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ORIGINAL ARTICLE

Caregiver Burden for Patients with Dementia with or Without Hiring Foreign Health Aides: A Cross-Sectional Study in a Northern Taiwan Memory Clinic

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Background: The aim of the present study was to determine the prevalence, profile, and severity of dementia and the relative impact of these factors on caregiver burden in a selected population of persons with dementia and their caregivers. **Methods:** A convenience sample of 100 outpatients and their family caregivers dyads who presented to a memory clinic in one medical center during one consecutive year were recruited. The diagnosis and severity of dementia were determined according to the Diagnostic and Statistical Manual of Mental Disorders, Version IV, Text Revision. The clinical dementia rating scale, mini-mental status examination, and Clinical Global Impression of severity were also administered. The caregiver strain index was used to assess caregiver burden. **Results:** Caregiver burden is related to the severity of dementia, impairment of cognitive function, and severity of neuropsychiatric symptoms. The caregivers who were younger, nonspousal family members, had a poor relationship with the dementia patient, and psychosomatic symptoms after caring for the patient, or provided longer hours of care-giving, experienced greater strains. Hiring foreign helpers was not associated with a lower caregiver burden. **Conclusions:** Greater caregiver burden is associated with several factors related to persons with dementia and their caregivers. A possible over-burden on caregivers should be of concern in Taiwan. Hiring foreign helpers was not associated with a lower caregiver burden.

Key words: Dementia, caregiver burden, foreign health aides

INTRODUCTION

There are 35.6 million people who have dementia and 7.7 million new cases every year worldwide.[1] Between 2011 and 2012, 130,000 people or 4.97% of those aged 65 and over in Taiwan had dementia.[2] In Taiwan, about 80% of the dementia patients are cared by their family members, a situation similar to that in Western countries.[3] Since family caregivers play an essential role in the care of these patients, the stress from care-giving often threatens the caregivers' mental and physical health or even their quality of life.[4-6] Caregiver strains have been defined as a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the care-giving experiences.[5-7]

Caregiver burdens or strains are often heavy and usually affect the health of both caregivers and care-recipients.[8] Several tools have been developed to assess caregiver burdens in terms of physical burden, psychological/emotion burden, social burden, economic burden and development restraint burden,[9,10] and even mental health problems.[11] Previous studies have suggested that disease-related factors, caregivers' sociodemographic factors, and care-giving-related factors are three important contributors to caregiver burdens.[10,12]

Since 1992, foreign workers have started immigrating to Taiwan, among these workers, up to 167,980 foreigners, in 2008, became foreign nurse aides and caregivers,[13] some of them work in long-term care facilities,[14,15] and some of them work at their employers' home as foreign home care helpers for the dementia patients.[13,16-19] The influence of whether

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hiring foreign helpers on the caregiver burden would also be investigated.

MATERIALS AND METHODS

Informed consents

All participants, patients with dementia, and their caregivers provide their written informed consents to participate in the study, and the next of kin or legally authorized representative consented on the behalf of participants with dementia.

Subjects and clinical assessments

Using convenience sampling, we recruited 100 dyads of patients with dementia and their caregivers who together visited the outpatient memory clinic in a medical center during 1 year. Individuals living in institutions or in-patients with severe physical disease were not eligible for inclusion. One senior board-certified psychiatrist with a subspecialty in geriatric psychiatry confirmed and assessed the diagnosis, type, and severity of each patient with dementia according to the Diagnostic and Statistical Manual of Mental Disorders, Version IV, Text Revision. Two certified psychiatric social workers interviewed the caregivers, with semi-structured questionnaires for collection of the demographic data, relationship between the family caregivers and the dementia patients, and self-report psychological and somatic symptoms, such as depression, anxiety, headaches, or digestive problems of the caregivers.

Data about dementia patients included their demographics, diagnosis, clinical dementia rating scale (CDR), mini-mental status examination (MMSE), and Clinical Global Impression of Severity (CGI-S) as determined by the psychiatrist. Caregiver data were collected during face-to-face interviews in the outpatient clinic, by the two experienced psychiatric social workers who then completed the caregiver strain index (CSI).

The CDR consists of six domains such as memory, orientation, judgment/problem solving, community affairs, home hobbies, and personal care. CDR scores range from 0 to 3, 0 means healthy, 0.5 questionable or very mild impairment, 1 mild impairment, 2 moderate impairment, and 3 severe impairment. This scale is commonly used to stage dementia of Alzheimer's type,[20-22] vascular or other types of dementia, and cognitive impairments.[23-25]

Dementia patients are frequently associated with behavioral and psychological disturbances or neuropsychiatric symptoms.[26] The CGI rating scale is commonly used to measure symptom severity, treatment response, and the efficacy of treatments.[27,28] The CGI-S scale is a 7-point scale that requires the clinician to rate the severity of the patient's illness at the time of assessment relative to the clinician's experience with patients who have the same diagnosis. Considering total clinical experience, a patient is assessed by the rater on the severity of mental illness at the time of rating as 1 normal not at all ill, 2 suspect mentally ill, 3 mildly ill, 4 moderately ill, 5 markedly ill, 6 severely ill, or 7 extremely ill. This scale has been used with different diagnoses including schizophrenia,[29,30] bipolar disorder,[31] panic disorder and depression,[32] and dementia.[33]

The MMSE is a brief 30-point questionnaire that is used to screen for cognitive impairment.[34] It samples functions including arithmetic, memory, and orientation. In our study, we used two cut-off points to divide patients' MMSE scores into 3 groups. Group 1 as MMSE scores <10 meant severe impairment. Group 2 as MMSE scores from 10 to 24 meant mild to moderate impairment. Group 3 as MMSE scores >24 meant normal. The MMSE has also been used to estimate the severity of cognitive impairment[35] and to follow the course of cognitive changes in an individual over time,[36,37] thus making it an effective way to document an individual's response to treatment.[38,39]

The CSI is a tool that can be used to identify quickly families with potential concerns about care-giving. It was developed by Robinson in 1983 to screen for strain in caregivers of patients with chronic illnesses.[40,41] The CSI is a 13-question tool that measures strain related to the provision of care. CSI scores range from 0 to 13 with a cut-off point of 7; scores under 7 mean a low burden and those above 7 mean a high burden. CSI covers physical, social, financial, and emotional domains. The internal consistency of the CSI, as assessed by Cronbach's α, was 0.86.[40] This index has been used to evaluate caregiver burden for major mental or physical illnesses, such as schizophrenia or bipolar disorder,[42] spinal cord injuries,[43] dementia,[44-48] Parkinson's disease,[49,50] and older patients with cancers.[51]

Approvals

All procedures performed in studies involving human participants were in accordance with the Ethical Standards of the Institutional and/or National Research Committee and with the 1964 Helsinki declaration and its later amendments or comparable Ethical Standards. (TSGHIRB-1-102-05-102).

Statistical analyses

Demographic data are presented as frequencies, percentages, means, and standard deviations (SD). Correlations between caregiver burden and variables including patient and caregiver demographic factors, disease-related factors, and care-giving-related factors were assessed with Pearson's correlation coefficient and Spearman's correlation coefficient according to the characteristics of the data. All statistical tests were two-tailed, and values of $P < 0.05$ were considered statistically significant. Data were analyzed with IBM SPSS statistics version 22 (IBM® SPSS® Statistics 22).

RESULTS

Dementia patients and disease-related characteristics

The ages of dementia patients ranged from 59 to 99 (mean = 79.9) and 56% were female. The mean age at diagnosis was 76.73 and the average disease course was 2.7 years. With regard to type of dementia, 64% were diagnosed as Alzheimer's dementia, 27% as vascular dementia, 7% as mixed dementia, and 2% as other. About 90.1% of the dementia patients had other physical problems. About 69% had significantly impaired memory function. In terms of behavioral and psychological disturbances, 37% had nighttime wandering and about 26% had agitated behavior and depressed mood. For cognitive enhancement pharmacotherapy, 72% received none, 7% donepezil, 12% rivastigmine, and 9% memantine.

CDR scores ranged from 0.5 (very mild) to 3 (severe) and were divided into 4 groups such as group 1 (very mild, CDR score = 0.5) accounted for 1%, group 2 (mild, CDR score = 1) 43%, group 3 (moderate, CDR score = 2) 37%, and group 4 (severe, CDR score = 3) 19%. MMSE scores ranged from 0 to 29 and were divided into 3 groups such as group 1 (MMSE score <10) accounted for 29%, group 2 (MMSE score = 10 and <24) 64%, and group 3 (MMSE score was ≥24) 7%. CSI-S scores ranged from 2 to 4 and were divided into three groups such as group 1 (CGI-S score = 2) made up 24%, group 2 (CGI-S score = 3) 56%, and group 3 (CGI-S score = 4) 20% [Table 1].

Caregiver and caring-related characteristics

The caregivers ranged in age from 18 to 86 (mean = 57.38) and 60% were female. With regard to marital status, 16% were single, 82% married, and 2% widowed. Of the dementia patients, 31% were cared for by spouses, and 69% were cared for by nonspousal family members, including children and their spouses (66%) and grandsons or granddaughters (3%). In terms of resident status, 74% lived together with the dementia patient. Twenty-eight percent were unemployed, 8% worked part time jobs, 33% had full-time jobs, and 31% were retired. For level of education, 3% were illiterate, 9% were elementary school graduates, 12% junior high school, 25% senior high school, 47% college, and 4% graduate school and above.

Most of the caregivers received help from others–74% from other family members and 32% from foreign domestic helpers. On average, caregivers spent 8.85 h/day and 2.87 years in care-giving. In caring for dementia patients, 77% developed psychological and somatic symptoms such as depression, anxiety, headaches, or digestive problems. Of the self-reported health condition of caregivers, 11% considered themselves very good, 22% good, 35% normal, 30% poor, and 2% very poor. Thirty-two percent of caregivers reported that their relationship with the dementia patient now at that time was very good, 30% good, 26% normal, 10% poor, and 2% very poor [Table 2].

Table 1: Demographics of persons with dementia

Variables	*n*=100	Percentage
Gender		
Male	44	44
Female	56	56
Age (years)		
Mean±SD, range	79.96±7.29, 59.7-99.3	
<65	5	5
65-85	71	71
>85	24	24
Diagnosis at age (years)		
Mean±SD, range	76.73±7.55, 55-99	
<65	7	7
65-85	81	81
>85	12	12
Disease course (years)		2.7
≤5	91	91
6-10	7	7
>10	2	2
Diagnosis		
AD	64	64
VaD	27	27
Mixed D	7	7
Others	2	2
CDR		
0.5	1	1
1	43	43
2	37	37
3	19	19
MMSE		
Mean±SD, range	13.79±6.79, 0-29	
<10	29	29
10-24	64	64
>24	7	7
CGI		
2	24	24
3	56	56
4	20	20

SD = Standard deviation; CGI = Clinical Global Impression; MMSE = Mini-mental status examination; CDR = Clinical Dementia Rating; VaD = Vascular dementia; AD = Alzheimer's disease

Table 2: Demographics of caregivers

Variables	*n*=100	Percentage
Gender		
Male	40	40
Female	60	60
Age (years)		
Mean±SD, range	57.38±13.07, 18-86	
Marital status		
Single	16	16
Married	82	82
Widowed	2	2
Education		
High school or less	49	49
College or higher	51	51
Kinship to persons with dementia		
Spouse	31	31
Nonspouse[a]	69	69
Co-residence		
Yes	74	74
No	26	26
Help from other family member		
Yes	74	74
No	26	26
Help from FDH		
Yes	32	32
No	68	68
Number of hours of care-giving/daily		
Mean±SD, range	8.85±6.18,0 0.5-24	
Number of years of care-giving		
Mean±SD, range	2.87±2.89, 0.08-20	
Employment		
Unemployed	28	28
Part time	8	8
Full time	33	33
Retired	31	31
Health condition (self-report)		
Very well	11	11
Well	22	22
Normal	35	35
Poor	30	30
Very poor	2	2
Psychosomatic symptoms after caring		
Yes	77	77
No	23	23

Contd...

Table 2: Contd...

Variables	*n*=100	Percentage
Relationship with dementia patient now		
Very well	32	32
Well	30	30
Normal	26	26
Poor	10	10
Very poor	2	2
CSI score		
High burden≥7	73	73
Low burden<7	27	27
Social Support Scale		
Family subscale		
Mean±SD, range	1.73±0.80, 0-3	
Hospital subscale		
Mean±SD, range	0.89±0.76, 0-3	
Hiring a foreign domestic helper	32	32

[a]Children or their spouse, grandson/granddaughter. SD = Standard deviation; CSI = Caregiver strain index; FDH = Family Drug Help

Caregiver burden and its association with dementia

CSI scores ranged from 0 to 13, the mean was 8.85 (SD = 3.675), and 73% were in the high burden (>7) group [Table 3].

The 3 highest scores were "some behavior is upsetting" (0.85 ± 0.359), "there have been emotional adjustments" (0.83 ± 0.378) and "there have been changes in personal plans" (0.83 ± 0.378). The 3 lowest scores were "I feel completely overwhelmed" (0.39 ± 0.490), "care-giving is a financial strain" (0.46 ± 0.501) and "there have been work adjustments" (0.52 ± 0.502).

Correlations among predictors and caregiver burden

There were small to moderate positive relationships between CDR, CGI-S, number of hours in care-giving, current relationship with the dementia patient, psychosomatic symptoms after caring, and caregiver burden. The CSI was correlated with the severity of dementia (CDR, $r = 0.507$, $P < 0.01$), impairment of cognitive function (MMSE, $r = -0.506$, $P < 0.01$), and severity of neuropsychiatric symptoms (CGI-S, $r = 0.225$, $P < 0.05$). The more severe the stage of impairment of cognitive function or progress of neuropsychiatric symptoms in persons with dementia the greater burden caregivers experienced. Caregivers who were younger ($r = -0.271$, $P < 0.01$), nonspouses ($r = 0.313$, $P < 0.01$) had a poor relationship with the dementia patient ($r = 0.240$, $P < 0.05$) had psychosomatic symptoms after caring ($r = 0.374$,

$P < 0.01$) or provided longer hours of care-giving ($r = 0.235$, $P < 0.05$) experienced greater burdens [Table 4].

Of the total of 100 caregivers, 32 hired foreign domestic helpers for assistance in caring for the dementia patients. There is no significant difference between the groups with or without hiring a foreign health aide in the MMSE scores, CDR, and CGI-S of the patients with dementia. However, 51 of those still had a high caregiver burdens (CSI score >7). Twenty-two of the 32 caregivers who had not hired any foreign helpers showed high caregiver burdens. There was no significant difference between the burdens of caregivers who hired foreign helpers and those who did not; however, the caregiver time spending to the dementia patients was significantly different between the two groups [Table 5].

DISCUSSION

The CGI-S, CDR, and MMSE of the patient were associated with the CSI of the caregiver. The higher the stage of dementia or severity of the neuropsychiatric symptoms or the lower the cognitive function of the patient the greater the burden on the caregiver. These findings are similar to those in previous studies.[24,52,53] We used CGI-S to rate patients' severity of neuropsychiatric symptoms, and most in this selected outpatient population were in the mild to moderately severe range. In previous studies that used the Neuropsychiatric Inventory (NPI) or other scales, similar findings suggested that the more severe the neuropsychiatric symptoms the greater the caregiver burden.[54-56] Even though we used a simple tool to rate the severity of neuropsychiatric symptoms, the findings were similar. This suggests that for clinicians, the CGI-S might be a good tool to evaluate both the symptom severity and the caregiver burden.

Previous studies have suggested that caregivers' gender, age, education, and living together with dementia patients were significantly related to caregiver burden. Caregivers with lower educational levels were at a disadvantage in accessing resources, had less ability to cope with stress and formulate strategies, tended to get depressed, and had higher case loading than those with higher levels of educational. In our study, however, caregivers' education level had no significant relationship with caregiver burden. In our study, when caregivers were younger, their burdens were greater. This finding was consistent with previous studies. Because 84% of caregivers were married (82% married, 2% widowed) and 69% were nonspouses (children and/or their spouses, grandsons or granddaughters), these caregivers not only cared for the dementia patient but also cared for their own children or worked. The caregivers played multiple roles at the same time, and overloading happened easily.

Table 3: CSI score distribution

	Mean±SD	Score
Total scores of CSI (n=100)	8.85±3.675	
My sleep is disturbed	0.7±0.461	70
Care-giving is inconvenient	0.74±0.441	74
Care-giving is a physical strain	0.58±0.496	58
Care-giving is confining	0.76±0.429	76
There have been family adjustments	0.76±0.429	76
There have been changes in personal plans	0.83±0.378	83
There have been other demands on my time	0.63±0.485	63
There have been emotional adjustments	0.83±0.378	83
Some behavior is upsetting	0.85±0.359	85
It is upsetting to find the person I care for has changed so much from his/her former self	0.8±0.402	80
There have been work adjustments	0.52±0.502	52
Care-giving is a financial strain	0.46±0.501	46
I feel completely overwhelmed	0.39±0.490	39

SD = Standard deviation; CSI = Caregiver strain index

Table 4: Correlations for the impact of caregiver demographics, disease and care-giving-related factors on caregiver burden

	Spearman's rho	P
CDR	0.507**	<0.001
MMSE	−0.506**	<0.001
CGI-S	0.225*	0.024
Caregiver age	−0.326**	<0.001
Number of hours of care-giving/daily	0.247*	0.013
Nonspouse caregivers	0.313	<0.001
Poor relationship with dementia patient	0.249*	0.013
Psychosomatic symptoms after care-giving	0.364**	<0.001

*P<0.05, **P<0.01. CDR = Clinical Dementia Rating; MMSE = Mini-mental status examination; CGI-S = Clinical Global Impression of Severity

Table 5: Comparison of cognitive functions, severity and caregiver burden between groups hiring a foreign aid or not

	Hiring a foreign health aide		P
	Mean value SD or n (%)		
	No (n=68)	Yes (n=32)	
CDR, ≤1/>1	30 (44.1)/38 (55.9)	14 (43.8)/18 (56.2)	1.000
MMSE	13.75±3.75	13.88±3.88	0.932
CGI-S	3.03±0.032	2.81±0.814	0.156
Caregiver time	9.83 giver	6.77 giver	0.020
CSI score	9.03 score	8.47 score	0.479
CSI, ≤7/>7	19 (27.9)/49 (72.1)	13 (40.6)/19 (59.4)	0.299

CDR = Clinical Dementia Rating; MMSE = Mini-mental status examination; CSI = Caregiver strain index; CGI-S = Clinical Global Impression of Severity; SD = Standard deviation

In general, closer kinship ties (spouse, child, and siblings) were an early factor found to influence caregiver burden.[12,57,58] In this study, those with a poor relationship with dementia patients experienced higher strains. Zarit *et al*. originally noted that wives experienced a greater caregiver burden, compared to other family members.[59] More recently, Chumbler *et al*. found no significant difference in caregiver burden between caregivers who were adult children or spouses.[60] Tang *et al*. found that about 52% of the caregivers in China were spouses.[61] Compared to Taiwan, Fuh found that most caregivers were adult children or daughters-in-law.[62,63]

In the Western literature, major caregivers were spouses,[64,65] but in the Asia-Pacific area, they were more often children. The profile of caregivers in our sample was comparable to that described in other Asia-Pacific studies.[66-68] In our study, many caregivers were adult male children, as well as female spouses, daughters, and daughters-in-law. The result was different from that in non-Asian countries. This may be related to oriental cultural values. "Xiao" or filial piety is considered a key virtue in Chinese culture and means to be good to or to take care of one's parents.[69-71] In our society, the percentage of elders living with the spouse or children was higher than that in Western countries as most family members believe that they have a responsibility to take care of elders because of Xiao. Having a good relationship between a patient and caregiver was related to greater caregiver burden. This paradoxical finding may partially explain the double-edged effects of ties between family members, either the caregivers or the recipients.

The average hours of care were 25–50 h/week in previous studies.[12,64,66] In our study, the average was 8.85 h/day or 61.95 h/week. Longer hours in caring resulted in a greater caregiver burden. In our study, psychosomatic symptoms after caring were positively correlated with caregiver burden. This suggests that when caring hour were longer, the caregiver burden increased, and psychosomatic symptoms also increased. In this study, 59.4% of the caregivers reported depression and anxiety and 59.4% sleeping disturbances, consistent with past studies. It is important to evaluate regularly the caregiver burden to decrease the risk of overload.

Tsao and Chiu reported that the assistance that foreign domestic helpers could provide reduced the psychological or physical burden on primary family caregivers for physically challenged elderly persons; however, these studies had smaller sample sizes (n = 13 and 17 respectively) and mixed disabilities.[16,17] In our study, there were no significant differences in caregiver burden between groups with or without foreign domestic helpers. These findings were not compatible with the anticipation that hiring foreign domestic helpers could reduce the caregiver burden. From the 2008 Report of Taiwan's Council of Labor Affairs, the main purpose (92.1%) in hiring foreign domestic helpers was to provide appropriate care to ill family members, share psychological stress (63.5%), and allow family to go to work (54.1%). In previous studies, 62% of the employers and families spend about 5 h/day taking turns with their foreign domestic helpers in caring for patients, instead of giving all the care work to the foreign domestic helpers.[13,18] In our study, the caregivers' time spending to the dementia patients in the group hiring foreign helpers is shorter than the group not hiring foreign helpers, as $6.77 \pm 5.57 < 9.83 \pm 6.25$ h a day ($P = 0.002$). However, the CSI scores are not significantly different between two groups. This hints that the caregivers who hire foreign helpers might have other stressors related to patient-caring, even though they have spared some time from caring the dementia patients. For example, the money expenditures on hiring foreign aides would be economic burden for them. The basic salary of one foreign health helper would cost a family additional 17,000 New Taiwan dollars (around USD 550 dollars) a month, not including the health insurance and other fees.[72]

Study limitations

Subjects were recruited from only one memory clinic in a medical center hospital in Northern Taiwan. The sample size was rather small, and the study utilized a cross-sectional design, and may describe only these patients and their caregivers and not all of Taiwan.

Considering the limitations of real-life clinical situations, we used the CGI instead of the NPI or other tools to evaluate the severity of neuropsychiatric symptoms and the behavioral and psychological symptoms of dementia, but the results were still consistent with those of studies using the NPI or other tools, in that caregiver burden was associated with symptom severity.[62,73]

The complex issues in caregiver-related factors should be included as predictors; these include caregiver overload, caregiver role captivity, and caregiver's experience with care-giving. More qualitative research is recommended to assess the true predictive value of the factors we investigated.

CONCLUSIONS

Greater caregiver burdens were related to moderate or severe dementia and the time spent in caring for the patients. The caregivers, who were younger, nonspousal family members, had a poor relationship with the dementia patient, had psychosomatic symptoms after caring, and provided longer hours of care-giving, experienced greater burdens. Hiring foreign helpers was not associated with a lower caregiver burden. The majority of the caregivers are offspring and, in this study, male offspring were over-represented. The great burden on caregivers should be of concern in Taiwan.

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Conflicts of interest

There are no conflicts of interest.

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