

SHORT REPORT

Caregiver burden and health-related quality of life among Japanese stroke caregivers

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Abstract

Objective: the present study had two main purposes: 1. To examine the relationship between caregiver burden and health-related quality of life in family caregivers of older stroke patients in Japan; and 2. To examine which characteristics of the caregiving situation significantly relate to increased burden.

Methods: subjects ($n=100$) were recruited from seven randomly selected neurological hospitals with out-patient rehabilitation clinics in western Japan and interviewed using the Zarit Burden Interview, the Modified Barthel Index, the Geriatric Depression Scale and the SF-12 Health Survey for health-related quality of life.

Results: increased caregiver burden was significantly related to worsening health-related quality of life, particularly worsening mental health (Geriatric Depression Scale and SF-12 items), even after controlling for caregiver age, sex, chronic illness, average caregiving hours/day, and functional dependence of the care-recipient.

Discussion: findings indicate that increased burden significantly relates to decreased health-related quality of life among stroke caregivers. In addition, the prevalence of depressive symptoms among caregivers was twice that of community dwelling older people. Roughly 52% of caregivers had Geriatric Depression Scale scores that warranted further evaluation. Despite the prevalence of depressive symptoms only one caregiver had received any psychiatric care during their caregiving tenure.

Keywords: caregiver burden, Geriatric Depression Scale, health-related quality of life, stroke caregivers

Introduction

Over the years, research on family caregivers has consistently demonstrated that increased caregiver burden relates to decreased mental and physical health [1–5], particularly among Alzheimer's and stroke caregivers [6]. Among stroke caregivers, mental health and social functioning have repeatedly been found to be the most severely compromised health-related quality of life domains [1, 7–9]. However, very little is known about stroke caregivers in Japan. In order to expand our knowledge of caregivers in different cultures we examined Japanese family caregivers of post-stroke patients. Based on the above studies, we hypothesised that as Japanese stroke caregivers' degree of burden increased, that their health-related quality of life (HRQOL) would significantly

decrease, particularly their mental health and social functioning.

Methods

Seven private neurological hospitals with outpatient rehabilitation clinics in a metropolitan area in western Japan were randomly selected (54% of total). All facilities agreed to participate in the study. Participation was limited to stroke patients who were 45 years or older with no diagnosis of Alzheimer's dementia. Family caregivers were defined as co-resident family members who assisted with most, if not all, of the patient's daily care needs. Sample inclusion was limited to patients and caregivers with no previous psychiatric history. The participation rate was 100% for the eligible family caregivers.

Measures

Caregiver burden was measured with the Zarit Burden Interview (ZBI) [10] which is widely used and has been translated and published in Japanese [11, 12].

Health-related quality of life was measured using 12 of the 36 items from the psychometrically and clinically validated Japanese version of the SF-36 Health Survey [13, 14]. These 12 items comprise the English version SF-12 [15]. These items measure 8 dimensions of HRQOL which are listed in Table 1.

Stroke patient functional dependency was measured using the Modified Barthel Index (MBI) developed by Shah [16].

Caregiver depressive symptoms were measured with the Japanese version of the GDS Short Form 15-item version [17]. A cut-off score of 6 or greater on the GDS 15 is considered to be symptomatic of depression [18, 19].

Data was also collected on other variables that influence caregiver burden and/or health status such as: caregiver/care-recipient age, sex (1= male; 2= female), relationship to care-recipient, education, duration of caregiving (in months), average daily hours of caregiving, and availability of a respite caregiver (either paid or unpaid) (1=yes, has subcaregiver; 2=no subcaregiver), and chronic illness (1=yes, 0=no). In this study 'respite caregiver available' was defined as the presence of any paid or unpaid person upon whom the primary caregiver could rely to provide care to the patient if they themselves became unavailable for any reason. Caregiving was defined as assisting with the physical functional limitations resulting from stroke injury. The question regarding average daily number of caregiving hours was asked after the caregiver had completed the MBI scale thus enabling them to focus on the functional care needs of the patient.

Statistical analysis was performed with SPSS version 10.

Results

The majority of caregivers were women (74%) and/or spouses (71%) (see Table 2). Men caregivers were significantly older as a group. Wives reported significantly higher burden than other caregivers. The majority of caregivers (57.9%) had been caregiving for less than 2 years, however, 22% had been caregiving for over 5 years.

Factors related to caregiver burden

ANOVA between groups revealed that neither duration of caregiving, degree of patient functional dependency (MBI score), caregiver chronic illness, nor presence of a respite caregiver related to the degree of caregiver burden. However, increased caregiving hours significantly related to increased burden.

Health-related quality of life

Out of the eight HRQOL dimensions, caregivers rated their General Health (GH) lowest (see Figure 1). The

next lowest ratings were for vitality (VT), and for Mental Health (MH). Physical functioning, bodily pain and social functioning were the highest dimensions among Japanese stroke caregivers. There were no significant differences between men and women on any of the HRQOL items or subscales. Only 42.3% of caregivers reported their general health as 'good' compared to 63% of the care-recipients.

Geriatric depression scale

In terms of depressive symptoms, 52% of caregivers scored ≥ 6 on the GDS which indicates the need for further evaluation. This prevalence of depressive symptoms was more than double the rate (23%) found among community-dwelling Japanese older persons [19]. However, only one caregiver reported having received any psychiatric treatment during their caregiving tenure. There was no significant difference between men and women caregivers in terms of their GDS scores. However, depressive symptoms were higher among caregivers with a chronic illness. Increased burden was significantly related to increased depressive symptoms.

Hierarchical multiple regression analysis

Hierarchical multiple regression analysis was used to test the study hypothesis that increased burden would be significantly related to decreased HRQOL. In the first step, the caregiver characteristics of age, sex, and chronic illness were entered, in the next step, care-recipient physical functioning (MBI score) and average daily hours of caregiving were entered, in the third and final step, the total burden score was added to the predictive model.

This model was run ten times using each of the HRQOL dimensions, including the Physical Component Score and Mental Component Score, as the dependent variables.

Table 1 shows that in all the models only burden, caregiver age, and presence of a chronic illness were significant predictors of declining HRQOL scores after controlling for the effects of all the other variables. Thus, part of the difference in health-related quality of life is attributable to age. However, as shown in Table 1, age was not a predictor of pain, vitality, general health, social function, role emotional, or mental health, although chronic illness did predict pain and general health scores. The regression analysis revealed that the strongest predictor of declining HRQOL overall, was caregiver burden.

Discussion

This study is a first attempt to understand the relationship between caregiver burden and health-related quality of life among caregivers of older stroke patients in Japan. In terms of our study hypothesis we found that:

Table 1. Hierarchical multiple regression models predicting caregiver HRQOL (SF-12) subscales

Predictors	SF-12 subscales									
	PCS ^a	MCS ^a	Physical function PF	Role physical RP	Pain BP	General health GH	Vitality VT	Social function SF	Role emotional RE	Mental health MH
Step 1:	F=8.97***	F=1.90	F=5.46**	F=6.57**	F=6.07**	F=6.33**	F=1.44	F=1.72	F=1.45	F=0.837
C/Giver characteristics	R ² =0.293	R ² =0.081	R ² =0.201	R ² =0.233	R ² =0.219	R ² =0.226	R ² =0.062	R ² =0.074	R ² =0.063	R ² =0.037
Sex	-0.106	-0.115	-0.153	-0.099	-0.06	-0.057	-0.068	0.012	-0.079	-0.148
Age	-0.304	-0.107	-0.288	-0.36	-0.223	-0.195	-0.087	-0.021	-0.08	-0.105
Chronic illness	0.332	0.198	0.226	0.205	0.326	0.356	0.191	0.263	0.193	0.059
Step 2:	F=0.622	F=1.82	F=0.229	F=0.184	F=0.382	F=0.822	F=1.94	F=2.01	F=0.031	F=1.09
C/Recep characteristics	R ² =0.014	R ² =0.050	R ² =0.006	R ² =0.019	R ² =0.009	R ² =0.020	R ² =0.055	R ² =0.056	R ² =0.001	R ² =0.032
MBI	-0.086	0.187	-0.084	-0.04	-0.039	0.147	0.219	0.251	-0.035	0.108
Caregiving hrs/day	-0.133	-0.086	-0.068	-0.157	-0.111	-0.134	-0.057	-0.006	-0.023	-0.113
Step 3:	F=11.40***	F=18.16***	F=3.87*	F=3.21	F=16.90***	F=5.13*	F=5.43*	F=5.06	F=7.69**	F=15.38***
Caregiver burden	R ² =0.108	R ² =0.197	R ² =0.047	R ² =0.037	R ² =0.165	R ² =0.058	R ² =0.071	R ² =0.066	R ² =0.103	R ² =0.185
Burden	-0.353	-0.477	-0.232	-0.206	-0.437	-0.258	-0.287	-0.276	-0.345	-0.462

Values in bold were significant at the 0.05 level or greater.

$P \leq 0.05^*$; $P \leq 0.01^{**}$; $P \leq 0.001^{***}$

^aNote: PCS represents the Physical Component Score and is the transformed mean of the sum of PF, RP, BP, GH.

MCS represents the Mental Component Score and is the transformed mean of the sum of VT, SF, RE, MH.

Table 2. Sample means and frequencies for study variables

	Caregivers Mean (SD)	Care-Recipients Mean (SD)	Statistical Significance*
Age	60.36 (13.31)	69.35 (10.46)	ns
Burden score	28.33 (13.07)	NA	
MBI score	NA	65.98 (30.47)	ns
Caregiving duration (years)	4.76 (5.75)	NA	ns
Caregiving h/day	9.43 (6.08)	NA	Pearson's corr 0.33 $P=0.005$
	<i>N</i> (%)	<i>N</i> (%)	
Gender			ns
Male	26 (26)	55 (55)	
Female	74 (74)	45 (45)	
Relation to care recipient			ns
Wife	52 (52)	NA	
Husband	18 (18)	NA	
Daughter	19 (19)	NA	
Daughter-in-law	5 (5)	NA	
Son	2 (2)	NA	
Sibling	2 (2)	NA	
Other	2 (2)	NA	
Sub-caregiver available			ns
Yes	39 (38.5)	NA	
Chronic illness			ns
Yes	50 (53.2)	NA	
Depressive symptoms			
GDS score ≥ 6	52 (52.9)	NA	Pearson's corr 0.502 $P=0.000$

Note: NA means that the variable does not apply to that type of subject.

HRQOL subscale means are reported in Figure 1.

*Statistical significance refers to whether the variable in question significantly related to caregiver burden.

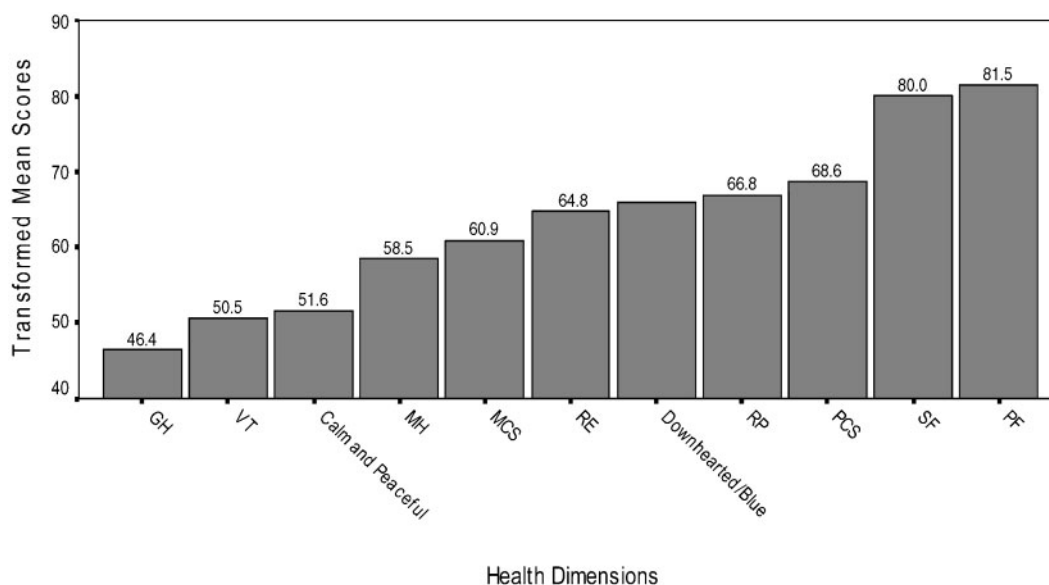


Figure 1. Comparison of mean health dimension scores among caregivers. Further detail is available to subscribers on the journal's website.

i. Increased burden is significantly related to decreased health-related quality of life, particularly mental health, among stroke caregivers even after controlling for caregiver age, sex, and chronic illness, as well as functional disability of the care-recipient, and average daily hours of caregiving. However,

there was no relationship between increased burden and caregiver physical functioning and role physical functioning in the regression analysis because age explained more of the variation in physical functioning.
ii. However, contrary to our expectations, although increased burden related to decreased social

functioning, compared to other studies [1, 7–9], social functioning was higher among Japanese caregivers.

Similar to other international studies of stroke caregivers, [1, 7] the rank ordering of HRQOL scores revealed that general health, vitality and mental health were ranked lowest. Stroke caregivers' perceptions of their own General Health were actually lower than those of their care-recipients', which concurs with other findings [8]. However, in contrast to these international studies, social functioning was higher among Japanese caregivers. This finding complements the data from the Zarit Burden Interview which revealed that unlike Western caregivers, Japanese caregivers do not report feeling that their social life has suffered due to their caregiving [20]. This may be an artefact related to differing cultural norms regarding the definition of 'social life'.

Although caregiver burden was not related to objective measures of care-recipient need such as functional dependency (MBI) or to social support factors such as the presence of a respite caregiver, increased daily hours of caregiving did relate to burden. Thus, caregivers who provided more hours of care did have the greatest burden but this burden was apparently not related to assisting with activities of daily living (MBI score). This finding supports the theory that caregiving hours are a subjective appraisal of care-recipient psychological, as well as physical, needs [21].

Several other studies have also found that burden among stroke caregivers is independent of the functional dependency or stroke severity of the care-recipient [7, 11, 22]. This is in contrast to characteristics of burden among Alzheimer's caregiving which have been found to relate to disease severity and decreased cognitive functioning [12, 23].

In our data, caregivers' total burden score was largely driven by their feelings of being 'depended on as the only one who could provide the care' and their subsequent lack of personal time [20]. Similarly, other studies have found that psychological changes in stroke patients such as dependency, irritability, and immature behaviour are often cited as the major cause of stress among caregivers [24, 25]. Thus, similar to other stroke caregivers, Japanese caregivers would be likely to benefit from counselling regarding how to deal with patient moods and how to manage their own private time in order to improve their sense of vitality and mental health. Current research suggests that caregiver stress is amenable to interventions such as support groups and counselling. Future research is needed to further investigate stroke caregiver needs in Japan and to test interventions to improve their quality of life.

Limitations

The generalisability of our findings is limited by small sample size and by the fact that only caregivers from one

area in Western Japan were examined. However, the sample was representative for this area and included a very diverse set of lifestyles and living situations from agrarian to urban. A further study limitation is that we relied on caregiver assessments of patient functional level (MBI score) rather than clinical reports, which may be different.

Key points

- Similar to their Western counterparts, Japanese stroke caregivers reported diminished general health, vitality, and mental health. However, in contrast, they did not report decreased social functioning. Differences in cultural norms pertaining to social functioning and its relationship to HRQOL warrant further investigations.
 - Greater caregiver burden among the Japanese stroke caregivers was related to age, sex, chronic illness, use of respite care, caregiving hours, and care-recipient functional status.
 - Although average daily hours of caregiving related directly to increased burden, care-recipient functional status was unrelated to burden. The bulk of stroke caregivers burden may derive from care-recipients stroke-related psychological, as opposed to physical dependency.
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