## Original Article

# Explore Factors Influencing Caregiver Burden on Family Caregivers of People with Neurocognitive Disorders in Penghu

**Wan-Chen Lin[1], Fen-Fen Shih[2*], Chia-Yi Chiao[3]**

[1] *Department of Nursing, Taipei Veterans General Hospital, Taipei, Taiwan.*
[2] *Department of Nursing, Chung Shan Medical University; Taichung, Taiwan.*
[3] *School of Nursing, College of Nursing, Asia University, Taichung, Taiwan.*

Penghu has been aging faster than Taiwan as a whole and its young people are also moving out for work or study, further exacerbating the problems of aging families and elderly-for-elderly care. Few studies have explored how the family functioning and caregiving burden of aging families relate to caregivers' depressive symptoms in Taiwan's offshore islands. The research with cross-sectional study design was applied in this study. The participants consisted of caregivers of people with neurocognitive disorders who accompanied them to seek outpatient treatment at two hospitals in Penghu. 148 valid responses were collected from November 2016 to January 2017. The IBM SPSS Statistics 20 software was used for data analysis. This study aimed to explore the relevant factors influencing burden on family caregivers of people with neurocognitive disorders. Research results: The correlations between caregivers' demographic variables and their caregiving burden were expressed as Pearson correlation coefficients. The results indicated that being female, non-employment of foreign care workers, and poor self-perceived health status correlated positively with caregiving burden. Based on the CES-D scale, 62.8% of caregivers had depressive symptoms, which correlated positively with the caregiving burden. 54% of them lacked family functioning, which correlated negatively with caregiving burden and depressive symptoms; while the depressive symptoms correlated positively with social resource usage. The linear regression analysis results showed that depressive symptoms had the strongest explanatory power for the caregiving burden, followed by self-perceived health status. Conclusion: The higher the caregivers' depressive symptoms, the higher their needs for social resource usage. However, their social resource usage cannot reduce their caregiving burden effectively. Therefore, improving the caregivers' health status, family functioning, and information access will be beneficial for reducing their burden and depressive symptoms. The results of this study could be used by health authorities to formulate policies for long-term care and family nursing.

**Keywords:** family functioning of aging families, depressive symptoms, caregiving burden on caregivers of people with neurocognitive disorders

## Introduction

* Correspondence Author: Fen-Fen Shih
  Address: No.110, Sec.1, Jianguo N. Rd., Taichung City 40201, Taiwan, ROC
  Tel: +886-4-24730022 ext. 12356(O), 0956080385
  E-mail: ritajack1107@gmail.com

With advancements in medicine, extension of longevity, and the rapid growth in older population, the aged population (proportion of those aged 65 years and over) in Penghu had reached 14.11% since 1999, which fulfills the World Health Organization's definition of an aged society.[1,2] Furthermore, Alzheimer's Disease International (ADI) estimates

that every three seconds will have a person being diagnosed with dementia globally, while the prevalence of neurocognitive disorders multiples for every five-year increment in age.[3,4] A systematic review and meta-analysis by Prince et al. revealed that the prevalence of dementia is growing rapidly in low- and middle-income countries,[5] in which 50% to 67% of people with dementia are Asians. The morbidity of dementia varies among regions, where most people with neurocognitive disorders are community dwellers taken care of by their families.[6] Even though family caregivers provide suitable care and support, their well-being often decreases due to such changes to their lifestyle and physical and mental health. In addition, poor family functioning and the lack of a support system can generate direct or indirect psychological, physiological, or social stresses on the caregivers.[6,7,8] Such effects have significant impacts on a country's economy, public policy, and society.[9, 10]

Albert believed that, under existed cultural values, care can be regarded as the views and commitment of caregivers to older care. This belief is not just a norm, but also a form of motivation within a cultural model. Studies by Taiwan-based scholars have indicated significant positive correlations between filial piety as a value, caregiving stressors, and caregiving stress burden.[11] Yang argued that the meaning of care should include the psychological expression of love and affection and actual caregiving work as two aspects as care (including assistance in terms of food, clothing, housing, and transportation); and that care should be seen as the provision of physical, material, and spiritual care by the caregiver to the care recipient, as well as the emotional connection between the caregiver and the care recipient.[12] Hunt referred to the negative physical and psychological effects of caregiving work as caregiver burden, caregiver strain, and caregiver stress,[13] implying that the degradation of cognitive function affects a caregiving relationship and caregiver burden, and that the long-term performance of caregiving tasks leads to physical and emotion distress in family caregivers.[14] Quinn, Clare, and Woods conducted a systematic literature review on the effects of caregiver-recipient relationship quality on well-being;[16] they found that

the provision of care is the main factor that affects the quality of this relationship, and that the items for which people with cognitive impairment require the most assistance are daily activities of living and behavioral problems.[15] These findings indicate that the factors that influence caregivers' assessment of the quality of life are the physical and psychological needs and caregiver-recipient relationship determined by the severity of the disability.

For people with cognitive impairment, their loved ones are important pillars. With the degradation of brain function, the caregiver-recipient relationship and family functioning are increasingly tested by issues such as the cohesiveness of family operations and family members, the fulfillment of family roles, responses to family problems, adaptation to new daily routines, and the ability to communicate effectively.[16] The state of these functions is an important influencing factor for predicting the stress response model of caregivers.[13] Social resources can be divided into three categories, namely medical resources, social welfare and care resources, and other resources.[17] However, resource use will differ depending on user characteristics, social status, health beliefs, family support, community resources, the perceived need for medical services, and expert judgments.[18] Taiwan-based scholars have proposed that supportive services for caregivers of dementia patients should include two forms of intervention measures, namely service-related solutions (such as respite services, information, psychological support) and cash subsidies (such as economic and work subsidies). Caregivers feel that there is a lack of information regarding how social resources can be obtained and how problematic behavior should be dealt with. Furthermore, the severity of dementia, cost of care, and characteristics of family caregivers are all predictive factors that affect caregivers' needs; the extent of resource use is influenced by the level of dependence that exists between the caregiver and care recipient; and a caregiver's views on the responsibility of care, as well as his or her subjective awareness of the various forms of caregiver burden, are the key factors that determine resource use.[19] These findings are in accordance with the study by Xu et. al.,[20] who showed that caregivers of people with dementia often seek professional assistance in

a passive manner. This suggests that society should pay more attention to the needs of caregivers of people with neurocognitive disorders.

Recently, scholars implemented a three-month intervention measure involving health education on neurocognitive disorders and information on social resource use. The results showed that the experimental group decreased their depressive symptoms from 36% to 17%, while that of the control group increased from 22% to 50%. This highlights the significant improvement of the caregivers' depressive responses and caregiving burdens after the intervention of information-based resources.[21] Such findings prove that identifying problems in a timely manner, giving education and guidance, and using social resources adequately can alleviate the caregivers' stress.[22] Therefore, providing more social support and formal home care, as well as implementing intervention measures based on social resources can help reduce caregiver burden and increase their quality-of-life.[23] Many studies have highlighted the factors influencing caregiver stress, which includes age, gender, lack of care experience, role conflicts, personal feelings, physiological and psychological health status, reduced socializing, lack of support network resources, economic burdens, and relationship with care recipient.[24-26] This suggests that older caregivers face more difficult caregiving tasks, thus experiencing higher care burdens.[27] Summarizing the aforementioned literature, caregiver burden is affected by the severity of the care recipient's disease and the recipient's performance in activities of daily living, the duration of the recipient's disease, the recipient's education level, the recipient's demographic variables, co-living status, relationship with spouse, care model

used, caregiver's training or preparation, sexual life, monthly income, family nursing expenses, age, gender, education level, caregiving skills, and medical and social resources.[23,27-29] All of these factors can generate depressive tendencies among caregivers, as well as increasing their stress and burden and their need for temporary day care services.[30,31]

In other words, the degree of dementia affects the caregiver burden and emotional hardships. Furthermore, many caregivers experience economic stress, which generates greater impacts on low-income families.[24] Therefore, the emergence of health problems in the caregiving burden may exacerbate the care recipient's severity of the disease. This calls for the need to resolve the physiological and psychological needs of caregivers more proactively.[23,32] Therefore, this study aimed to explore factors influencing caregiver burden on caregivers of people with neurocognitive disorders in Penghu. In addition, this study also aimed to understand the degree of influence of the caregivers' family functioning and social resource usage on their caregiving burden.

## Materials and Methods

### Research design and framework:

The cross-sectional research design was applied in this study to explore the relationship between family functioning, social resource usage, and the burden of care in caregivers of people with neurocognitive disorders. Following data collection, SPSS statistical software version 20 was used to perform descriptive and inferential statistical
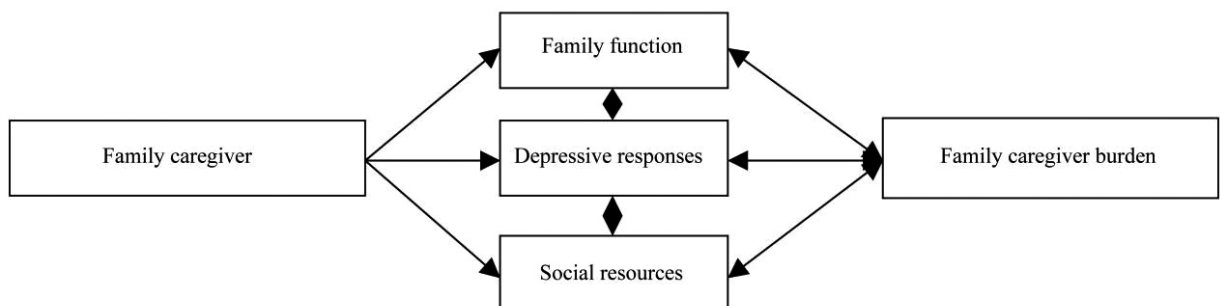


Fig 1. Research framework

analyses to understand the correlations between these three variables (Fig. 1).

### Research participants

Inclusion criteria:

1. Primary caregivers of people with neurocognitive disorders diagnosed through the Clinical Dementia Rating (Must give care for more than four hours per day for at least three months)
2. Aged below 70 years, able to express themselves clearly in Mandarin or Taiwanese
3. Agree to take part in questionnaires or face-to-face interviews
4. Willing to participate after the researcher had explained the research objectives

Exclusion criteria:

1. Foreign care workers
2. Hard of hearing
3. Diagnosed with neurocognitive disorders
4. Vulnerable subjects as defined in human trials

### Research tools

1. Family APGAR scale: The Family APGAR scale developed by Smilkstein based on the five components of adaptation, partnership, growth, affection, and resolve was used in this study. It is measured on a three-point Likert scale (0=hardly ever; 1=sometimes; 2=most of the time). A total score of 7 to 10 indicates good family functioning; 4 to 6 indicates moderate dysfunctioning; while 0 to 3 indicates severe dysfunctioning. The scale is user-friendly and has an internal consistency (Cronbach's α) of .80 to .85 and item-to-total correlations of .50~ .65. The reliability and validity of the Chinese version scale have been verified in Taiwan.

2. The Center for Epidemiological Studies Depression scale (CES-D): Developed by Radloff, the CES-D is a self-reported questionnaire on the frequency of having depressive symptoms over the past week. The total Link score ranges from 0 to 60, in which higher scores indicate the greater presence of depressive symptoms. Statements 4, 8, 12, and 16 are reversely scored. The CES-D score used by Taiwan-based and foreign scholars as the cutoff for screening depressive responses is 16, where 0~15 indicates no depressive symptoms while 16 and

above indicate depressive symptoms. Chien and Chang used the scale to calculate the sensitivity, specificity, and error of community-dwelling care recipients and non-care recipients in Taiwan, which were determined to be 92.0%, 91.0%, and 8.2%, respectively. The internal consistency of the scale is .85.

3. Caregiver burden scale: This study adopted Chou et al.'s Chinese version of Caregiver Burden Inventory (CBI) developed by Novak and Guest (1989).[33] The CBI measures the subjective burdens perceived by caregivers through five dimensions: time dependence, developmental, physical burden, social burden, and emotional burden. Each item is scored from 1 to 4, in which 1=disagree, 2=neutral, 3=agree, 4=strongly agree. The total score ranges from 24 to 96, with higher scores indicating a higher degree of caregiver burden. Caregivers with a score of above 36 are suggested to have more respite or assistance from social services.

4. Satisfaction of social resource usage: Refers to the social resources used by family caregivers of people with neurocognitive disorders, which include the dementia hotline provided by social organizations and government agencies, dementia-related websites, dementia outpatient treatment, support groups for families of care recipients with dementia, bracelets for tracking down missing loved ones, fingerprint registration, "School of Wisdom" health promotion service for people with mild dementia, day care centers, dementia care and nursing institutions, group homes for older dementia patients, foreign care workers, in-home caregiving services, in-home nurses, family foster care services, community and in-home rehabilitation, food services for the older people, purchase and rental of assistive devices, accessible home environment improvement services, respite services, transportation services (shuttle bus), legal inquiry services, disability card application, living subsidy for middle-to-low-income seniors, special allowance for middle-to-low-income seniors, national pension, subsidy for nursing and care, personalized professional services (patient management services), medical subsidy for middle-to-low-income (including hospitalization nursing fees), health insurance subsidy for low-income

households, house renovation subsidy for middle-to-low-income seniors, subsidy for self-paid social insurance, home purchase or rental subsidy for the disabled, disabled parking lot permits, free or half-priced local public transportation, tax reliefs, free or half-priced admission to scenic areas, recreational sites, and cultural and educational facilities, and application of IC cards for severe illness. The caregivers' satisfaction with these resources were

taken to understand the most frequently used, most satisfied, most dissatisfied, and most wanted social resources.

## Results

1. Demographic Variables
2. Correlation and regression analysis of the demographic variables, family functioning, caregiver burden,

**Table 1.** Personal attributes of primary caregivers of care recipients with neurocognitive disorders (n=148)

| Personal attribute | | Number | Percentage (%) |
|---|---|---|---|
| Gender | Male | 35 | 23.6 |
| | Female | 113 | 76.4 |
| Age | 21-40 years | 30 | 20.3 |
| | 41-60 years | 77 | 52.0 |
| | above 61 years | 41 | 27.7 |
| Education level | Elementary school | 32 | 21.6 |
| | Junior high school | 17 | 11.5 |
| | Senior high school | 36 | 24.3 |
| | Junior college or college | 54 | 36.5 |
| | Graduate school or higher | 9 | 6.1 |
| Marital status | Unmarried | 28 | 18.9 |
| | Married | 112 | 75.7 |
| | Widowed | 4 | 2.7 |
| | Divorced | 4 | 2.7 |
| Self-perceived health status | Healthy | 59 | 39.9 |
| | Neutral | 76 | 51.4 |
| | Unhealthy | 13 | 8.7 |
| Relationship with the care recipient | Spouse | 28 | 17.6 |
| | Child/child-in-law | 110 | 74.3 |
| | Sibling | 1 | 0.7 |
| | Grandchild | 8 | 5.4 |
| | others | 3 | 2.0 |
| Living with the care recipient | Yes | 101 | 68.2 |
| | No | 47 | 31.8 |
| Duration of care giving per day | 4~8 hours | 72 | 48.6 |
| | 8~12 hours | 19 | 12.8 |
| | more than 12 hours | 57 | 38.5 |

**Table 2.** Regression analysis of demographic variables and caregiver burden

| | Correlation coefficient | | Beta distribution | t | Significance |
|---|---|---|---|---|---|
| (constant) | Pearson correlation coefficient | Significance | | 4.277 | .000 |
| Gender | .226** | .006 | .179 | 2.386 | .018* |
| Self-perceived health status | .377*** | .000 | .307 | 3.544 | .001* |

Dependent variable: Caregiver burden

**Table 3.** Regression analysis of demographic variables and depressive symptoms

| | Correlation coefficient | | Beta distribution | t | Significance |
|---|---|---|---|---|---|
| (constant) | Pearson correlation coefficient | Significance | | 1.060 | .291 |
| Gender | .261** | .001 | .221 | 2.859 | .005* |
| Education level | -.228** | .005 | .049 | .537 | .592 |
| Self-perceived health status | .286**** | .000 | .193 | 2.270 | .025* |

Dependent variable: Depressive symptoms

depressive symptoms, and social resource usage of family caregivers of care recipients with neurocognitive disorders.

Pearson correlation coefficients were used to evaluate the correlations between the caregivers' demographic variables and their burden in this study. The results were as follows: there was a significant and positive correlation between caregiver burden and female caregivers (r= .226, p< .05) and poor self-perceived health (r= .377, p< .001); there was a significant and negative correlation between caregiver burden and education level (r=- .289, p< .001), monthly family income (r=- .164, p< .05), and living with care recipient (r= .264, p< .01). The regression analysis showed that self-perceived health status had the highest explanatory power on caregiver burden (Beta= .307, p< .01). This is followed by gender (as shown in Tables 2 and 3).

(3) Correlation between family functioning, depressive symptoms, caregiver burden, and social resource usage

Table 4 indicated that from the 148 samples in this study, there was a negative and significant correlation between depressive symptoms and family functioning (r=- .453, p< .001), while there was a significant and positive correlation between depressive symptoms and social resource usage (r=-.207, p< .05); there was also a positive correlation between caregiver burden and depressive symptoms (r= .747, p< .001), as well as a negative correlation between caregiver burden and family functioning (r= .396, p< .001). However, there was no significant correlation between social resource usage and caregiver burden (Table 2). The regression analysis between caregiver burden and family functioning, depressive symptoms, and social resource usage revealed that depressive symptoms had the strongest explanatory power on caregiver burden (Beta= .726, p< .001), while the other factors had no significance (Table 3). A further regression of correlating factors such as family functioning, depressive symptoms, self-perceived health status, gender, employment of a foreign care worker, and caregiver burden also showed that depressive symptoms had the strongest explanatory power on caregiver burden (Beta= .646, p< .001), followed by self-perceived health status (Beta= .171, p< .01) (Table 5).

## Discussion

**Table 4.** Regression analysis of caregiver burden and family functioning, depressive symptoms, and social resource usage

|  | Correlation coefficient | | Beta distribution | t | Significance |
|---|---|---|---|---|---|
| (constant) | Pearson correlation coefficient | Significance | | 12.698 | .000 |
| Family functioning | -.396*** | .000 | .073 | -1.189 | .237 |
| Depressive symptoms | .747*** | .000 | .726 | 11.579 | .000 |
| Social resource usage | .100 | .227 | .057 | -1.021 | .309 |

**Table 5.** Family functioning, depressive symptoms, education level, self-perceived health status

|  | Correlation coefficient | | Beta distribution | t | Significance |
|---|---|---|---|---|---|
| (constant) | Pearson correlation coefficient | Significance | | 12.698 | .000 |
| Family function | -.396*** | .000 | .073 | -1.189 | .237 |
| Depression | .747*** | .000 | .726 | 11.579 | .000 |
| Social resources | .100 | .227 | .057 | -1.021 | .309 |

Dependent variable: Caregiver burden

This quantitative study aimed to explore the relationship between family functioning, depressive symptoms, caregiving burden, and social resource usage on family caregivers of people with neurocognitive disorders. The results were as follows:

(1) In terms of demographic variables: Most of the caregivers in this study were female (daughters/daughters-in-law), most of them were married and were aged between 41-60 years. A majority of participants had the education level of high school and college. Their monthly incomes were between NTD20,000 to NTD50,000. Qver half of the caregivers lived with their care recipients, and most of them provided care for four to eight hours per day. Furthermore, since the caregivers themselves are also parents, they also needed to care for their own children. This result was consistent with those of other studies. However, as the incomes of the caregivers in Penghu was relatively lower, they had to rely on their own finances or the social resources provided by the government to give care to their care recipients.

(2) In terms of the depressive symptoms on caregivers of people with neurocognitive disorders in Penghu: Their average depressive score was 19.50, which was eight points higher than the average depressive score of 11.3 of caregivers in Taiwan.[34] In addition, 62.8% of caregivers had depressive symptoms, which showed that caregivers in Penghu had rather high depressive levels. With regard to the demographic variables influencing the depressive levels of caregivers, gender had the highest influence, followed by self-perceived health status. These findings are similar to those of recent studies.[13,35] Furthermore, 54% of the caregivers of people with neurocognitive disorders in Penghu had dysfunctional families. Most of the families lacked adaptation, which indicated that the caregivers had to face difficulties on their own as their family members were unable to provide assistance. Statistical results also showed a negative correlation between the caregivers' depressive symptoms and their family functioning, which solidified the close relationship between good family functioning and psychological health as mentioned in the literature

(B=1.27, OR=3.55, CI=1.39, 9.08, p< 0.01). Overall, support groups for families have a high contribution towards promoting the caregivers' quality of life.

(3) In terms of the social resource usage of the caregivers: The results showed that the resources mostly used by caregivers in Penghu were outpatient treatment, disability card application, foreign care workers, and in-home care services; while the most satisfied resource was in-home care services. Meanwhile, the employment of foreign care workers can reduce caregivers' depressive symptoms. However, the inconsistent nature of foreign care workers had generated polarizing reviews from the caregivers; since most of the families without foreign care workers were low-income households, there is a possibility that the need to employ foreign care workers could be forcibly decreased due to economic burdens, which leads to increased depressive symptoms and caregiving burden among caregivers. The interviews also revealed that the caregivers lacked a sense of trust toward the application and allocation of social resources, as they perceived that the social resources were mostly pork barrels and were not willing to apply for the resources. Moreover, they had complaints toward the contents and application procedure and process of the resources, nor did not know where the resources can be obtained. 68.9% of the caregivers perceived that the existing social resources fail to meet their requirements. Yet, 53.8% revealed that they would still use any available social resources. This finding is in line with that of Peng and Lee, as the higher the caregivers' depressive symptoms, the more social resources utilized by them. However, the social resource usage had no significant correlation with their caregiving burden. Therefore, issues related to the application and allocation of social resource usage in Penghu require further exploration to identify the social resources that fully meet the requirements of caregivers of people with neurocognitive disorders in Penghu, which is beneficial for reducing the caregivers' burdens and depressive symptoms.

(4) In terms of caregiver burden: The caregiver burden is associated with various demographic variables such as gender, employment of foreign care workers, education level, monthly income, self-perceived health status and living with the care recipient. The variable with the highest influence on caregiver burden was self-perceived health status, followed by gender. The caregiver burden correlated negatively with family functioning and correlated positively with depressive symptoms. There was no significant correlation between caregiver burden and social resources. The regression analysis showed that depressive symptoms had the most influence on caregiver burden, followed by self-perceived health status. Education level was the main factor influencing caregiver depressive symptoms, as those with a college education had lower depressive tendencies. This showed that in rural and conservative regions with less access to information, education has positive influences on alleviating the depressive symptoms on caregivers of people with neurocognitive disorders.

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