Community Service Utilization | Continuous variable | Used = 1 |
| | | | Not used = 0 |

**AD = Alzheimer's Disease; FTD =frontotemporal dementia; MD = mixed dementia; Lewy = Lewy body associated; VD =vascular dementia; PAC =positive aspects of caregivers.**

Table 2: Social-demographic and disease characteristics of the PWDs

| Characteristics | | Mean±SD | N(%) |
|---|---|---|---|
| Socio-demographic characteristics | Age(year) | 76.02 ±8.78 | |
| | Gender | | |
| | *Female* | | 63(57.8%) |
| | Education level | | |
| | *Below primary* school | | 14(12.8%) |
| | *Middle* school | | 12(11.0%) |
| | *High school or above* | | 83(76.1) |
| Disease characteristics | Type of dementia | | |
| | *Alzheimer's* | | 37(33.3%) |
| | *Frontotemporal* | | 15(13.5%) |
| | *Mixed* | | 22(19.8%) |
| | *Lewy bodies-associated* | | 12(10.8%) |
| | *Vascular dementia* | | 23(20.7%) |
| | MoCA total score | 12.50 ±5.84 | |
| | NPI total symptom scale | 21.50 ±14.94 | |
| | ADL total score | 42.94 ±14.17 | |
| | Poor Sleep quality | | 80(72.1%) |
| | Score of PSQI | 5.57 ±5.00 | |
| | *Subjective Sleep Quality* | 0.85 ±1.02 | |
| | *Sleep Latency* | 1.23 ±2.01 | |
| | *Sleep Duration* | 0.58 ±0.83 | |
| | *Habitual Sleep Efficiency* | 0.64 ±1.00 | |
| | *Sleep Disturbances* | 0.64 ±1.00 | |
| | *Use of Sleep Medications* | 1.34 ±1.49 | |
| | *Daytime Dysfunction* | 1.34 ±1.49 | |

**NPI = the Neuropsychiatric Inventory; PSQI = Pittsburgh Sleep Quality Index; ADL =activities of daily life**

Table 3: Social-demographic characteristics and caregiver burden of caregivers

| Characteristics | Mean±SD | n(%) |
|---|---|---|
| Age(year) | 65.18 ±12.03 | |
| Gender | | |
| *Female* | | 64(58.7%) |
| Education level | | |
| *Below primary* school or | | 12(11.0%) |
| *Middle* school | | 12(11.0%) |
| *High school or above* | | 85(78.0%) |
| Relationship with PWDs | | |
| *Spouse* | | 66(59.5%) |
| *Children* | | 42(38.5%) |
| *Relatives* | | 3(2.7%) |
| Caregiving hours/week(h) | | |
| *<20* | | 12(10.8%) |
| *21–40* | | 53(47.7%) |
| *>40* | | 44(39.6%) |
| Caregiving year (years) | | |
| *≤1* | | 12(11%) |
| *1－5* | | 86(77.5%) |
| *>5* | | 11(10.1%) |
| Score of SDS | 25.53 ±3.84 | |
| PAC | 29.49 ±3.86 | |
| Coping strategy | 92.90 ±5.78 | |
| Social Support | 8.61 ±1.32 | |
| Community Service Utilization | 2.46 ±1.74 | |
| Score of CBI | 65.92 ±16.74 | |
| *Time-Dependence Burden* | 16.03 ±5.59 | |
| *Development Burden* | 13.72 ±3.93 | |
| *Physical Burden* | 9.79 ±3.48 | |
| *Social Burden* | 7.09 ±3.07 | |
| *Emotional Burden* | 10.28 ±3.50 | |

**CBI =caregiver burden inventory; SDS = Self-rating Depression Scale; PAC =Positive aspects of caregiving.**

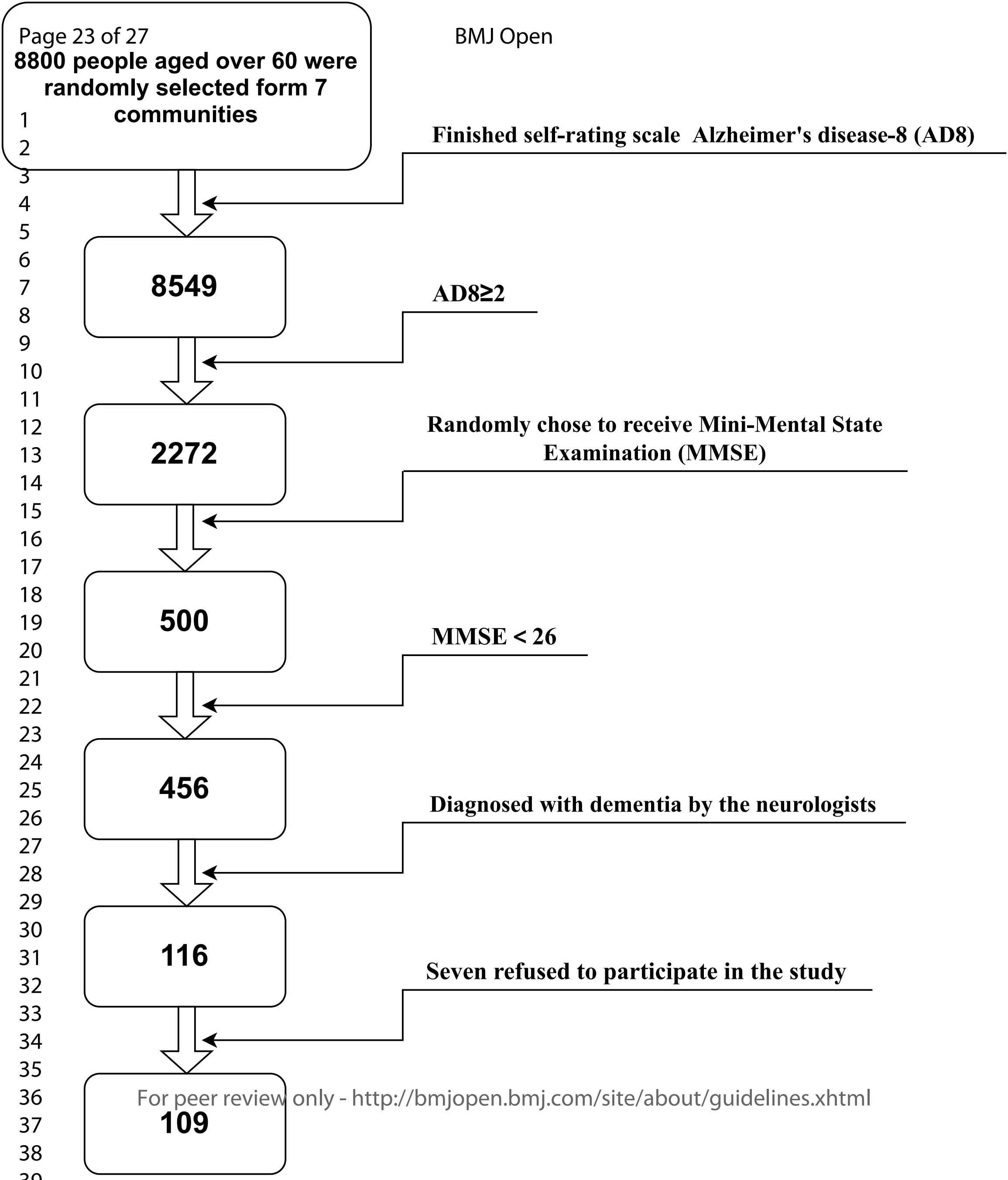
Table 4: Linear regression of CBI

| Variables | Univariate analyses | | | | | Multivariate analyses | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | b | p | SE | 95%CI | | b | p | SE | 95%CI | |
| | | | | Lower | Upper | | | | Lower | Upper |
| Age of PWDs | 0.48 | 0.008 | 0.18 | 0.126 | 0.835 | 0.11 | 0.19 | | | |
| Gender of PWDs | 0.41 | 0.90 | 3.26 | -6.06 | 6.87 | | | | | |
| Education level of PWDs | | | | | | | | | | |
| *Primary school* | -10.43 | 0.25 | 9.00 | -28.28 | 7.42 | | | | | |
| *Middle school* | -1.79 | 0.82 | 8.01 | -17.67 | 14.09 | | | | | |
| *High school or above* | -4.60 | 0.49 | 6.63 | -17.74 | 8.54 | | | | | |
| Type of dementia | | | | | | | | | | |
| *FTD* | -3.65 | 0.48 | 5.11 | -13.78 | 6.49 | | | | | |
| *MD* | 2.624 | 0.56 | 4.96 | -6.29 | 11.54 | | | | | |
| *Lewy* | -1.65 | 0.77 | 5.55 | -12.65 | 9.35 | | | | | |
| *VD* | 6.74 | 0.13 | 4.43 | -2.05 | 15.54 | | | | | |
| Score of MoCA | -0.80 | 0.003 | 0.10 | -1.33 | -0.27 | -0.84 | ＜0.001 | 0.22 | -1.29 | -0.40 |
| Total score of NPI | 0.30 | 0.005 | 0.06 | 0.09 | 0.50 | 0.16 | 0.05 | | | |
| Score of ADL | 0.41 | ＜0.001 | 0.11 | 0.20 | 0.63 | 0.14 | 0.13 | | | |
| Score of PSQI | 0.33 | 0.60 | 0.001 | -0.304 | 0.973 | | | | | |
| Age of caregivers | 0.14 | 0.30 | 0.32 | -0.13 | 0.40 | | | | | |
| Education level of caregivers | | | | | | | | | | |
| *Primary school* | 14.75 | 0.15 | 10.28 | -5.66 | 35.13 | | | | | |
| *Middle school* | 5.75 | 0.55 | 9.69 | -13.46 | 24.96 | | | | | |
| *High school or above* | 7.31 | 0.40 | 8.59 | -9.71 | 24.34 | | | | | |
| Relationship | | | | | | | | | | |
| *Children* | 3.71 | 0.27 | 3.31 | -2.85 | 10.26 | | | | | |
| *Relatives* | -17.71 | 0.07 | 9.74 | -37.02 | 1059 | | | | | |
| Caregiving time for each week | | | | | | | | | | |
| *9－20* | -5.00 | 0.65 | 10.94 | -26.67 | 16.70 | | | | | |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| *21–40* | -0.93 | 0.93 | 9.74 | -20.24 | 18.39 | | | | | |
| *>40* | 6.89 | 0.48 | 9.80 | -12.54 | 26.31 | | | | | |
| caregiving years | | | | | | | | | | |
| *0.5* | -17.00 | 0.36 | 18.28 | -53.45 | 19.45 | | | | | |
| *0.5–1* | -15.78 | 0.32 | 15.82 | -47.15 | 15.59 | | | | | |
| *1－4* | -12.44 | 0.41 | 15.09 | -42.37 | 17.49 | | | | | |
| *5–9* | 11.86 | 0.46 | 16.04 | -19.95 | 43.67 | | | | | |
| *>9* | 16.00 | 0.34 | 16.78 | -17.27 | 49.27 | | | | | |
| PAC | -1.33 | 0.001 | 0.40 | -2.12 | -0.54 | -1.22 | 0.001 | 0.34 | -1.90 | -0.55 |
| Coping strategy | -0.25 | 0.38 | 0.28 | -0.80 | 0.31 | | | | | |
| Social Support | -3.32 | 0.006 | 1.18 | -5.667 | -0.972 | -3.61 | ＜0.001 | 0.99 | -5.58 | -1.64 |
| Community Service Utilization | 3.54 | ＜0.001 | 0.87 | 1.82 | 5.26 | 3.46 | ＜0.001 | 0.76 | 1.96 | 4.96 |

**AD = Alzheimer's Disease ;FTD =frontotemporal dementia ;MD = mixed dementia ;Lewy = Lewy body associated; VD =vascular dementia;**

**PAC =positive aspects of caregivers; NPI = the Neuropsychiatric Inventory; PSQI = Pittsburgh Sleep Quality Index; ADL =activities of daily life.**


8800 people aged over 60 were randomly selected form 7 communities
Finished self-rating scale Alzheimer's disease-8 (AD8)
8549
AD8≥2
2272
Randomly chose to receive Mini-Mental State Examination (MMSE)
500
MMSE < 26
456
Diagnosed with dementia by the neurologists
116
Seven refused to participate in the study
109

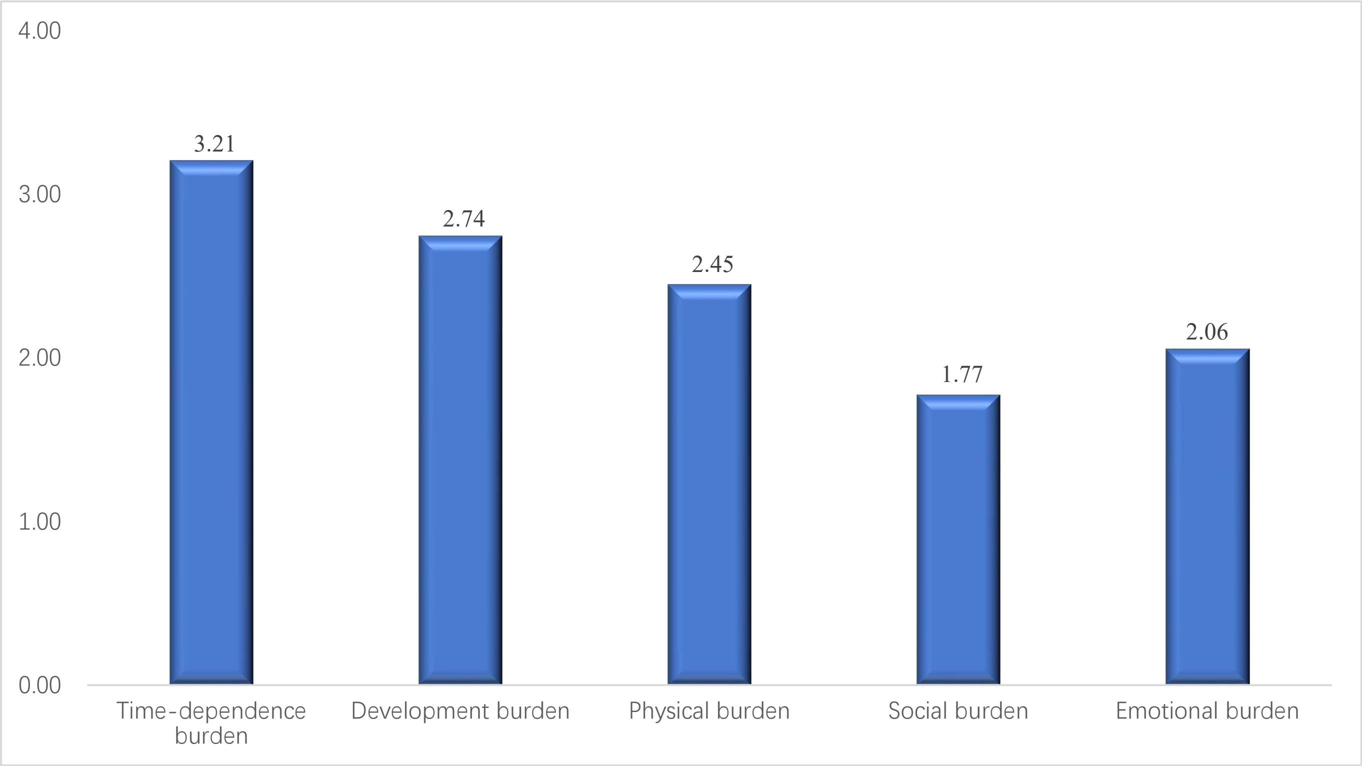


**Figure 2: Average score of five domains of the Caregiver burden index.**

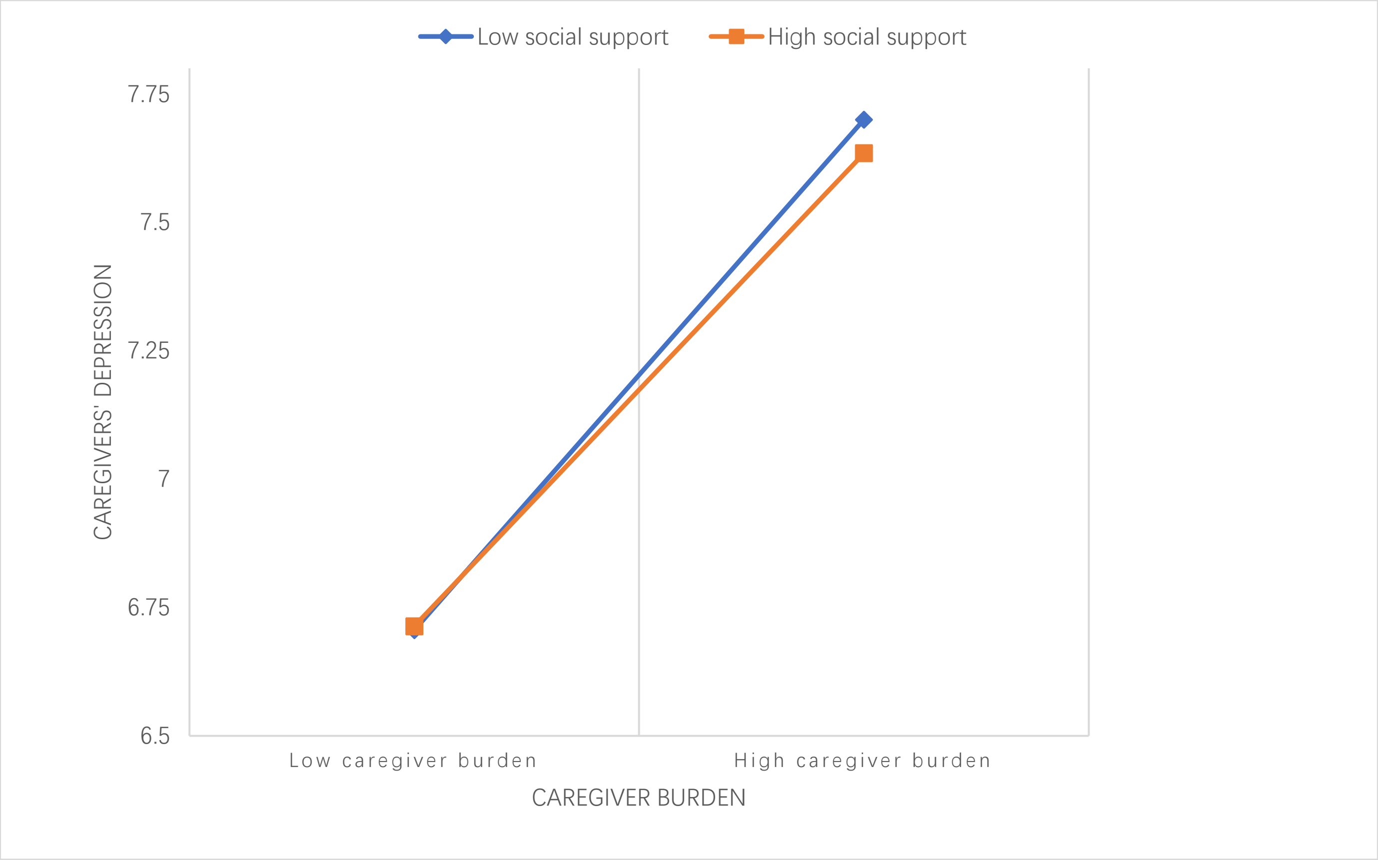


**Figure 3 Moderation effect of social support on the relationship between caregiver burden and caregivers' depressive symptom.**

STROBE Statement—Checklist of items that should be included in reports of ***cross-sectional studies***

| | **Item No** | **Recommendation** | **Page No** |
|---|---|---|---|
| **Title and abstract** | 1 | (*a*) Indicate the study's design with a commonly used term in the title or the abstract | 1 |
| | | (*b*) Provide in the abstract an informative and balanced summary of what was done and what was found | 1 |
| **Introduction** | | | |
| Background/rationale | 2 | Explain the scientific background and rationale for the investigation being reported | 1-2 |
| Objectives | 3 | State specific objectives, including any prespecified hypotheses | 3 |
| **Methods** | | | |
| Study design | 4 | Present key elements of study design early in the paper | 3 |
| Setting | 5 | Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection | 3 |
| Participants | 6 | (*a*) Give the eligibility criteria, and the sources and methods of selection of participants | 3 |
| Variables | 7 | Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable | 4 |
| Data sources/ measurement | 8* | For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group | *3* |
| Bias | 9 | Describe any efforts to address potential sources of bias | |
| Study size | 10 | Explain how the study size was arrived at | 3 |
| Quantitative variables | 11 | Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why | |
| Statistical methods | 12 | (*a*) Describe all statistical methods, including those used to control for confounding | 6 |
| | | (*b*) Describe any methods used to examine subgroups and interactions | 6 |
| | | (*c*) Explain how missing data were addressed | Not Applicable |
| | | (*d*) If applicable, describe analytical methods taking account of sampling strategy | 5 |
| | | (*e*) Describe any sensitivity analyses | Not Applicable |
| **Results** | | | |
| Participants | 13* | (a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed | 6 |
| | | (b) Give reasons for non-participation at each stage | 3 |
| | | (c) Consider use of a flow diagram | 20 |
| Descriptive data | 14* | (a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders | 6 |

| | | | |
|---|---|---|---|
| | | (b) Indicate number of participants with missing data for each variable of interest | Not Applicable |
| Outcome data | 15* | Report numbers of outcome events or summary measures | 7 |
| Main results | 16 | (*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included | 7 |
| | | (*b*) Report category boundaries when continuous variables were categorized | 16 |
| | | (*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period | Not Applicable |
| Other analyses | 17 | Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses | 7 |
| **Discussion** | | | |
| Key results | 18 | Summarise key results with reference to study objectives | 7 |
| Limitations | 19 | Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias | 10 |
| Interpretation | 20 | Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence | 9 |
| Generalisability | 21 | Discuss the generalisability (external validity) of the study results | 8 |
| **Other information** | | | |
| Funding | 22 | Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based | 10 |

*Give information separately for exposed and unexposed groups.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

BMJ Open

# Caregiver Burden and Its Associated Factors among Family Caregivers of Persons with Dementia in Shanghai, China: A Cross-Sectional Study

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| | |

# Caregiver Burden and Its Associated Factors among Family Caregivers of Persons with Dementia in Shanghai, China: A Cross-Sectional Study

Zhijian Liu[#a,b], Wenjing Sun[#b,c], Honglin Chen[#d], Jianhua Zhuang[b], Bei Wu[e]， Hanzhang Xu[f,g], Peng Li[b], Xiaohan Chen[b], Juan Li**[h,a], You Yin*[b]

a Navy Medical University School of Nursing, Shanghai, China

b Department of Neurology, Changzheng Hospital, Navy Medical University, Shanghai, 200003, China

c Department of Neurology, Third Affiliated Hospital of the Naval Medical University, Shanghai, 200003, China

d Department of Social Work School of Social Development and Public Policy, Fudan University, Shanghai, China

e New York University Rory Meyers College of Nursing, New York, NY, United States,

f Duke University School of Nursing, Durham, NC, United States

g Duke University School of Medicine, Durham, NC, United States

h Huashan Hospital affiliated to Fudan University, Shanghai, China

# Wenjing Sun[#b,c], Honglin Chen equal to Zhijian Liu.

*Corresponding author: You Yin, yinyou179@163.com;

**Corresponding author: Juan Li, lijuanjr@126.com

**Keywords:** Dementia, Caregiver burden, Family caregivers, Community

## ABSTRACT

**Objective** To assess the level of caregiver burden and factors associated with it among family caregivers of persons with dementia (PWD) living in communities of Shanghai, China.

**Design** Cross-sectional study

**Setting** Communities in Hongkou District of Shanghai, China.

**Participants** A random sample of 109 older adults with dementia and their primary family caregivers.

**Main outcome measure** Caregiver burden measured by the Caregiver Burden Inventory (CBI), and the Caregivers' depressive symptom measured by the simplified Chinese version of Self-rating Depression Scale (SDS) was the outcome variable of the study. The independent variables, including the cognitive function (measured by Montreal Cognitive Assessment (MoCA), sleep quality assessed by the Pittsburgh Sleep Quality Index (PSQI), abilities of daily life assessed by the Activities of Daily Living Scale (ADL), and behavioral and psychological symptoms assessed by the Neuropsychiatric Inventory (NPI) of PWDs, the community service utilization (measured by the Community Service Utilization Measurement), perceived social support (assessed by three questions), positive aspects of caregiving (assessed by the Positive Aspects of Caregiving, PAC) of dementia caregivers were analyzed. Multivariate linear regression was employed to determine the factors related to caregiver burden.

**Results** The average level of CBI was 65.92 ±16.74. The score of MoCA, PAC, and perceived social support of caregivers were negatively associated with caregiver burden ( $\beta = -0.84$, $p < 0.001$, $\beta = -3.61$, $p = 0.03$, and $\beta = -1.22$, $p = 0.001$, respectively). Community service utilization was positively associated ( $\beta = 3.46$, $p < 0.001$) with caregiver burden. Perceived social support by the caregiver moderated the relationship between caregiver burden and caregivers' depression symptoms.

**Conclusion** Dementia caregivers experienced a high level of caregiver burden. The cognitive function of PWD, PAC, social support, and community service utilization were factors associated with caregiver burden. Strengthening social support, providing more high-quality home care services, promoting positive aspects of caregiving are imperative to reduce caregiver burden.

## Strengths and limitations of this study

- The study was conducted in Shanghai, which is the most aging city in China.
- The participants were randomly sampled from a convenient sample of 8,800 older adults in seven different communities.
- We explored the association between factors of PWDs as well as their family caregivers and caregiver burden.
- We cannot generalize the conclusion of the present study to the whole country since the socioeconomic status, healthcare services, and culture vary between different regions of China.
- A longitudinal study with larger sample size is needed to explore the linkage between caregiver burden and influencing factors.

## INTRODUCTION

With the advancement of society, the prevalence of the aging population has increased. With the increasing age, numerous underlying physiological changes occur, and the risk of the chronic disease rises[1]. Dementia is one of the predominant diseases occurring in the aging population. The age-standardized prevalence of dementia in older adults (age≥60 years) varies from 5% to 7% in most regions worldwide[2]. According to the global population report in 2017, there were nearly 25% of older adults in China and their number is expected to increase to 478.8 million (35.1%) in 2050, according to the Department of Economic and Social Affairs of the United Nations[3]. The age-standardized prevalence of dementia in China is 6%. There are approximately 7.4 million PWDs in China. The number is expected to reach 18 million by 2030 if effective measures are not undertaken[4].

Dementia is character-rized by the deterioration of intellectual functions, executive dysfunction, sleeping disorders, emotional problem, and behavioral and psychological symptoms[5]. PWD rely on their family caregivers' support for daily activities. Family caregivers have to handle deteriorative function and progressive dementia-related symptoms of PWD, thereby increasing the burden. Dementia also has a financial impact on society. The estimated total annual cost of dementia in China is predicted to increase from 0.9 billion US dollars (US$) in 1990 to 114.2 billion US$ in 2030. The costs of informal care accounted for 81.3% of the total estimated cost in 2010[6]. Caregiver burden is defined as the extent to which caregivers perceive their emotional or physical health, social life, and financial status due to caring for their relatives[7]. Due to the negative consequences of dementia, caregiver burden is higher among them compared to the population without dementia[8]. To reduce the dementia caregiver burden of PWDs, it is essential to identify factors that influence caregiver burden. Previous studies from Ireland, America, Korea, and Spain have reported significant caregiver burden in family caregivers of PWD, and it was associated with age, the severity of dementia, duration of the illness, level of neuropsychiatric symptoms, frontal lobe dysfunction, antidepressant drugs, and functional status of PWD[9-12]. A cross-section study in Hong Kong revealed that the prevalence of caregiver burnout was 15.5%. Caregiver burnout was associated with PWDs' ADL dependence and history of falls in the previous 90 days. Factors such as primary caregivers being adult children and the utilization of allied health services were found to be protective to caregiver burnout[13]. As the social services and healthcare systems are different between Hong Kong and mainland China, factors contributing to caregiver burden may also differ between the two settings. Studies on caregiver burden of dementia caregivers conducted in northern cities of China showed that the average score of caregiver burden measured by the Zarit Burden Interview(ZBI) was 12.2 ± 13.2, which lies in the mild range. Moreover, caregiver burden was associated with the functional status of PWDs, physical status, life satisfaction, depression, and anxiety of caregivers[14]. The study conducted by Wang et al. in central China showed that the mean score of caregiver burden measured by the caregiver burden inventory was 44.56 ±10.18. Caregiver burden was associated with the risk of caregiver's committed abuse. However, caregiver burden was not found to be associated with social support[15]. Liu et al. reported that severity of dementia, daily caregiving time, depressive symptom, and anxiety of caregivers were associated with caregiver burden in Beijing [16]. Abdollahpour et al. reported that positive aspects of caregiving was negatively associated with caregiver burden among 153 caregivers of people with Alzheimer's disease after controlling for caregivers' age, marriage, and dependence of patients [17].

Previous studies conducted in northern and central parts of China did not include key factors associated with caregiver burden, such as positive aspects of caregiving, social support and community service utilization. Shanghai, located in Eastern China, is one of the most developed and aging cities in the country. However, studies about level of caregiver burden of PWD and related factors in Shanghai was limited. Data available for factors such as positive aspects of caregiving, perceived social support and utilization of community services associated with the level of caregiver burden was sparse. To address the knowledge gap, this study aimed to explore the level and factors associated with dementia caregivers' burden in communities in Shanghai. We hypothesized that the factors associated with caregiver burden were cognitive function, sleep quality, ability of daily life, the behavioral and psychological symptoms of PWDs as well as community service utilization, social support, and positive aspects of caregivers.

Psychological health deterioration is one of the consequences of caregiver burden[21]. Caregivers experience psychological issues like depression and anxiety after caring for persons with dementia for a long period of time[14]. Social support refers to an individual or a collective resource that can provide emotional and mental assistance[18]. The study conducted by Cohen and Thoits proposed and verified the buffering hypothesis and confirmed that social support was a buffer against life stress and protects physical and mental health[19,20]. As for dementia caregivers, the antecedents of caregiver burden consist of insufficient financial resources, multiple responsibilities, and lack of social activities[21]. Adequate social support from family and community can release stress and burden of caregivers and allow them to participate in social activities. A cross-sectional study among people with Alzheimer's disease in Taiyuan North China showed that social support was the moderating variable in the relationship between the cognitive function of people with AD and caregiver burden. It can be seen that social support can buffer the negative aspects of caring for people with dementia[22]. We proposed that with different levels of social support, the impact of caregiver burden on depressive symptom vary, the social support was the moderating variable in the relationship between caregiver burden and depressive symptoms.

In China, most PWDs live in communities and depend on their family members for caregiving. China's pilot long-term care (LTC) insurance policy was implemented in 15 cities since 2016. However, the supply and demand of LTC services are unmatched and unbalanced[23]. Formal care service is difficult to access at home. Support to family dementia caregivers is limited in most areas of China[24], which is insufficient to reduce the caregiver burden. Furthermore, the Chinese are influenced by Confucianism, which promotes the value of filial piety and family responsibility[25]. Especially, in traditional Chinese culture, family secrets should be confined to family members and not be revealed to those outside the family[25]. The cultural sense of caregiving obligation may be a barrier for caregivers to seek help outside of the household, which leads to a high level of caregiver burden[26]. Therefore, we aimed to conduct this study to examine the level of dementia caregiving burden in Chinese communities and explore the factors related to caregiver burden. Besides, we also explored the relationship between social support, caregiver burden , and depression of caregivers. The results of the study may provide insight into the development of programs and services to reduce caregiver burden.

## PARTICIPANTS AND METHODS

### Participants

This was a cross-sectional study conducted from March 2017 to March 2018. A total of 8800 older adults were randomly selected from seven community healthcare centers in Hongkou District, Shanghai, China. The healthcare providers in these community centers screened the cognitive function of 8549 older adults using the measure of Alzheimer's disease-8 (AD8), A score of 2+ was considered as cognitive impairment. A total of 2272 of the screened persons were designated as cognitively impaired out of which 500 persons were randomly selected using random seed generated by SAS. These selected individuals underwent further cognitive testing using the Mini-Mental State Examination (MMSE). A total of 456 older adults with cognitive impairment (MMSE＜26 ) were identified, and they were invited along with their primary family caregivers to the Neurology Clinic of Changzheng Hospital for further comprehensive neuropsychological assessment by neurologists. The primary family caregivers were defined as unpaid family members who were primarily taking care of the older adults and were well aware of their condition and environment[27]. A total of 116 older adults were diagnosed with dementia. All the PWDs met the NIA-AA criteria(2011) for probable Alzheimer's Disease(AD), the NINDS-AIREN criteria for vascular dementia (VaD), the Gorno-Tempini criteria (2011) for frontotemporal dementia, and dementia with Lewy body (DLB) clinical diagnostic criteria(2005) for DLB, and underwent thorough clinical examinations, medical history taking and assessment of the physical, neurological and psychiatric status, including the Hamilton Anxiety Scale; psychological test; laboratory screening test; electrocardiography (ECG); chest radiography; electroencephalography (EEG); magnetic resonance imaging (MRI) of the brain; neuropsychological assessment with the use of the mini-mental state examination (MMSE); functional autonomy evaluation using Activities of Daily Living Scale. The exclusion criteria of PWDs included: (1) visual and auditory impairment (2) severe aphasia, (3) the acute stage of chronic disease, (4) unable to sit for more than 40 min, (5) the presence of other nervous system diseases. Seven dyads of PWDs and their family caregivers refused to participate in the study. A total of 109 dyads of PWDs and their primary family caregivers consented to participate in the study. The flow chart of the sampling is shown in Figure 1. The study was approved by the ethics committees of Changzheng Hospital, and all the participants signed the informed consent.

The power of the sample size was calculated by the *G*power* 3.1; we chose Linear multiple regression: Fixed model, single regression coefficient. The effect size $f^2$ was set as a large of 0.35[28], the number of predictors was 7, the results showed that the power of the sample was 99.81%, indicating a sound power of the test.

### Patients and Public Involvement

Patients and the public were not involved in this study, including the recruitment, data collection, analysis, interpretation and dissemination of the results.

### Variables

### Outcome Variable

The caregiver burden of the caregivers was measured by the CBI developed by Novak in 1989 to measure the caregiver burden of PWDs. CBI was widely used in disabled stroke patients, spinal cord injuries, chronic-acquired brain injury, and neurologic Wilson disease in the previous studies[29]. CBI included 24-items, which were divided into five domains. Each item was evaluated from “never” (0 points) to “always” (4 points) 5 levels. The five domains were: time-dependence (Items 1 to 5, with 20 points), developmental (Items 6 to 10, with 20 points), physical (Items 11 to 14, with 16 points), social (Items 15 to 18, with 16 points), and emotional (Items 19 to 24, with 24 points) [29]. The total score of CBI was 96. A higher score correlates with increased caregiver burden. Chou tested the reliability and validity of the Chinese version of CBI, which showed adequate internal consistency reliability, appropriate content validity, and concurrent validity[30]. The Cronbach α coefficients of the five domains ranged from 0.79 to 0.93. The content of validity index (CVI) of the Chinese version was 95.8%. The exploratory factor analysis showed that there were five common factors for the original scale. The accumulative variance contribution of the five common factors was 62.78%[30]. The inventory was used to measure the caregiver burden of dementia caregivers in central China, with a Cronbach α coefficient of 0.92[15]. The score of CBI＞36 indicated the caregivers’ “risk of burning out”[31].

### Independent Variables

*Caregivers’ Variables*

The socio-demographic characteristics included age, gender, education, employment, and relationship of caregiver with PWDs.

The caregivers’ depressive symptom was measured by the Self-rating Depression Scale (SDS) developed by Zung in 1965 to measure the level of depression of adults[32]. We used a simplified Chinese version that includes 12 items and has been used in the previous study[33].

The community service utilization was measured by the Community Service Utilization Measurement included 10 items: nursing assistant, housekeeper, doctor, psychologist, daycare center, food delivered, ambulance, hospitalization, nursing home, and other services. Each item had two options: used or not. These items were developed according to the existing services in the communities of Shanghai.

Caregivers were asked to choose the community service they had used in the past three months. The measurement has been used in the previous study[33].

Three questions measured social support perceived by caregivers: (1) How many people can be relied on when the situation is urgent; (2) How do people care about the current situations; (3) How easy it is to receive help from neighbors or colleagues when needed—total score ranges from 3 to 14, with higher scores indicating stronger social support. The measurement has been used in the previous study[33].

The positive aspects of caregivers were measured by PAC. This scale was developed by Tarlow to evaluate the positive aspects of caregiving in 2004 and was translated and tested by Zhang. Cronbach's α coefficient of PAC and two domains were 0.89, 0.86, and 0.80, respectively[34]. The scale is a self-rating scale that includes nine items with two domains, namely self-affirmation and outlook on life. The items used a 5-point Likert-type scale. The higher score indicated more positive aspects of caregiving. The content validity and structural validity of the scale were acceptable[34].

*Participants variables*

The socio-demographic characteristics were age, gender, and education. The disease characteristics included types of dementia (Alzheimer's disease (AD), vascular dementia, frontotemporal dementia, mixed dementia, and dementia with Lewy bodies), cognitive function, subjective sleep quality, behavioral and psychological symptoms, and activities of daily living.

The cognitive function of the PWDs was assessed by MoCA developed by Nasreddine in Canada in 2004[35]. It incorporates 8 domains of cognitive function, including attention, executive function, memory, language, visuospatial skills, abstract thinking, calculation, and orientation. MoCA score ranges from 0 to 30, with a lower score indicating poorer cognition. MoCA has been widely used in assessing cognitive function among patients with stroke, Parkinson's disease, and other diseases. It has stable sensitivity and specificity. MoCA has been translated into 30 different versions. Wang translated the MoCA-Beijing (BJ) version, and the assessment is available from *www.mocatest.org*. Chen tested the reliability and validity of the MoCA-BJ in people with obstructive sleep apnea-hypopnea syndrome. The Cronbach's α of the MoCA-BJ was 0.73[36].

The sleep quality of the PWDs was assessed by the PSQI where the PWDs and their caregivers answered the index. PSQI was developed by Buysse in 1989 and was translated by Liu[37]. The sensitivity and specificity of the Chinese version of PSQI were 98.3% and 90.3%, respectively[37]. The PSQI is a self-report questionnaire that accesses seven dimensions of sleep during the past month. The seven dimensions included subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medication, and daytime dysfunction. PSQI score ranged from 0 to 21, with higher scores representing poorer subjective sleep quality[37].

The abilities of daily life were assessed by the ADL scale. The response was recorded from the dementia caregivers. The scale was modified by Mingyuan Zhang[38]. It included 20 items with stable reliability and validity[38]. Each item score ranged from 1 (completely independent) to 4 (completely dependent). The total score ranged from 20 to 80, with a lower score indicating a higher level of ADL.

The behavioral and psychological symptoms of PWDs were assessed by the NPI answered by the dementia caregivers. The inventory was used to evaluate the severity and frequency of 10 common abnormal behaviors in PWDs[39]. Tao[39] translated the inventory and tested the reliability and validity of the Chinese version among persons with Alzheimer's disease. The Chinese version of NPI is a reliable and valid tool for measuring neuropsychiatric disturbances in people with AD.

## DATA ANALYSIS

To summarize the socio-demographic status and clinical characteristics, descriptive statistics were used. For continuous variables, mean and standard deviation (SD) were reported, and for categorical variables, numbers and proportions were reported. The univariate linear regression was used to test the association between demographic, PWDs' disease-related, and caregivers' caregiving-related variables and caregiver burden. Then only the statistically significant variables were entered into the multivariate linear regression. The statistically significant value of the univariate linear regression was set as $p < 0.1$[40]. Categorical variables were transferred to dummy variables. The coding of the variables is shown in Table 1. The Statistical package for social science (SPSS) 26.0 was used to analyze the data. The statistically significant value was $p < 0.05$.

Multiple regression analysis was performed to examine the moderating effect of social support on the relationship between caregiver burden and caregivers' depressive symptom. Caregiver burden and depressive symptom reduced on receiving social support.

## RESULT

In total, 109 dyads of PWDS and their caregivers were included in the study. Of these PWDs, 37(33.3%) were diagnosed with AD, 15(13.5%) with frontotemporal dementia, 22(19.8%) with mixed dementia, 12(10.8%) with DLB, and 23(20.7%) with VaD. The average age of the PWDs was 76.02 ±8.78 years. The percentage of females was 57.8%. Among 109 PWDs, 83 (76.1%) have received education till high school education or above, 12(11.0%) studied till middle school, 7(6.4%) till primary school, and 7(6.4%) were illiterate. The average MoCA was

12.50 ±5.84. The average PSQI was 5.57 ±5.00. Eighty (72.1%) PWDs reported poor sleep quality. Socio-demographic and disease characteristics of the PWDs are shown in Table 2.

The mean age of the caregivers was 65.18 ±12.03 years. The percentage of females was 58.7%. Among the 109 caregivers, 66 (50.6%) were spouses, and 42 (36.7%) were children of the PWDs. 86 (77.0%) caregivers cared for the PWDs for 1 to 4 years. 53 (47.7%) caregivers spent 21 to 40 hours per week on caregiving. The mean score of CBI was 65.92 ±16.74, which indicated a high level of caregiver burden. The average score of five domains of CBI is shown in Figure 2. The socio-demographic characteristics of the caregivers and caregiver burden are shown in Table 3.

The results of univariate and multivariate linear regression were shown in Table 4. PWD age, MoCA, PAC, community service utilization, and the level of social support all had a significant impact on caregiver burden. MoCA, PAC, and social support of caregivers were negatively associated with caregiver burden ( $\beta$ =-0.84, $p<0.001$, $\beta$ =-3.61, $p = 0.03$, and $\beta$ =-1.22, $p = 0.001$, respectively), which indicated better PWDs' cognitive function, more PAC and a higher level of social support were related to less caregiver burden. The community service utilization were positively associated with caregiver burden ( $\beta = 3.46$, $p<0.001$), which indicated more community service utilization were related to more caregiver burden.

The moderation effect of social support on the relationship between caregiver burden and caregivers' depressive symptom was tested. The level of social support independently contributed to caregivers' depressive symptom. Specifically, a higher level of caregiver burden displayed a high level of depressive symptom ($b = 0.1235$, $p<0.001$). Moreover, the two-way interaction between social support and caregiver burden significantly contributed to caregivers' depressive symptom (unstandardized $B = -0.027$, $p = 0.011$), as reflected in Figure 3.

## DISCUSSION

The level of caregiver burden in the present study was relatively higher than that in previous studies[15],[16]. The study conducted by Wang et al. in central China demonstrated that the average CBI score of dementia caregivers was 44.6 ±10.2[15]. Liu et al. reported that the average CBI scores for caregivers with mild dementia, moderate dementia, and severe dementia were 19.63 ±10.75, 36.48 ±14.20, and 45.29 ±10.71, respectively in Beijing[16]. The caregiver burden level of our study was higher than that in previous studies conducted in Central and Northern China. It may be due to the different sample source. Our participants were recruited from the general communities in Shanghai. Wang's study sampled from the Clinical medical Center of Dementia and Cognitive Impairment in Hubei Province while Liu's Study sampled from 24 military communities in Beijing. The participants from the clinical center were able to get professional guidance while the participants from the military community can easily get the service and supplies from the military support compared to the general communities. Our study was a cross-sectional study to explore the level of caregiver burden and factors related to it in PWDs in communities of Shanghai. After controlling for covariates, PWDs' cognitive function, PAC, social support, and community service utilization were significantly associated with caregiver burden. Social support was a moderator for the relationship between caregiver burden and caregivers' depressive symptoms.

Firstly, the present study has shown that worse cognitive function and older age of PWDs are related to higher caregiver burden, which is consistent with the previous studies in Beijing and Taiyuan of China[16,41]. Dementia is always accompanied by neuropsychiatric behaviors and decreased ADL[42]. With disease progression, PWD's dependence on their caregiver increases. The participants suffered from moderate to severe cognitive dysfunction in our study, and the age of the caregivers (65.18 ±12.03 years) in our research was more than in previous studies(57.5 ±12.3)[16].

Secondly, the level of caregiver burden in our study was relatively high compared to western countries, which can be attributed to the different social environments, cultures, healthcare policies, ethnicity, and age of caregivers[23,42,43]. Caregiver burden was defined as "a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience"[44]. Caregiver burden derived from the perceived stressors is influenced by psychosocial factors like social, environmental, and cultural[42]. A cultural sense of caregiving obligation may augment the distress and burden felt by the caregivers[26]. Sharing family affairs with outsiders is not acceptable in Chinese culture[25]. A strong sense of family responsibility may prevent caregivers from sharing their caregiving burnout with others. These aspects are not conducive to releasing the burden of caregiving.

Thirdly, although an LTC insurance policy has been introduced since 2016 in 15 cities of China, many PWDs were not included in the policy in the pilot phase[24]. The LTC insurance policy was still fragmented. The serious problem included service coverage, service beneficiaries, funding source, payment rates, medical service& senior service, supply option, public-private partnership, and management capacity. Therefore, the actual coverage did not match the actual needs of the disabled elderly[45]. The policy did not cover the participants in our study who were from Hongkou District until January 2018, the participants may not be covered by the LTC insurance policy during the interview period. Informal care from family members is the primary source of care for PWDs in China. However, due to the rapid socioeconomic shifts and changing demographic structure, reliance on the care provided by families has become untenable[23]. Formal care in most high-income countries has evolved into the home-and community-based care[23]. The situation might be responsible for more caregiver burden in our study compared to other countries.

Community service was delivered at community healthcare centers. Caregivers needed to take PWDs to community healthcare centers to accept such service. The traffic between home and community healthcare centers may increase caregiver burden. The reimbursement of community service by China's healthcare insurance was limited. Without the support of insurance, community service utilization may cause an additional financial burden to dementia caregivers. It has been reported that informal dementia caregivers seldom used respite services[46]. The service provided in the communities healthcare centers was limited and it has not met the needs of the PWDs' caregivers[47]. The gap between diverse needs of PWDs' caregivers and limited supportive community services, especially home visiting services is needed to be closed in the future.

PAC was known to be associated with a lower level of caregiver burden[48]. The positive aspects of caregiving refer to the satisfaction and reward stemming from the caregiving relationship[49]. PAC is associated with a higher level of well-being and better health condition of caregiver[49]. Furthermore, PAC can help caregivers cope with challenges related to caregiving[49]. Therefore, we found that a higher level of PAC was associated with a lower level of caregiver burden. For further analysis, after controlling for age of PWDs, MoCA, NPI, ADL of PWDs, social support, and community service utilization to caregiver burden the regression analysis showed that the outlook on life (sub-domain of PAC) was associated with caregiver burden ($\beta$=-0.45, $p<0.001$), while the association of self-affirmation (sub-domain of PAC) and caregiver burden was not statistically significant ($\beta$=0.14, p=0.25). The outlook of life contributed the most to the protective effect on caregiver burden.

We found that caregivers with low-level social support had more depressive symptoms than those with high-level social support. Caregiver burden and depression are complex clinical and social problems[50]. Depression of caregivers was associated with providing care, social isolation, limited money, and decreased leisure time[51]. It has been reported that a higher level of social support is associated with a lower level of caregiver burden[52]. In our study, dementia caregivers received social support from family members, relatives, neighbors, and colleagues. An earlier study has confirmed that emotional support like reassurance from supporters is critical in reducing depressive symptoms[53]. Social support positively influences resilience, and caregivers with strong family support depict elevated resilience[54]. Besides, it has been found that sharing in the caregiving role can reduce the caregiver burden effectively[53]. Therefore, strengthening social support for caregivers may diminish the adverse effects of depressive symptoms in them.

The results of this study confirmed that the caregiver burden of PWDs was relatively high, and it was dependent on the factors associated with both PWD and the caregiver. Some of these factors could not be altered, such as PWDs' cognitive function. However, social support and community service are modifiable. Supportive services can be made readily available for dementia caregivers to relieve the caregiver burden. According to the China pilot, LTC insurance policy, the level of disability of older adults is assessed to determine whether the individual met the criterion of long-term care insurance. However, the assessment in European and American countries is more in-depth and comprehensive and more detailed regarding specific diseases such as dementia[55,56]. The evaluation in China is required to be refined in the future. The Chinese government is now continuously improving the LTC insurance policy, and the coverage is extending to more cities. LTC insurance can provide more specific services to PWDs and caregivers to alleviate depression and reduce their burden. LTC insurance may also effectively reduce the financial burden of PWDs in the future[57].

This study had a few limitations also. The participants were recruited from the Hongkou district, part of the center of Shanghai with high socioeconomic status, advanced community services, and improved healthcare resources. Therefore, findings from this study may be restricted as caregiver burden is expected to be higher among family caregivers living in more disadvantaged areas. A large multi-site study is needed to confirm the conclusions of this study. Moreover, the study was cross-sectional; thus, the cause-and-effect relationships were not established, and it was not possible to explore the trajectory of caregiver burden of PWD across different stages of the disease. Longitudinal studies are required to overcome these limitations in the future.

## CONCLUSION

This study highlights the emerging issues of dementia and the burden perceived by their family caregivers living in Shanghai communities. Furthermore, the factors associated with caregiver burden were explored. The result verified that caregiver burden is substantial among the family caregivers of PWDs. The cognitive function of PWD, caregivers' perceived social support, and community service utilization were found to be associated with caregiver burden. Providing adequate social support and home-visit service may alleviate the caregiver burden.

## ETHICS STATEMENT

The study was reviewed and approved by the Institutional Review Board (IRB) of Changzheng Hospital, Second Military Medical University. Written informed consent was taken from PWDs/participants for this study. The IRB approval number was 2019SL026.

## CONFLICT OF INTEREST

Authors have no conflict of interest to declare.

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## CONTRIBUTORSHIP STATEMENT

Zhijian Liu designed the concept, analyzed data, interpreted data, and prepared the manuscript.

Wenjing Sun designed the concept, analyzed data, interpreted data, and prepared the manuscript.

Honglin Chen designed the concept, analyzed data, interpreted data, and prepared the manuscript.

Jianhua Zhuang interpreted the outcome and reviewed the manuscript.

Bei Wu, interpreted the outcome and reviewed the manuscript.

Hanzhang Xu, interpreted the outcome and reviewed the manuscript.

Peng Li, collected the data.

Xiaohan Chen, collected the data.

You Yin, designed the concept, interpreted the outcome, and reviewed the manuscript.

Juan Li, designed the concept, interpreted the outcome, and reviewed manuscript

All authors have read and approved the submission and ensure that this is the case.

## DATA AVAILABILITY STATEMENT

Data are available upon reasonable request.

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**Figure legends**

**Figure1.Flow chart of the sampling.** Flow chart to identify how the participants were recruited in the study.

**Figure 2. Average score of five domains of the Caregiver burden index.** The Average score of the five domains of the Caregiver Burden Index were shown in the figure.

**Figure 3. Moderation effect of social support on the relationship between caregiver burden and caregivers' depressive symptom. Social support was the moderate variables in the relationship.** The effect of caregiver burden on depressive symptoms varies with different levels of social support.

Table 1: List of the associated variables

| Associated variables | Variables | | Coding |
|---|---|---|---|
| Socio-demographic characteristics | Age | Continuous variable | |
| | Gender | Categorical variable | Male = 1, female = 0 |
| | Education level | Categorical variable | Illiteracy = 1<br>Primary school = 2<br>Middle school = 3<br>High school or above = 4 |

| | | | |
|---|---|---|---|
| | Status of work | Categorical variable | |
| | Relationship | Categorical variable | Spouse = 1 |
| | | | Children = 2 |
| | | | Relatives = 3 |
| Characteristics of disease | Type of dementia | Categorical variable | AD = 1, FTD = 2, MD = 3, Lewy = 4, VD = 5 |
| | MoCA | Continuous variable | |
| | PISQ | Continuous variable | |
| | NPI | Continuous variable | |
| | ADL | Continuous variable | |
| Characteristics of caregivers | Caregiving years | Categorical variable | No caring = 1 |
| | | | <0.5years = 2 |
| | | | 0.5years-1year = 3 |
| | | | 1years-4years = 4 |
| | | | 5years-9years = 5 |
| | | | More than 9years = 6 |
| | Education | | |
| | Caring hours/week | Categorical variable | 0 hour-8 hours = 1 |
| | | | 9 hours-20 hours = 2 |
| | | | 21 hours-40 hours = 3 |
| | | | More than 40 hours = 4 |
| | Depressive symptoms | Continuous variable | |
| | Coping Style Questionnaire | Continuous variable | |
| | PAC | Continuous variable | |
| | Social support | Continuous variable | |
| | Community Service Utilization | Continuous variable | Used = 1 |
| | | | Not used = 0 |

**AD = Alzheimer's Disease; FTD =frontotemporal dementia; MD = mixed dementia; Lewy = Lewy body associated; VD =vascular dementia; PAC =positive aspects of caregivers.**

Table 2: Social-demographic and disease characteristics of the PWDs

| Characteristics | | Mean±SD | N(%) |
|---|---|---|---|
| Socio-demographic characteristics | Age(year) | 76.02 ±8.78 | |
| | Gender | | |
| | *Female* | | 63(57.8%) |
| | Education level | | |
| | *Below primary* school | | 14(12.8%) |
| | *Middle* school | | 12(11.0%) |
| | *High school or above* | | 83(76.1) |
| Disease characteristics | Type of dementia | | |
| | *Alzheimer's* | | 37(33.3%) |
| | *Frontotemporal* | | 15(13.5%) |
| | *Mixed* | | 22(19.8%) |

| | | |
|---|---|---|
| *Lewy bodies-associated* | | 12(10.8%) |
| *Vascular dementia* | | 23(20.7%) |
| MoCA total score | 12.50 ±5.84 | |
| NPI total symptom scale | 21.50 ±14.94 | |
| ADL total score | 42.94 ±14.17 | |
| Poor Sleep quality | | 80(72.1%) |
| Score of PSQI | 5.57 ±5.00 | |
| *Subjective Sleep Quality* | 0.85 ±1.02 | |
| *Sleep Latency* | 1.23 ±2.01 | |
| *Sleep Duration* | 0.58 ±0.83 | |
| *Habitual Sleep Efficiency* | 0.64 ±1.00 | |
| *Sleep Disturbances* | 0.64 ±1.00 | |
| *Use of Sleep Medications* | 1.34 ±1.49 | |
| *Daytime Dysfunction* | 1.34 ±1.49 | |

**NPI = the Neuropsychiatric Inventory； PSQI = Pittsburgh Sleep Quality Index； ADL =activities of daily life**

Table 3: Social-demographic characteristics and caregiver burden of caregivers

| Characteristics | Mean±SD | n(%) |
|---|---|---|
| Age(year) | 65.18 ±12.03 | |
| Gender | | |
| *Female* | | 64(58.7%) |
| Education level | | |
| *Below primary* school or | | 12(11.0%) |
| *Middle* school | | 12(11.0%) |
| *High school or above* | | 85(78.0%) |
| Relationship with PWDs | | |
| *Spouse* | | 66(59.5%) |
| *Children* | | 42(38.5%) |
| *Relatives* | | 3(2.7%) |
| Caregiving hours/week(h) | | |
| *<20* | | 12(10.8%) |
| *21–40* | | 53(47.7%) |
| *>40* | | 44(39.6%) |
| Caregiving year (years) | | |
| *≤1* | | 12(11%) |
| *1－5* | | 86(77.5%) |
| *>5* | | 11(10.1%) |
| Score of SDS | 25.53 ±3.84 | |
| PAC | 29.49 ±3.86 | |
| Coping strategy | 92.90 ±5.78 | |
| Social Support | 8.61 ±1.32 | |
| Community Service Utilization | 2.46 ±1.74 | |
| Score of CBI | 65.92 ±16.74 | |

| | |
|---|---|
| *Time-Dependence Burden* | 16.03 ±5.59 |
| *Development Burden* | 13.72 ±3.93 |
| *Physical Burden* | 9.79 ±3.48 |
| *Social Burden* | 7.09 ±3.07 |
| *Emotional Burden* | 10.28 ±3.50 |

**CBI =caregiver burden inventory; SDS = Self-rating Depression Scale; PAC =Positive aspects of caregiving.**

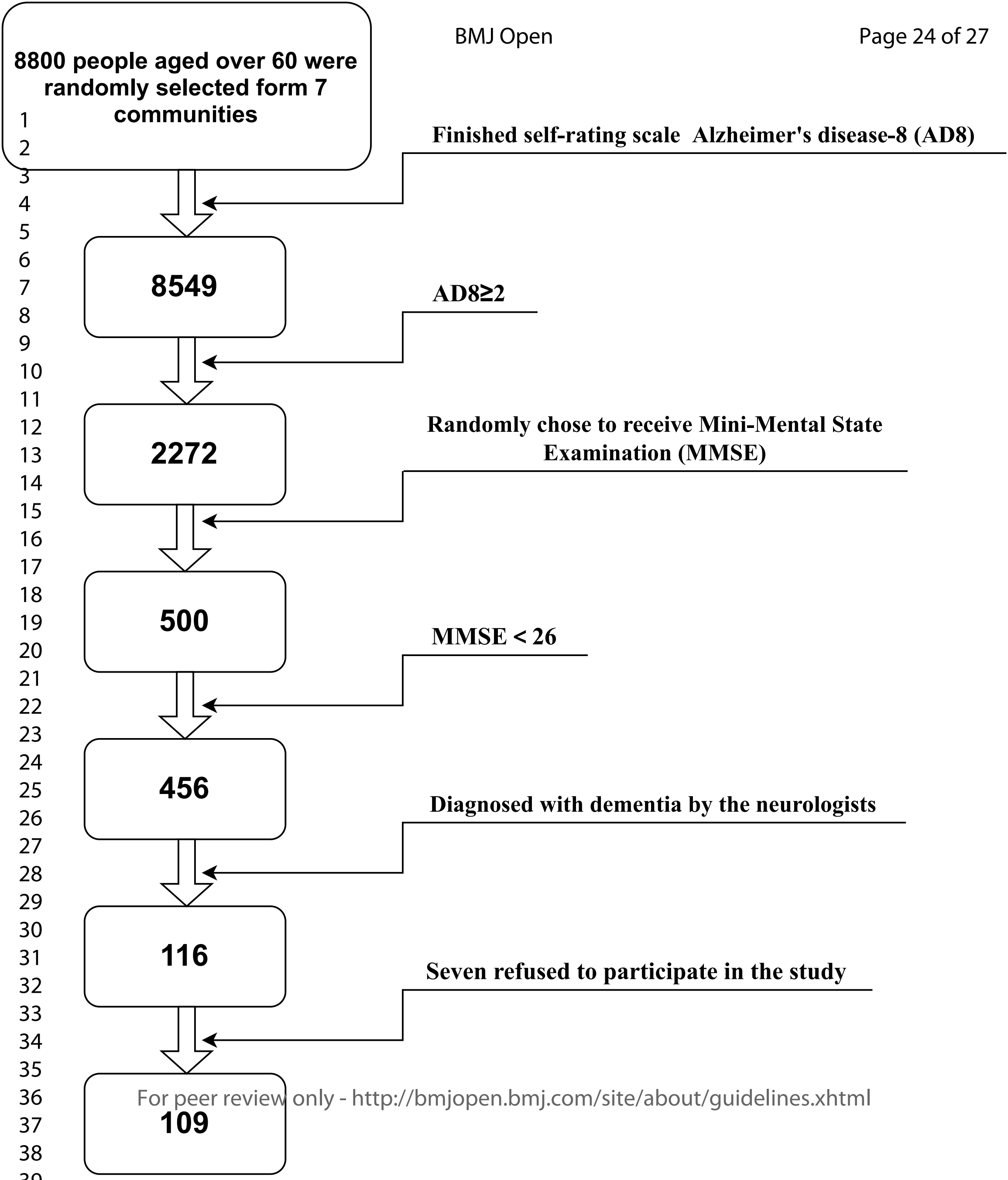
Table 4: Linear regression of CBI

| | Univariate analyses | | | | | Multivariate analyses | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| Variables | b | p | SE | 95%CI | | b | p | SE | 95%CI | |
| | | | | Lower | Upper | | | | Lower | Upper |
| Age of PWDs | 0.48 | 0.008 | 0.18 | 0.126 | 0.835 | 0.11 | 0.19 | | | |
| Gender of PWDs | 0.41 | 0.90 | 3.26 | -6.06 | 6.87 | | | | | |
| Education level of PWDs | | | | | | | | | | |
| *Primary school* | -10.43 | 0.25 | 9.00 | -28.28 | 7.42 | | | | | |
| *Middle school* | -1.79 | 0.82 | 8.01 | -17.67 | 14.09 | | | | | |
| *High school or above* | -4.60 | 0.49 | 6.63 | -17.74 | 8.54 | | | | | |
| Type of dementia | | | | | | | | | | |
| *FTD* | -3.65 | 0.48 | 5.11 | -13.78 | 6.49 | | | | | |
| *MD* | 2.624 | 0.56 | 4.96 | -6.29 | 11.54 | | | | | |
| *Lewy* | -1.65 | 0.77 | 5.55 | -12.65 | 9.35 | | | | | |
| *VD* | 6.74 | 0.13 | 4.43 | -2.05 | 15.54 | | | | | |
| Score of MoCA | -0.80 | 0.003 | 0.10 | -1.33 | -0.27 | -0.84 | ＜0.001 | 0.22 | -1.29 | -0.40 |
| Total score of NPI | 0.30 | 0.005 | 0.06 | 0.09 | 0.50 | 0.16 | 0.05 | | | |
| Score of ADL | 0.41 | ＜0.001 | 0.11 | 0.20 | 0.63 | 0.14 | 0.13 | | | |
| Score of PSQI | 0.33 | 0.60 | 0.001 | -0.304 | 0.973 | | | | | |
| Age of caregivers | 0.14 | 0.30 | 0.32 | -0.13 | 0.40 | | | | | |
| Education level of caregivers | | | | | | | | | | |
| *Primary school* | 14.75 | 0.15 | 10.28 | -5.66 | 35.13 | | | | | |
| *Middle school* | 5.75 | 0.55 | 9.69 | -13.46 | 24.96 | | | | | |
| *High school or above* | 7.31 | 0.40 | 8.59 | -9.71 | 24.34 | | | | | |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| Relationship | | | | | | | | | | |
| *Children* | 3.71 | 0.27 | 3.31 | -2.85 | 10.26 | | | | | |
| *Relatives* | -17.71 | 0.07 | 9.74 | -37.02 | 1059 | | | | | |
| Caregiving time for each week | | | | | | | | | | |
| *9－20* | -5.00 | 0.65 | 10.94 | -26.67 | 16.70 | | | | | |
| *21–40* | -0.93 | 0.93 | 9.74 | -20.24 | 18.39 | | | | | |
| *＞40* | 6.89 | 0.48 | 9.80 | -12.54 | 26.31 | | | | | |
| caregiving years | | | | | | | | | | |
| *0.5* | -17.00 | 0.36 | 18.28 | -53.45 | 19.45 | | | | | |
| *0.5–1* | -15.78 | 0.32 | 15.82 | -47.15 | 15.59 | | | | | |
| *1－4* | -12.44 | 0.41 | 15.09 | -42.37 | 17.49 | | | | | |
| *5–9* | 11.86 | 0.46 | 16.04 | -19.95 | 43.67 | | | | | |
| *＞9* | 16.00 | 0.34 | 16.78 | -17.27 | 49.27 | | | | | |
| PAC | -1.33 | 0.001 | 0.40 | -2.12 | -0.54 | -1.22 | 0.001 | 0.34 | -1.90 | -0.55 |
| Coping strategy | -0.25 | 0.38 | 0.28 | -0.80 | 0.31 | | | | | |
| Social Support | -3.32 | 0.006 | 1.18 | -5.667 | -0.972 | -3.61 | ＜0.001 | 0.99 | -5.58 | -1.64 |
| Community Service Utilization | 3.54 | ＜0.001 | 0.87 | 1.82 | 5.26 | 3.46 | ＜0.001 | 0.76 | 1.96 | 4.96 |

**AD = Alzheimer's Disease ;FTD =frontotemporal dementia ;MD = mixed dementia ;Lewy = Lewy body associated; VD =vascular dementia;**

**PAC =positive aspects of caregivers； NPI = the Neuropsychiatric Inventory； PSQI = Pittsburgh Sleep Quality Index； ADL =activities of daily life.**


8800 people aged over 60 were randomly selected form 7 communities
Finished self-rating scale Alzheimer's disease-8 (AD8)
8549
AD8≥2
2272
Randomly chose to receive Mini-Mental State Examination (MMSE)
500
MMSE < 26
456
Diagnosed with dementia by the neurologists
116
Seven refused to participate in the study
109

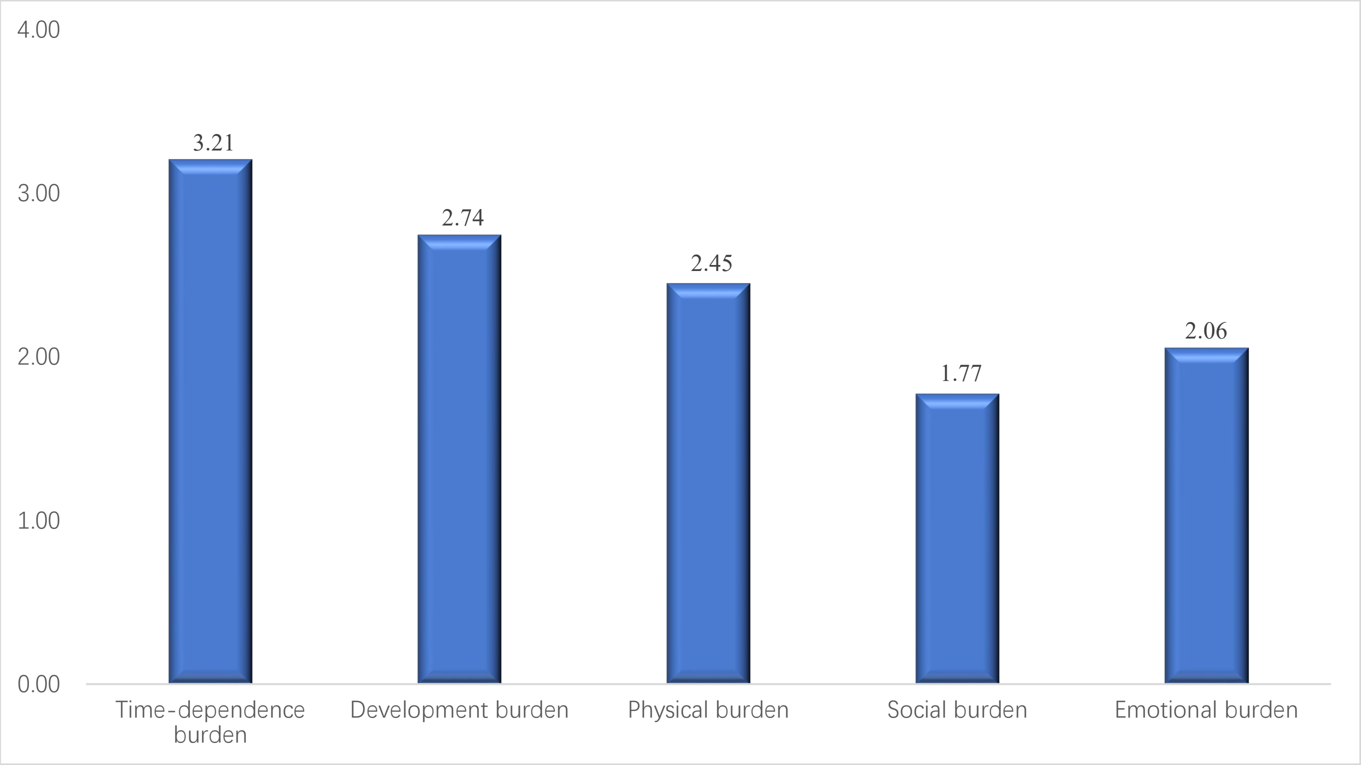


**Figure 2: Average score of five domains of the Caregiver burden index.**

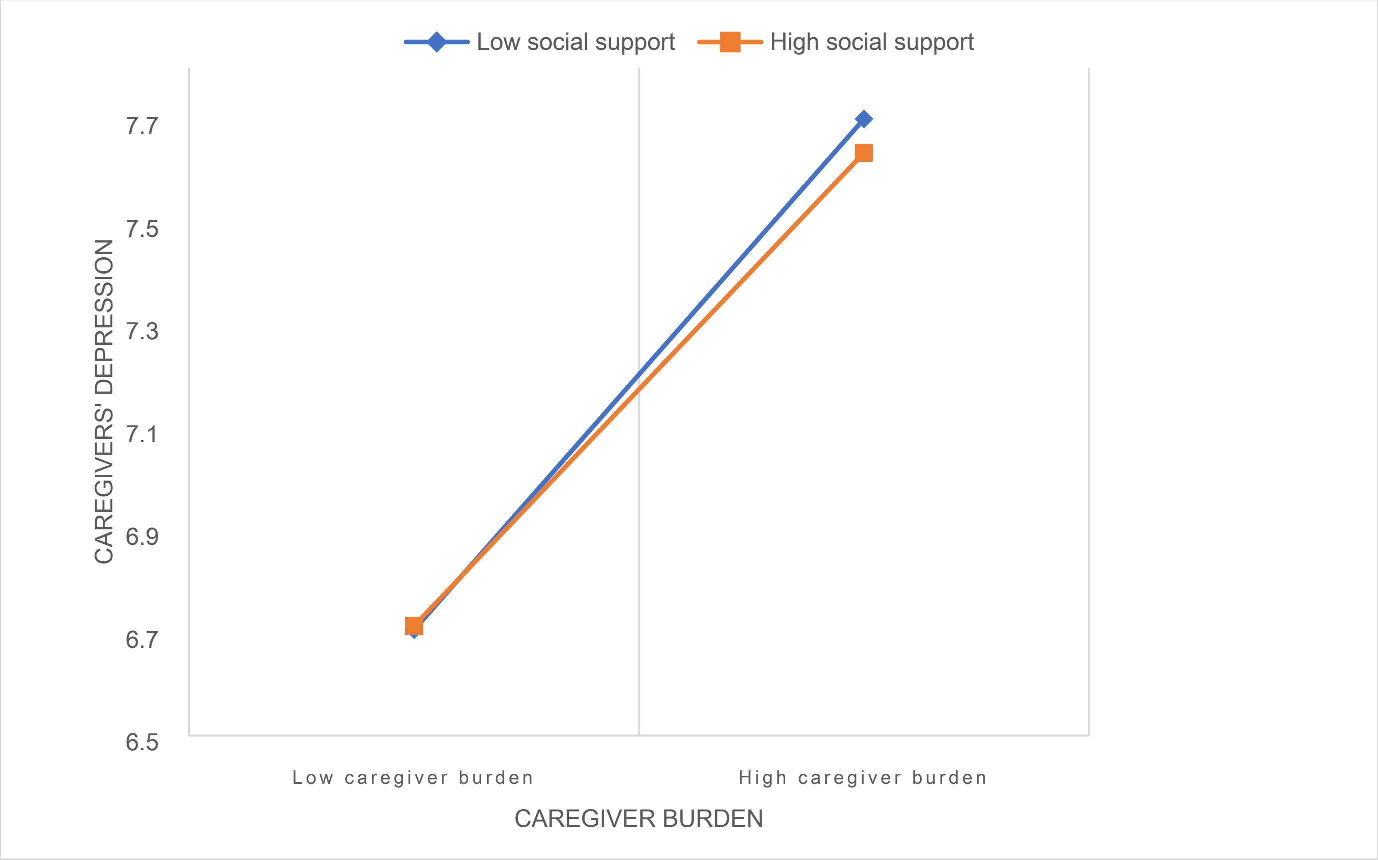


**Figure 3 Moderation effect of social support on the relationship between caregiver burden and caregivers' depressive symptom.**

STROBE Statement—Checklist of items that should be included in reports of ***cross-sectional studies***

| | **Item No** | **Recommendation** | **Page No** |
|---|---|---|---|
| **Title and abstract** | 1 | (*a*) Indicate the study's design with a commonly used term in the title or the abstract | 1 |
| | | (*b*) Provide in the abstract an informative and balanced summary of what was done and what was found | 1 |
| **Introduction** | | | |
| Background/rationale | 2 | Explain the scientific background and rationale for the investigation being reported | 1-2 |
| Objectives | 3 | State specific objectives, including any prespecified hypotheses | 3 |
| **Methods** | | | |
| Study design | 4 | Present key elements of study design early in the paper | 3 |
| Setting | 5 | Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection | 3 |
| Participants | 6 | (*a*) Give the eligibility criteria, and the sources and methods of selection of participants | 3 |
| Variables | 7 | Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable | 4 |
| Data sources/ measurement | 8* | For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group | *3* |
| Bias | 9 | Describe any efforts to address potential sources of bias | |
| Study size | 10 | Explain how the study size was arrived at | 3 |
| Quantitative variables | 11 | Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why | |
| Statistical methods | 12 | (*a*) Describe all statistical methods, including those used to control for confounding | 6 |
| | | (*b*) Describe any methods used to examine subgroups and interactions | 6 |
| | | (*c*) Explain how missing data were addressed | Not Applicable |
| | | (*d*) If applicable, describe analytical methods taking account of sampling strategy | 5 |
| | | (*e*) Describe any sensitivity analyses | Not Applicable |
| **Results** | | | |
| Participants | 13* | (a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed | 6 |
| | | (b) Give reasons for non-participation at each stage | 3 |
| | | (c) Consider use of a flow diagram | 20 |
| Descriptive data | 14* | (a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders | 6 |

| | | | |
|---|---|---|---|
| | | (b) Indicate number of participants with missing data for each variable of interest | Not Applicable |
| Outcome data | 15* | Report numbers of outcome events or summary measures | 7 |
| Main results | 16 | (*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included | 7 |
| | | (*b*) Report category boundaries when continuous variables were categorized | 16 |
| | | (*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period | Not Applicable |
| Other analyses | 17 | Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses | 7 |
| **Discussion** | | | |
| Key results | 18 | Summarise key results with reference to study objectives | 7 |
| Limitations | 19 | Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias | 10 |
| Interpretation | 20 | Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence | 9 |
| Generalisability | 21 | Discuss the generalisability (external validity) of the study results | 8 |
| **Other information** | | | |
| Funding | 22 | Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based | 10 |

*Give information separately for exposed and unexposed groups.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.