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〈原著論文〉

Perceptions of Burden Among Family Caregivers of Post-Stroke Elderly

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Abstract

The present study examines perceptions of caregiver burden among family caregivers of elderly stroke patients. From August of 1999 to March of 2000, 95 caregiver/care-recipient pairs (n=190) were interviewed at their outpatient rehabilitation clinics using the Zarit Burden Interview. Data was also collected on participants' age, sex, education and other variables. Care-recipients' functional dependence was measured using the Modified Barthel Index (MBI). Duration of caregiving, presence of a respite caregiver, and MBI score were not related to caregiver burden. However, burden did increase with daily caregiving hours. Patients' dependence on caregivers, caregivers' fears for the future, and their lack of personal time, comprised the greatest sources of burden. In contrast to American findings, factor analysis identified one factor containing all burden items except the two self-evaluations of caregiving ability, which loaded together on a second factor. Findings suggest that care-recipient's stroke-related psychological dependency and mood instability is the main source of burden among family caregivers of elderly stroke patients.

要約

目的：日本における高齢脳卒中後遺症患者の介護者の介護負担について明らかにすることである。

方法：脳卒中後遺症患者およびその介護者のペア（計190人）に，面接法による調査を行った．主な調査内容は基本属性のほか，介護期間，副介護者の存在などである．なお，介護者の介護負担はZarit Burdenスケール，脳卒中後遺症患者の機能的自立度はModified Barthel Index(MBI)を用いた．調査期間は1999年8月～2000年3月であった．

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結果：1日の介護時間の増加に伴い，介護負担も増加することが示唆された．介護負担の項目では，介護者に対する被介護者の依存度，将来への不安，介護者が自分自身の時間がもてないこと，および介護者の怒りに関する項目で，負担スコアの平均値が高く，また，高い度数(頻度)がみられた．一方，因子分析の結果，介護の質における介護者の自己評価に関する2項目を除き，すべての負担項目が含まれる一因子が明らかになった．

議論：調査結果によると，介護者への依存が負担の主要な要因となっている．しかし，ここでの負担は身体的というよりも心理的な負担であった．脳卒中障害による被介護者の心理的依存と情緒不安定が介護負担の主な原因の1つと考えられる．

キーワード

高齢脳卒中後遺症患者	post-stroke elderly
介護者	caregiver
介護負担	caregiver burden
Zarit Burden Interview	

I　INTRODUCTION

Despite recently increased long-term care benefits and services, family members will continue to provide a great deal of elderly care[1] . Given the population dynamics and the extent of long term care benefits, family caregiving is virtually an economic necessity. Among family caregivers, stroke caregivers are numerous. Stroke is the third leading cause of death in Japan and a source of great morbidity[2].

Family caregivers of elderly are themselves often elderly, frequently spouses, with their own health problems[3]. Numerous studies have shown that family caregivers are at increased risk for both decreased mental and physical health[4] . However, the characteristics of caregiver burden have been found to differ in terms of the patient's illness[3]. International studies of stroke caregivers' in particular have found especially high negative psychological outcomes[5-7] and depressed mood[8].

Similarly, Japanese studies have found that increased behavioral disturbances and/or cognitive decline among patients relate to increased caregiver burden9)-11). Caregiver's physical and mental health have also been reported to decline with increased burden10), particularly among older caregivers. However, care recipients in these studies represent various illnesses and conditions such as "frail elderly"12) or "elderly eligible for home health visits"13-14) or elderly with unspecified "dementia"10). Stroke caregivers were undoubtedly included in these heterogeneous samples. But there has been little examination of the characteristics of burden specific to stroke caregivers.

The present study examines perceptions of caregiver burden among family caregivers of post-stroke elderly in order to understand their unique experience and to gain insight into the types of services that would be of greatest benefit to this population.

II METHODS

Sample

Seven outpatient rehabilitation clinics in western Japan were randomly selected and all facilities agreed to participate in the study. The facilities included inner city, suburban and rural sites, thus the sample was geographically diverse. Stroke patients who lived with a family caregiver and who did not also have a diagnosis of Alzheimer's dementia were identified from the patient records and invited to participate in the study. The participation rate was 100% for both caregivers and care-recipients. This high rate was due to the involvement of physicians at each site who helped explain the study to the participants.

Methods

The family caregivers and post-stroke care-recipients were interviewed at the rehabilitation clinic by the principal investigators after receiving informed consent. Caregivers and care-recipients were interviewed separately. Interviews took approximately 40-60 minutes per subject.

Measures

Caregiver Burden

The Zarit Burden Interview (ZBI) was selected to measure caregiver burden as the reliability and validity of the Japanese version has been found to be high[9,13] . The present study used the translation by Hirono et al. (1998)[9]. Higher scores indicate greater burden.

Stroke Patient Physical Functioning Level

The Modified Barthel Index (MBI)[15] was used to measure the care-recipients' degree of physical dependence on the caregiver. The MBI measures self-care ability in personal hygiene, bathing, feeding, toileting,

Table 1 Sample Characteristics

	Caregivers			Care-Recipients		
	Male	Female	Total	Male	Female	Total
Sex	34.90%	65.10%		56.30%	43.70%	
Mean Age	65.62	59.66	61.27	69.48	70.82	70.07
ZBI Mean Score	26.25	29.11	28.33			
MBI Mean Score	(care-recipient only)			67.84	68.83	65.96
Mean Caregiving Duration (in years)	4.69	4.79	4.76			
Mean Daily Caregiving Hours	10.25	9.13	9.43			
High School Education or Higher	53.80%	73.10%	68.50%	60.00%	68.40%	73.00%
Sub-Caregiver Available	30.20%	47.10%	38.50%			

stair climbing, dressing, bowel control, bladder control, ambulation, and bed/chair transfers. Scores rank patients into the following severity levels: 0-49 points=Total to Severe Dependency; 50-74 points=Moderate Dependency; 75-90 points=Mild Dependency; and 91-105 points=Minimal Dependency. Higher scores indicate greater independence.

Control variables

Data was also collected on caregiver/care-recipient age, sex (1=male; 2=female), education, duration of caregiving, average daily hours of caregiving, and presence of a respite caregiver (1=yes, has respite caregiver; 2=no respite caregiver).

Table 2 Caregiver Relationship to Care-recipient, Caregiving Duration and Daily Hours Spent Caregiving

■ Caregiver Relationship to Care-recipient	Percent	Mean Age
Wife	52.7	65.92
Husband	19	69.13
Daughter	16.5	43.53
Daughter-in-law	6.5	54.2
Son	2.7	37.5
Sibling	2.6	63.5
■ Duration of caregiving		
less than 24 months	48.68	
24-48 months	17.11	
49-60 months	6.58	
61 months or more	27.63	
■ Hours spent caregiving per day		
less than 3	6.76	
3-5 hours	33.78	
6-15 hours	32.43	
16 hours or more	27.03	

III RESULTS

Sample Characteristics

Sample characteristics are reported in Table 1. Similar to other studies, most caregivers were wives with an average age of 60.84 (see Table 2). Care-recipients average age was 70.77. Men were slightly older as caregivers (65.6 vs 59.6) but the age difference was not significant. There was

Table 3 Means and Intercorrelations of Zarit Burden Interview Items

	Mean										
ZBI 1	1.08	ZBI 1									
ZBI 2	1.70	0.45	ZBI 2								
ZBI 3	1.39	0.57	0.38	ZBI 3							
ZBI 4	1.05	0.40	0.29	0.44	ZBI 4						
ZBI 5	1.97	0.21	0.24	0.42	0.19	ZBI 5					
ZBI 6	0.41	0.38	0.28	0.37	0.28	0.21	ZBI 6				
ZBI 7	2.48	0.22	0.32	0.22	0.21	0.20	0.09	ZBI 7			
ZBI 8	3.09	0.21	0.47	0.26	0.11	0.30	0.07	0.07	ZBI 8		
ZBI 9	0.60	0.08	0.11	0.13	0.19	0.04	0.10	0.10	0.05	ZBI 9	
ZBI 10	1.19	0.24	0.52	0.37	0.21	0.32	0.20	0.23	0.31	0.13	ZBI 10
ZBI 11	0.45	0.33	0.32	0.39	0.17	0.23	0.48	0.16	0.02	0.03	0.16
ZBI 12	1.04	0.36	0.19	0.40	0.08	0.27	0.20	0.16	0.02	−0.13	0.20
ZBI 13	0.95	0.21	0.17	0.07	0.19	0.16	0.42	0.27	−0.04	0.16	0.21
ZBI 14	2.89	0.32	0.46	0.24	0.15	0.27	0.14	0.18	0.69	0.09	0.30
ZBI 15	1.16	0.28	0.24	0.33	0.17	0.29	0.20	0.35	0.08	−0.08	0.07
ZBI 16	0.45	0.43	0.31	0.33	0.28	0.28	0.13	0.13	0.02	−0.13	0.42
ZBI 17	1.19	0.28	0.29	0.38	0.12	0.33	0.29	0.32	0.24	0.27	0.50
ZBI 18	1.00	0.44	0.29	0.42	0.06	0.37	0.37	0.06	0.29	0.03	0.43
ZBI 19	1.00	0.35	0.18	0.18	0.37	0.26	0.14	0.29	0.07	−0.01	0.03
ZBI 20	1.57	0.26	0.07	0.21	0.20	0.08	0.09	0.21	−0.01	0.18	−0.12
ZBI 21	1.60	0.17	0.03	0.27	0.23	0.16	0.04	0.21	0.01	0.10	−0.08
ZBI 22	1.45	0.29	0.41	0.50	0.33	0.45	0.25	0.34	0.19	0.17	0.53
ZBI SUM	28.33	0.664053	0.634308	0.705911	0.49718	0.543953	0.481724	0.496943	0.422972	0.225716	0.547014

Numbers in gray indicate correlation is significant at the 0.01 level (2-tailed).

essentially no difference in mean age of stroke patients by sex. Seventy-three percent of stroke subjects and 68.5% of caregivers had a high school or higher education. Average duration of caregiving, was 4.76 years (see Table 1 for frequency distribution) and average daily hours of caregiving was 9.43 (see Table 1). The mean Modified Barthel Index (MBI) score for the patients was 65.96 indicating a moderate level of functional dependence.

Structure of Burden

Table 3 reports on means and intercorrelations (Pearson's correlations)

ZBI 11											
0.42	ZBI 12										
0.20	0.26	ZBI 13									
0.19	0.04	0.05	ZBI 14								
0.15	0.27	0.07	0.16	ZBI 15							
0.23	0.56	0.19	0.14	0.15	ZBI 16						
0.43	0.40	0.30	0.21	0.25	0.28	ZBI 17					
0.22	0.26	0.24	0.21	0.34	0.26	0.44	ZBI 18				
0.22	0.15	0.21	0.08	0.28	0.29	0.15	0.18	ZBI 19			
0.29	0.26	0.24	0.01	0.13	0.09	0.16	0.11	0.44	ZBI 20		
0.14	0.24	0.18	0.05	0.12	0.17	0.08	0.06	0.39	0.62	ZBI 21	
0.32	0.25	0.25	0.23	0.40	0.43	0.56	0.45	0.33	0.14	0.38	ZBI 22
0.51412	0.519662	0.444115	0.494403	0.47243	0.505847	0.641459	0.581679	0.493138	0.432373	0.403367	0.68

of Zarit Burden Interview (ZBI) items. ZBI SUM represents the sum of ZBI items 1-21. The correlation between this sum and question 22, which is an overall global indicator of burden, was .68 (p=.001) indicating that the survey had high internal validity. Cronbach's Alpha for all the 21 items was .85. Some of the highest correlations are between items measuring feelings of dependency I(ZBI 8 & 14) and loss of personal time (ZBI 2). These items, along with feelings of anger and fear of the future, also had the highest means.

Frequency Distribution of Items

Table 4 reports on the items with the lowest and highest frequencies of "never" responses. The items with the lowest frequency of "never", i.e. the highest burden, concerned feelings of being depended on and being the only one who could provide care (ZBI 8 & 14). The highest burden was evidenced by this feeling with 56% and 58.7% of caregivers, respectively, stating that they "nearly always" felt this way. As noted in Table 3 these items were highly intercorrelated (.69). Only 8% of caregivers reported that they "never" felt anger regarding their caregiving role.

The items with the least reported burden concerned the effect that caregiving had on relationships with other family members, personal privacy, and social life. These items comprise a factor described as "Role Strain" in US data[16]. In general, the majority of caregivers reported "never" having these feelings. Loss of privacy or social life (i.e. "Role Strain") were not major concerns in this sample.

Intercorrelations Between All Study Variables

Caregiver burden was not related to duration of caregiving, nor having a respite caregiver, nor patient's functional level (MBI) (see Table 5). However, higher average daily caregiving hours was significantly related to greater burden. Although MBI score did not relate to burden it was signifi-

Table 4 ZBI Items with the Heaviest and Lightest Degree of Burden Among Stroke Caregivers

	Lowest Percent of 'Never' Responses		
Heaviest Burden	Nearly Always	Quite Frequently	Never
ZBI 8 feel that your relative is dependent on you?	56	16	4
ZBI 5 feel angry around your relative?	5.3	21	8
ZBI 7 afraid of what the future holds for your relative?	37.3	9	12
ZBI 14 relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?	58.7	8	15
ZBI 20 should be doing more for your relative?	12	13	30
ZBI 21 could do a better job in caring for your relative?	13.3	13	33
ZBI 2 because of the time you spend with your relative that you don't have enough time for yourself?	18.9	11	35
ZBI 3 stressed between relative care and other responsibilities	6.7	17	41
ZBI 10 health has suffered because of involvement with relative	12	4	43
ZBI 18 wish you could leave care to someone else	1.3	5	44
ZBI 4 embarrassed over relative behavior	2.7	9	45
ZBI 19 uncertain about what to do about relative	2.7	9	49
	Highest Percent of 'Never' Responses		
Lightest Burden	Nearly Always	Quite Frequently	Never
ZBI 6 relationship with other family members affected in a negative way	4	11	77
ZBI 16 feel unable to take care of relative much longer	1.3	3	75
ZBI 11 lack privacy because of relative	4	11	73
ZBI 9 strained when around relative	2.7	3	68
ZBI 13 uncomfortable about having friends over	9.3	7	59
ZBI 15 don't have enough money to care for relative	12	11	53
ZBI 1 relative asks for too much help	1.4	15	51
ZBI 12 social life suffered because of caring for relative	6.7	5	51
ZBI 17 lost control of life since relative's illness	13.3	4	51

Note : Items in shadow represent items on factor identified as Role Strain (Whitlatch et al. (1991).

Table 5 Intercorrelations Between Study Variables

Spearman's Correlations	Care-Recipients sex			
Caregiver sex	−0.50	Caregiver sex		
Care-Recipient age	0.02	0.15	Care-Recipient Age	
Caregiver age	−0.23	−0.22	0.39	Caregiver Age
Duration of Caregiving(months)	−0.09	0.09	0.17	0.15
Education of Care-Recipient	0.14	−0.15	−0.35	−0.01
Education of Caregiver	0.23	−0.01	−0.11	−0.32
Average Daily Caregiving Time	−0.15	−0.07	0.03	0.19
Presence of Respite Caregiver	0.03	0.11	−0.15	−0.12
ZBI SUM(sum of items 1-21)	−0.19	0.07	−0.12	0.16
MBI Score	−0.05	0.00	−0.22	−0.27

Gray indicates correlation is significant at the .01 level (2 tailed)

cantly and positively correlated with average daily caregiving hours. To examine this relationship in greater detail a multiple regression model was tested using caregiver age and sex, patient MBI score and average daily caregiving hours as predictors of burden. Only caregiving hours was found to be significantly related to burden ($ß = .363$, $p = .009$) after controlling for the effects of the other predictors. This suggests that the amount of time caregivers spend taking care of stroke patients is not based primarily on actual physical needs but rather on caregivers' subjective assessment or appraisal of stroke patient needs.

Average daily caregiving hours were also strongly correlated with feelings of health suffering (ZBI 10) as a result of caregiving. Interestingly, older caregivers perceived care-recipients as more dependent on them (ZBI 8) and felt they were perceived as the only one who could provide the care (ZBI 14).

Factor Analysis

Exploratory analysis with unrotated principal factors solution identified two factors which explained 37.4% of the variance in the data (Table 6). Confirmatory analysis using both unrotated and rotated principal compo-

Duration of Caregiving					
−0.15	Education of Care-Recipient				
−0.19	0.60	Education of Caregiver			
−0.02	−0.27	−0.22	Average daily caregiving time		
0.10	0.12	0.05	−0.13	Respite caregiver	
0.04	−0.12	−0.20	0.33	0.11	ZBI SUM
0.08	0.17	0.02	−0.46	0.08	−0.23

nents solutions produced the same results. The first factor was comprised of all items except ZBI 20 & 21 (feeling you should be doing more and feeling you could do a better caregiving job).

In contrast to American findings, burden did not separate into Personal Strain versus Role Strain dimensions[16]. Role Strain, the degree to which caregivers felt their private and social life was hindered by caregiving, did not comprise a separate dimension of burden. Instead, Japanese caregivers perceived Role Strain and Per-

Table 6 Factor Analysis of Zarit Burden Interview Items

Factor 1		Factor 2
ZBI 1	0.695	
ZBI 2	0.635	
ZBI 3	0.737	
ZBI 4	0.493	
ZBI 5	0.562	
ZBI 6	0.527	
ZBI 7	0.451	
ZBI 8		-0.575
ZBI 9	0.165	
ZBI 10	0.568	-0.464
ZBI 11	0.557	
ZBI 12	0.554	
ZBI 13	0.421	
ZBI 14	0.460	-0.495
ZBI 15	0.464	
ZBI 16	0.554	
ZBI 17	0.645	
ZBI 18	0.619	
ZBI 19	0.471	0.446
ZBI 20		0.654
ZBI 21		0.613
Eigenvalue	5.780	2.143
%Variance	26.5%	37.4%

Principal Compenent Analysis (Unrotated). SPSS version 9 sonal Strain as a single dimension but had concerns about the scope and quality of their caregiving which were not related to other feelings of burden. The factor analysis suggests that many caregivers felt that they were not doing enough and not doing it well enough, regardless of how much they actually did.

Ⅳ DISCUSSION

Burden was reported the highest among wives and older caregivers. Burden was significantly correlated with hours of caregiving per day but not with caregiving duration or patient functional level.

The feeling of being overly depended on and the lack of personal time, rather than the actual physical functioning level of the care-recipient, were the greatest sources of burden. Arai et al. (1997)[13] also found the most prevalent and frequent kind of burden to be dependency. Similarly, Scholte et al. (1998)[7] found stroke caregivers' highest burden in the following item: "I feel that my partner seems to expect me to take care of him/her as if I were the only one he/she could depend on." (Sense of Competence Questionnaire). However, their sample of Dutch caregivers, in contrast to the Japanese, did express feelings of loss of social life (Role Strain) secondary to their caregiving role. Bugge, Alexander & Hagen's (1999)[17] study of stroke caregivers also found that this feeling of being completely depended on was the single greatest component of burden.

Importantly, Scholte et al. (1999)[7] found that patient physical disability only explained a small amount of the variation in caregiver burden. Anderson et al. (1995)[5] also found that patient physical disability was unrelated to the degree of caregiver emotional distress (as measured by anxiety and depression scales).

The fact that burden did not relate to physical functioning in most studies suggests that this is an emotional or psychological dependency that could be related to caregiver and/or care-recipient pre-stroke personality or to psychological changes from stroke injury. A qualitative study by Williams (1994)[18) found that patient irritability, dependence, and immature behavior were reported by caregivers as the most stressful aspects of caregiving.

V CONCLUSION

The findings clearly indicate that the main type of stroke caregiver burden is feeling overly depended upon and the subsequent lack of personal time. This dependency did not relate to patients' actual physical needs. In contrast, it appears to derive from patient's emotional needs or what Bethoux, Camels, Gautheron & Minaire's (1996)[19) stroke caregivers identified as the "psychological changes demonstrated by the patients".

In their review of caregiving literature, Given, Given, Stommel, & Azzouz (1999)[20) concluded that research has not demonstrated that patient physical demands, caregiver sex or relationship to caregiver affect caregiver mental health in any predictable or reliable way. However, the effect of stroke-specific psychological changes such as emotional dependency and mood swings on caregiver burden has not been rigorously examined. In addition, the relationship between caregiver personality and perceptions of burden warrants further analysis.

During the lengthy interviews with the caregivers various themes emerged. Firstly, the caregivers were very eager to talk about their caregiving experiences. It was clear that they were lacking an opportunity to express their caregiving experience and its challenges. Secondly, many caregivers expressed concern that their partner would not be able to tolerate the interview and became anxious if their partner was kept waiting for their interview to conclude. Several caregivers expressed concern that their partner would become angry and that this anger was a taken-for-granted aspect of their lives now.

Finally, this study is limited by its small sample size. It represents a first attempt to try to understand the needs of caregivers of post-stroke elderly. Findings suggest that, what stroke caregivers need most is counseling on how to deal with mood changes resulting from stroke injury and how to balance their caregiving role to make it less emotionally and physically stressful rather than services that help with actual caregiving tasks. More research needs to be done on stroke caregivers to identify how both interventions and individual differences may mediate their sense of burden.

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