

Factors Influencing the Burden on Caregivers of Stroke Patients with Hemiplegia Living at Home

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Abstract

Objective: The purpose of this study was to clarify the factors influencing burden on the caregivers of stroke patients with hemiplegia who live at home under their family's care.

Methods: From July 2009 to July 2013, 20 hemiplegic stroke patients who provided written informed consent and met the following criteria were included in the study: Brunnstrom recovery stage < 4, living at home at 6 months after discharge, and Barthel index < 95 at 6 months after discharge. Age, sex, number of caregivers, Barthel index, frequency of using nursing-care services, and frequency of voluntary standing or walking training were evaluated as independent variables. Results of the Zarit Burden Interview, which reflects the burden for caregivers, were evaluated as dependent variables. Variables were analyzed with a stepwise regression analysis.

Results: Factors that influenced the burden on caregivers were frequency of using nursing-care services, number of caregivers, sex of patients, and frequency of voluntary training.

Conclusion: In stroke patients with a high dependence on nursing-care services, the burden on caregivers was large. Caution must be used in extending the findings of this study to general practice, but our study suggests that a higher frequency of voluntary training and a larger number of caregivers reduces the burden on caregivers of stroke patients after discharge.

Keywords: Stroke; Burden on caregiver; Voluntary training

Introduction

When stroke patients with hemiplegia live at home, care by the patient's family is important. According to a 2013 report [1] on nursing care at home, the disease that necessitated the most nursing care was stroke, accounting for 21.7% of all patients in nursing care in Japan, and accounting for more than 30% with a high level of nursing care. Families with members in need of nursing care tend to consist of nuclear families and ageing spouses and 69.4% of caregivers reported experiencing "distress or stress in everyday life". Additionally, 72.6% of male caregivers and 78.3% of female caregivers reported "the family's sickness and nursing care" as a reason for "distress or stress in everyday life". During hospitalization, it is necessary to assess the burden on caregivers after the patient is discharged home. Kamel et al. [2] reported that caregivers of stroke patients had high scores on the Center of Epidemiologic Studies of Depression and the Caregiver Strain Index. Jaracz et al. [3] also reported that a higher burden on caregivers of stroke patients was associated with a lower capacity to deal with stress, higher emotional distress, and lower functional status of the patient.

In Japan, to address the accelerated ageing of the society and the increased needs for nursing care for the elderly, the government

launched the Long-Term Care Insurance System [4] for the elderly (LTCI, or Kaigo Hoken) in April 2000. The main purposes of this system were to promote independent living of the elderly in the community, to share the burden of care for the elderly among all members of society, and to reduce the burden on family caregivers. Evidence from micro-level household data suggests that the introduction of LTCI helped Japanese households reduce income losses associated with caring for a disabled family member [5].

The convalescent rehabilitation ward of Hanno-Seiwa Hospital in Japan also recommends a voluntary training program [6] that specializes in patient mobility, so that the patient's family may master the methods of care. However, it is unknown whether the LTCI and voluntary training program are useful for reducing the burden on caregivers of stroke patients. The purpose of this study was to clarify the factors influencing the burden on caregivers of stroke patients with hemiplegia who live at home under their family's care.

Methods

Subjects

Stroke patients with hemiplegia who were hospitalized in a convalescent rehabilitation ward of Hanno-Seiwa Hospital from July

2009 to July 2013 were retrospectively assessed, and those who met the following four criteria were included: (1) Brunnstrom recovery stage [7] (BRS) of the lower extremity <4 at discharge; (2) the patient living at home at 6 months after discharge; (3) Barthel index [8] (BI) <95 at 6 months after discharge; and (4) written informed consent provided by the patient. BI is a method of evaluating a patient's activities of daily living (ADL) and consists of 10 activity items, with a total score for each activity item of 100. The higher the total BI scores are the greater is patient's ability in ADL [8]. BRS is a method of evaluating hemiplegic recovery in stroke patients that consists of six stages, with selective joint motion impossible from stages 1 to 4 [7]. All patients underwent physiotherapy (PT), occupational therapy (OT), and speech therapy (ST), as described in the Appendix.

Outcome measures and statistical analysis

Age of the patient and primary caregiver, sex of the patient and primary caregiver, number of caregivers, patient BI, frequency of nursing-care service use through LTCI, and frequency of voluntary training were assessed. The main categories of at-home nursing care services used through LTCI include home-visit care, home-visit nursing, home-visit bathing service, home-visit rehabilitation, management guidance for in-home care, and rental service for assistive devices. Commuting services in Japan are defined as services delivered in a community-based facility, where users commute to receive personal care, support for ADL, and physical exercises, and they return home the same day [9]. Definition of voluntary training was "standing more than 100 times per day" or "walking outdoors more than 1 km per day".

These evaluations were conducted by a mail-back survey. The rehabilitation centre of Hanno-Seiwa Hospital mailed a survey form to all patients at 6 months after discharge, and patients who chose to participate mailed a completed survey form to the rehabilitation centre within 2 weeks. The Japanese version of the Zarit Caregiver Burden Interview [10] (J-ZBI) for primary caregivers was evaluated and used as a dependent variable; the J-ZBI is the Zarit Burden Interview [11] translated by Arai [10] into Japanese, and its high reliability and validity have been demonstrated [10]. Stepwise regression analysis was used for statistical analysis, and p values less than 0.05 were considered statistically significant. Statistical analysis was performed using Microsoft Excel with the "Statcel3" add-in.

Ethical approval was obtained from the Ethics Committee of Hanno-Seiwa Hospital, Japan (Approval No. 140104). The survey form mailed to the patients and family included a paper explaining how the assessment data would be used in this study. Therefore, patients and family who returned a survey form agreed to this study.

Procedure

Conventional rehabilitation program in the convalescent rehabilitation ward of Hanno-Seiwa Hospital

PT, OT, and ST based on the Japanese 2009 guideline for the management of stroke [12] were conducted daily for 1-3 units each (1 unit is 20 minutes, total 6-9 units). When the patient's general condition was unstable, PT was started from the bedside and included range of motion exercises, positioning, sitting exercises, and standing exercises. If the patient's general condition was stable, standing, mat, transfer, wheelchair movement, walking, and stair-climbing exercises were performed incrementally in a training room (gym). Additionally, in the walking and stair-climbing exercises for stroke patients with

hemiplegia, physiotherapists used a knee-ankle-foot orthosis or an ankle-foot orthosis, depending on the severity of the hemiplegia and exercise capacity. OT included ADL training, such as using the bathroom, grooming, dressing, and bathing, and arm exercises, including changing hand dominance. ST included exercises for dysphagia and aphasia.



Figure 1: Scenes of voluntary training with family members. The characteristics of this training are that the family members assist patients' mobility to acquire methods of voluntary training and mobility assistance at home. The characteristics of this program are a focus on standing training with the aim of improving trunk and dynamic balance and an emphasis on transferring, walking, and stair climbing/descent, which are directly linked to the ability to perform ADL.

Voluntary training program in the convalescent rehabilitation ward of hanno-seiwa hospital

Voluntary training was recommended to the patients and caregivers. The training included standing, transferring, walking, and stair climbing. The voluntary training for patients and caregivers was performed in addition to the conventional rehabilitation program. The voluntary training program is shown in Table 1, and scenes of voluntary training activities are shown in Figure 1. The voluntary training program used in the recovery phase was developed by Hirano et al. [6] and based on the acute phase voluntary training with family participation reported by Maeshima et al. [13,14]. The objective of this voluntary program was to help patients' families understand their relatives' conditions and learn appropriate assistance methods. Voluntary training was carried out apart from the conventional rehabilitation program; it was conducted focusing on four abilities, standing, transferring, walking, and stair climbing. Tasks were repeated so that family members could help the patient perform them safely and easily. There were also seven stages of training that comprised varying amounts and levels of difficulty, corresponding to each patient's degree of functional recovery. A physiotherapist provided the family members with initial instruction in the assistance methods, and the family members learned the methods by performing them under the supervision of the physiotherapist to confirm that the

training was being conducted safely. The voluntary training aimed to support the family members in preventing patients from falling. According to our previous study [15], the average frequency with

which patients over 65 years old trained voluntarily at home was 2.2 times per week.

Exercise stage	Standing training	Transferring training	Walking training	Stair climbing/ descent training
M1	Standing from a chair 100 times/day			
M2	Standing from a chair 200 times/day	Transferring from the direction of the non-paralyzed side: 10 times/day Pivoting foot: non-paralyzed side		
M3	Standing from a chair 300 times/day	Transferring to the contralateral side: 10 times/day Pivoting foot: non-paralyzed side	Walking with parallel bars: 2-3 repetitions (14-21 m) (forward walking, side walking)	
M4	Standing from a chair \geq 300 times/day	Transferring from the paralyzed side: 10 times/day Pivoting foot: paralyzed side	Walking with cane on the flat: 40 m twice	Stairs in the gym Step height: 13 cm 4 steps \times 2 repetitions
M5	Standing from a chair \geq 300 times/day		Walking with cane on the flat: 100 m twice	Stairs in the gym Step height: 13 and 15 cm 7 steps \times 2 repetitions
M6	Standing from a chair \geq 300 times/day		Walking with cane on the flat: 100 m \geq twice	Stairs in the hospital Step height: 20 cm 20 steps \times 2 repetitions
M7	Standing from a chair \geq 300 times/day		Walking with cane on the flat: 100 m \geq twice Walking outdoors: 20-30 m	Stairs in the hospital Step height: 20 cm 20 steps \times 2 repetitions

Table 1: The voluntary training program.

Results

Twenty patients met the inclusion criteria and were enrolled in this study. Patients' demographic characteristics and the evaluated data are shown in Table 2. Seventy-five percent of the patients were male, although 90% of caregivers were female. The results of multiple regression analysis are shown in Table 3. The frequency of nursing-care service use through LTCl, number of caregivers, sex of patients, and frequency of voluntary training significantly affected the burden on caregivers, with $R^2=0.82$, $F(4,15)=17.16$ and $p=0.00002$. High-frequency of nursing-care service use through LTCl and male patients associated with increased the burden on caregivers. Large number of caregivers and high-frequency of voluntary training associated with decreased the burden on caregivers.

Age of patients, mean \pm SD (years)	68.2 \pm 10.8
Sex of patients, male/female (n)	15/5
Disease, cerebral haemorrhage/cerebral infarction (n)	10/10
Age of primary caregiver, mean \pm SD (years)	63.9 \pm 13.9
Sex of caregivers, male/female (n)	2/18
Number of caregivers, mean \pm SD (n)	1.3 \pm 0.5

BI of patients, median, range (score)	70, 5-95
Frequency of nursing-care service use by LTCl, Mean \pm SD (times/week)	3.4 \pm 2.3
Mean \pm SD (times/week)	
Number of users of nursing care services by LTCl (n)	
Commuting for care (day care)	10
Commuting rehabilitation (day service)	8
Home-visit long-term care (short-stay care)	4
Home-visit rehabilitation	3
Home-visit nursing	1
Frequency of voluntary training, mean \pm SD (times/week)	2.4 \pm 3.0
J-ZBI of primary caregiver, mean \pm SD (score)	25.1 \pm 17.0

Table 2: Distribution of each evaluation item and of patients' primary diseases.

	Partial regression coefficient	Standard partial regression coefficient
Value of constant	56.74	
Frequency of use of nursing-care service through LTCI (times/week)	2.83	0.60
Number of caregivers	-9.32	-0.55
Sex of patients (male: 1, female: 0)	-18.69	-0.70
Frequency of voluntary training (times/week)	-2.62	-0.69
R ² =0.82, F (4, 15)=17.16, p=0.00002		

Table 3: Factors influencing J-ZBI selected by multiple regression analysis.

Discussion

Among the factors investigated in this study, those influencing the burden on caregivers of hemiplegic stroke patients were (1) frequency of nursing-care service use through LTCI, (2) number of caregivers, (3) patient's sex, and (4) frequency of voluntary training. Because of the small number of female patients, however, it is difficult to conclude that patient sex influenced ADL after discharge.

Kitahama et al. [16] reported that the use of nursing-care services through LTCI by stroke patients decreased the burden on caregivers. By contrast, Kamimura et al. [17] reported that the use of nursing-care services through LTCI by stroke patients did not influence the burden on caregivers. Moreover, Watanabe et al. [18] reported that the burden on caregivers of stroke patients did not decrease after introducing LTCI. Therefore, use of nursing-care services through LTCI does not always reduce the burden on caregivers for stroke patients. In this study, frequent use of nursing-care services through LTCI by stroke patients was associated with a higher burden on caregivers. Chang et al. [19] reported that caregiver's mental health and burden were significantly associated with caregivers' simultaneous health problems. Caregiver's health status and ability of care may have a greater influence than nursing-care services through LTCI. Although stroke patients posing a greater burden on a caregiver might use nursing-care services more willingly, it is possible that alleviation of the caregiver's burden is difficult even with the availability of professional nursing services.

Nishii et al. [20] reported that the burden on caregivers of stroke patients increased due to limitations on the caregivers' abilities to engage in housework and social activity. In this study, a smaller number of caregivers resulted in a higher burden on the caregivers of stroke patients. It is thought that fewer caregivers of a stroke patient, leading to limitation of housework or social activity, may have a bad influence on the burden on those caregivers. In such cases, the caregivers themselves also need care.

The voluntary training program at the convalescent rehabilitation ward of Hanno-Seiwa Hospital is useful to allow stroke patients living at home to gain independence in ADL by specializing in mobility. According to our previous report [15], a shorter hospitalization, including voluntary training with family participation, and continued

training at home are factors contributing to the improvement of ADL after discharge. Karla et al. [21] have reported that training caregivers in the basic skills of moving and handling the patient, facilitating ADL, and simple nursing tasks reduced the burden of care and improved quality of life (QOL) for both the patients and caregivers. Additionally, Isaac et al. [22] reported that the level of caregiver burden was significantly correlated with QOL of elderly stroke patients. Morimoto et al. [23] also reported that increased burden significantly related to decreased health-related QOL among stroke caregivers. In this study, the higher the frequency of voluntary training divided by stroke patients at home, the lower the burden on their caregivers. It is important to educate caregivers of stroke patients that mobility, which is the basis of ADL, may improve even after discharge. To learn methods of assisting mobility seems useful to understanding the disease and reducing confusion for caregivers. Educating patients and families about the voluntary training program for mobility during hospitalization may decrease the burden on caregivers after discharge from the hospital.

For stroke patients highly dependent on nursing-care services and with few caregivers, the burden on caregivers was heavy. However, a high frequency of voluntary training reduced this burden. Because this study was performed with few inpatients in one medical institution recommending one voluntary training program, our results may not apply to patients at other medical institutions. The male/female ratio of the patients to caregivers and as well as the frequency of hemorrhagic stroke, do not reflect those in general. These issues are possible limitations in this study. However, it appears that high-frequency nursing-care service does not always reduce the burden on caregivers. Voluntary training, involving family participation in particular, is quite important to reduce the burden on caregivers of stroke patients after discharge.

References

1. <http://www.mhlw.go.jp/toukei/saikin/hw/k-tyosa/k-tyosa13/index.html>
2. Kamel AA, Bond AE, Froelicher ES (2012) Depression and caregiver burden experienced by caregivers of Jordanian patients with stroke. *Int J Nurs Pract* 18: 147-154.
3. Jaracz K, Grabowska-Fudala B, Kozubski W (2012) Caregiver burden after stroke: towards a structural model. *Neurol Neurochir Pol* 46: 224-232.
4. <http://www.mhlw.go.jp/english/policy/care-welfare/care-welfare-elderly/index.html>
5. Olivares-Tirado P, Tamiya N, Kashiwagi M (2012) Effect of in-home and community-based services on the functional status of elderly in the long-term care insurance system in Japan. *BMC Health Serv Res* 12: 239.
6. Hirano Y, Maeshima S, Osawa A, Nishio D, Takeda K, et al. (2012) The effect of voluntary training with family participation on early home discharge in patients with severe stroke at a convalescent rehabilitation ward. *Eur Neurol* 68: 221-228.
7. Brunnstrom S (1970) Movement therapy in hemiplegia: A Neurological Approach, Harper & Row.
8. MAHONEY F, BARTHEL DW (1965) FUNCTIONAL EVALUATION: THE BARTHEL INDEX. *Md State Med J* 14: 61-65.
9. Olivares-Tirado P, Tamiya N, Kashiwagi M, Kashiwagi K (2011) Predictors of the highest long-term care expenditures in Japan. *BMC Health Serv Res* 11: 103.
10. Arai Y, Kudo K, Hosokawa T, Washio M, Miura H, et al. (1997) Reliability and validity of the Japanese version of the Zarit Caregiver Burden interview. *Psychiatry Clin Neurosci* 51: 281-287.
11. Zarit SH, Reever KE, Bach-Peterson J (1980) Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 20: 649-655.

12. Shinohara Y, Yanagihara T, Abe K, Yoshimine T, Fujinaka T, et al. (2011) Rehabilitation. *Journal of Stroke and Cerebrovascular Diseases* 20: S145-180.
13. Maeshima S, Okita R, Yamaga H, Ozaki F, Moriwaki H, et al. (2000) Effectiveness of early stroke rehabilitation program performed by family members. *Sogo Rehabilitation* 28: 1161-1166.
14. Maeshima S, Ueyoshi A, Osawa A, Ishida K, Kunimoto K, et al. (2003) Mobility and muscle strength contralateral to hemiplegia from stroke: benefit from self-training with family support. *Am J Phys Med Rehabil* 82: 456-462.
15. Nishio D, Maeshima S, Osawa A, Hirano Y, Minakawa T, et al. (2014) Factors influencing activities of daily living of elderly stroke patients who were discharged to their home from a convalescence rehabilitation ward. *Rigakuryoho kagaku* 29: 725-730.
16. Kitahama S, Takemasa S, Shimada T (2003) Effect of Long-term care insurance on physical ability and psychological status of its clients and care-burden of their caregivers. *Bulletin of Kobe university graduate school of health sciences* 19: 15-25.
17. Kamimura S, Akiyama S (2007) Assessments of caregiver burden in the family using the Japanese version of the Zarit caregiver burden interview (J-ZBI). *Rigakuryoho kagaku* 22: 61-65.
18. Watanabe A, Nagayama H, Kawaguchi T, Fukuda M, Akutsu T, et al. (2013) Care situation and caregiver burden of home-care stroke patients before and after introduction of long-term care insurance. *Rigakuryoho kagaku* 28: 511-516.
19. Chang HY, Chiou CJ, Chen NS (2010) Impact of mental health and caregiver burden on family caregivers' physical health. *Arch Gerontol Geriatr* 50: 267-271.
20. Nishii M, Izuta M, Sukeno O, Yuri Y, Tsuzumi M (2011) Factors affecting the sense of caregiver burden: From the perspective of ADL. *Journal of Kansai university of welfare sciences* 15: 93-105.
21. Kalra L, Evans A, Perez I, Melbourn A, Patel A, et al. (2004) Training carers of stroke patients: randomised controlled trial. *BMJ* 328: 1099.
22. Isaac V, Stewart R, Krishnamoorthy ES (2011) Caregiver burden and quality of life of older persons with stroke. *Journal of applied gerontology* 30: 643-654.
23. Morimoto T, Schreiner AS, Asano H (2003) Caregiver burden and health-related quality of life among Japanese stroke caregivers. *Age Ageing* 32: 218-223.