ORIGINAL ARTICLE

FACTORS INFLUENCING THE BURDEN ON CAREGIVERS OF PATIENTS AT ONE MONTH AFTER DISCHARGE FROM CONVALESCENT WARD

Masakazu Murakami[1),2)], Akiyoshi Takami[3)], Ai Shimaya[1)], Misato Makino[3)], Hideki Yoshida[3)]

Abstract   The purpose of this interdisciplinary and longitudinal study was to clarify the factors influencing the burden on caregivers of patients at one month after their hospitalization in the convalescent ward. The study participants were 25 pairs of family caregivers and care receivers who were living at home under their family's care. Basic characteristics, cognitive function, and activities of daily living (ADL) were evaluated in the care receivers, Characteristics, ADL, burden, and the difference between the expected and actual amount of care provided at one month after hospitalization were evaluated in caregivers. The results suggested that the factors affecting caregiver burden are sleeping hours per day, which is consistent with findings in previous studies, and the difference between the expected and actual amount of care provided, which to our knowledge, is reported here for the first time. Therefore, to reduce caregiver burden, caregivers should get adequate sleep and be given a concrete framework regarding patient care.

Introduction

In Japan, the aging population is rapidly progressing and the number of elderly people requiring long-term care is increasing annually. In 2001, nearly 3 million elderly people were certificated as requiring long-term care, but by 2012, this number had nearly doubled to almost 5.5 mllion[1)]. This situation has placed an increased burden on family caregivers.

CiNii, an academic research navigation service in Japan, returned 225 hits from a keyword search on February 18, 2017 comprising "caregivers' burden" AND "at home", but only six hits from a search comprising "caregivers' burden" AND "convalescent stage". Furthermore, none of the six studies found were accessible or included a statistically analyzed thesis. This result shows that although numerous studies have investigated factors influencing caregiver burden, almost all of them have focused on families providing nursing care to a family at home. To our knowledge, the present study is the first to focus on caregiver burden at one month after hospitalization.

Niina et al. advocated the "stress model of family caregivers of elderly with dementia" as a simulated theory for caregiver burden and the way to deal with it[2)]. This model describes numerous types of nursing care incidents and care receivers' characteristics as potential stressors. When these stressors are cognitively evaluated negatively by family caregivers, they cause mental and physical "stress symptoms" that require coping. On the other hand, in convalescent wards, caregivers can comprehend care receivers' activities of daily living (ADL) and potential stressors such as problem behaviors and dementia before starting in-home care. Then, family caregivers judge that they can

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care for the patient at home, and this judgment leads to discharge from the hospital. Thus, by cognitively evaluating the predicted potential stressors after discharge in advance, we believe that we can comprehend caregivers' burden. If this hypothesis holds true, cross-sectional studies based on data from within a few months after discharge are insufficient to identify the factors affecting caregiver burden after discharge from convalescent wards. Therefore, longitudinal elements focusing on the influence from care receivers' potential stressors during hospitalization and the difference between the expected and actual amount of care provided are needed.

The purpose of this study was to clarify the factors influencing the burden on caregivers of patients at one month after discharge from a convalescent ward in terms of care receivers' characteristics at discharge, the difference between the expected and actual amount of care provided, and the characteristics of care receivers and their family caregivers at one month after discharge.

Methods

1. Ethical considerations

This study was approved by the ethics committee of the Social Medical Corporation Jinseikai Nishibori Hospital (approval number 2015-02). Consent was obtained in advance from the research participations after being informed about the purpose, significance, methods, and risks associated with this study, as well as the privacy policy.

2. Participants

Both family caregivers and care receivers who were hospitalized and discharged from the convalescent ward to home from June 2015 to December 2016 were assessed (25 pairs). Care receivers who decided to live alone after

discharge and who already experienced nursing care at home before discharge were excluded. We explained the purpose and outline of this study to the other participants, and targeted those who provided their consent for inclusion.

3. Research methods and items

This study was conducted while the care receiver was hospitalized and at one month after discharge from the convalescent ward. For the research at one month after discharge, the rehabilitation trainer visited the participants' home. The research items are described below.

\<Research items after discharge\>
① **Care receivers' characteristics**
1) General and medical characteristics

We collected data regarding the characteristics of the care receivers' such as age, gender, and nursing care level from medical records.
2) Degree of independence of ADL

Functional independence measure (FIM; full score of 126) which was known for the high reliability, validity and versatility was used to assess ADL. This research was conducted by the rehabilitation trainers.
3) Cognitive function

The Mini-Mental State Examination (MMSE; 24 points or above out of 30 points was the cut-of value) which consisted 11 questions (disorientation, memory skills, calculation, etc.) was used to measure the care receivers' cognitive function.

  Family caregivers' characteristics

All of the family caregivers' characteristics were collected at one month after discharge; no data were collected while the care receivers were hospitalized.

\<Research items at one month after discharge\>
① **Care receivers' characteristics**
1) Degree of independence of ADL

The FIM was used to assess ADL. This

research was conducted by the rehabilitation trainers.

② **Family caregivers' characteristics**

1) General information

We collected data regarding the characteristics of the care receivers' such as age, gender, and the relationship with their care receiver through interviews.

2) Caregiver burden

The Zarit Burden Interview (ZBI)[3] was used to measure caregiver burden. The short version of the Japanese version of the ZBI[4] (J-ZBI_8) was based on the Japanese version of the ZBI[5] (J-ZBI), the reliability and validity of which was verified by Arai et al. Whereas the original J-ZBI is composed of 22 items, the short form is only composed of eight, making it more practical in the clinical setting.

3) Difference between the expected and actual amount of care provided

To clarify the difference between the expected and actual amount of care provided, we asked family caregivers the following question: "How do you feel about the actual amount of nursing care, compared with your expectations before discharge?" They were asked to respond on the following four-point scale: 1) Much easier, 2) Slightly easier, 3) Slightly more difficult, and 4) Much more difficult.

4) Time factors in terms of nursing care

We researched both the hours involved in nursing care and the sleeping hours per day by caregivers.

5) Relationship with care receivers while hospitalized

Regarding the relationship with care receivers, we researched the frequency of visits with care receivers in the hospital and rehabilitation observation. This item was based on the caregivers' judgment of average frequency per week.

4. Procedure

Spearman's rank correlation coefficient was used to confirm the relevance of the J-ZBI_8, care receivers' age, nursing care level, MMSE and FIM scores, caregivers' age, the difference between the expected and actual amount of care provided, sleeping hours, and the frequency of visits and rehabilitation observation. In addition, the chi-square test was used to analyze the care receivers' gender, the caregivers' gender, and the relationships between them after dividing the J-ZBI_8 into two groups by median. Next, a multiple regression analysis was conducted with J-ZBI_8 as the dependent variable and the other items involved in the J-ZBI_8 as independent variables. SPSS (version 22.0; IBM, Tokyo, Japan) was used for statistical analysis, and the significance level was set to less than 5%.

Results

<Research items after discharge>

① **Care receivers' characteristics**

The mean age was 77.6 ±11.1 years, 8 males and 17 females were participated. 2 participants were required support nursing care level and 23 participants were required long term nursing care level (level 2~4 were 85%). The mean MMSE score was 23.4 ±5.3. The mean FIM score was 91.9 ±25.4.

<Research items at one month after discharge>

① **Care receivers' characteristics**

The mean FIM score at one month after discharge was 103.6 ±20.1, showing an improvement of the score. A summary of the care receivers' characteristics is shown in Table 1.

② **Family caregivers' characteristics**

The mean age was 62.6 ±16.0 years. 6 males and 19 females were participated. Relationship with care receiver were 7 (daughters-in-law), 6 (daughters), 5 (wives), 5 (husbands), 1 (son), 1 (mother). The mean J-ZBI_8 score was 7.1 ±5.6. Difference between the expected and

Table 1. Care receivers' characteristics

Variable	Total (N=25)
Age, (y)	77.6 ±11.1
Gender, (%)	Male: 32, Female: 68
Nursing care level, (%)	Support need 1:4
	Support need 2:4
	Long-term care 1:4
	Long-term care 2:32
	Long-term care 3:20
	Long-term care 4:32
	Long-term care 5:4
MMSE, (points)	23.4 ±5.3
FIM, (points)	91.9 ±25.4, 103.6 ±20.1
FIM-Motor	62.8 ±20.2, 71.7 ±18.5
FIM-Cognitive	29.0 ±6.8, 31.8 ±3.9
Eating	6.6 ±0.9, 6.8 ±0.4
Grooming	5.7 ±1.5, 6.4 ±1.6
Bathing	3.8 ±2.0, 4.6 ±1.6
Dressing, upper body	4.8 ±2.5, 6.2 ±1.5
Dressing, lower body	4.5 ±2.5, 5.6 ±2.2
Perineal care	5.1 ±2.1, 5.8 ±2.1
Bladder management	5.6 ±2.2, 5.6 ±2.1
Bowel management	5.6 ±2.0, 4.7 ±2.3
Transfer, bed, wheelchair	5.4 ±1.7, 6.2 ±1.6
Transfer, toilet	5.4 ±1.9, 6.1 ±1.6
Transfer, tub or shower	2.8 ±2.1, 4.5 ±2.3
Walking/Wheelchair	4.6 ±1.8, 5.4 ±2.2
Stairs	2.7 ±2.1, 3.3 ±2.5
Comprehension	6.3 ±1.3, 6.8 ±0.5
Expression	6.2 ±1.4, 6.7 ±0.9
Cooperation	6.1 ±1.5, 6.4 ±1.2
Problem solving	5.2 ±2.0, 6.2 ±1.1
Memory	5.3 ±1.9, 5.6 ±1.6

Data are expressed as mean ± standard deviation. MMSE: Mini Mental State Examination; FIM: functional independence measure (at discharge, at one month after discharge).

actual amount of care provided were 4 (Much more difficult), 12 (Slightly more difficult), 5 (Slightly easier), 4 (Much easier) which showed around 65% of participants were exceeding their expected amount of care. Average amount of time spent on caregiving per day was 3.5 ± 4.3 hours. While average number of sleeping hours per day was 5.6 ±4.3. The frequency of observations per week was 1.5 ±1.4 times. The frequency of visits per week was 3.1 ±1.2 times. A summary of the caregivers' characteristics is shown in Table 2.

<Relationship between J-ZBI_8 scores and each item>

① **Relationship between care receiver factors**

The relationship between factors of the care receivers' is shown in Tables 3 and 4. FIM scores for bowel management (r=−0.50, P=0.012) and memory at one month after discharge (r=−0.61, P=0.0017) were significantly correlated with J-ZBI_8 scores.

② **Relationship between caregiver factors**

The relationship between J-ZBI_8 scores and the factors of the caregivers is shown in Table 5. The difference between the expected and actual amount of care provided (r=0.68, P=0.00020) and sleeping hours per day (r=−0.71, P=0.000078) were significantly correlated with

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Table 2. Caregivers' characteristics

Variable	Total (N=25)
Age, (y)	62.6
Gender, (%)	Male: 24, Female: 76
Relationship, (%)	Daughter-in-law: 28
	Daughter: 24
	Wife: 20
	Husband: 20
	Son: 4
	Mother: 4
J-ZBI_8, (points)	7.1ints
Difference between expected and actual amount of care provided, (%)	Much more difficult: 16
	Slightly more difficult: 48
	Slightly easier: 20
	Much easier: 16
Time spent on caregiving, (h/day)	3.5
Sleeping (h/day)	5.6
Frequency of observation of rehabilitation, (times/week)	1.5
Frequency of visit, (times/week)	3.1

Data are expressed as mean ± standard deviation. J-ZBI_8: The short version of the Japanese version of the Zarit Caregiver Burden Interview.

Table 3. Relationship between J-ZBI_8 scores and care receivers' characteristics

Variable	Correlation coefficient	*P* value
Age	0.15	N.S.
Gender	-	N.S.
Nursing care level	−0.08	N.S.

Spearman's rank correlation coefficient and the chi-square test were used.
N.S.: not significant; J-ZBI_8: The short version of the Japanese version of the Zarit Caregiver Burden Interview.

J-ZBI_8 scores.

<Multiple regression analysis with J-ZBI_8 as the dependent variable>

Based on these results, FIM scores for bowel management and memory at one month after discharge, the difference between the expected and actual amount of care provided, and sleeping hours per day were introduced as independent variables in multiple regression analysis using the stepwise method. The results showed that sleeping hours per day (β=0.47, P=0.0038) and the difference between the expected and actual amount of care provided (β=0.46, P=0.0045) were significant factors (R^2=0.57, P=0.004). The excluded variables were, bowel management (β=0.07, P=0.47) and memory (β=−0.01, P=0.93).

The results of multiple regression analysis are shown in Table 6.

Discussion

In the present study, we used cross-sectional and longitudinal data to investigate the factors influencing caregiver burden. Based on the results of multiple regression analysis, sleeping hours per day and the difference between the expected and actual amount of care provided at one month after discharge from the convalescent ward were significant factors.

Previous studies have reported finding a significant correlation between sleeping hours and caregiver burden[6, 7]. The results of the present study support those results. In addition,

Table 4. Relationship between J-ZBI_8 scores and care receivers' activities of daily living and cognitive ability

Variable	Correlation coefficient	
	At discharge	At one month after discharge
MMSE	–0.38	-
FIM	–0.18	–0.16
FIM-Motor	–0.20	–0.15
FIM-Cognitive	–0.07	–0.35
Eating	0.04	–0.23
Grooming	0.01	0.04
Bathing	–0.22	–0.13
Dressing, upper body	–0.27	0.03
Dressing, lower body	–0.29	0.19
Perineal care	–0.20	0.11
Bladder management	–0.09	–0.37
Bowel management	–0.08	–0.50*
Transfer, bed, wheelchair	–0.12	0.14
Transfer, toilet	–0.18	0.07
Transfer, tub or shower	–0.02	–0.23
Walking/Wheelchair	0.23	0.04
Stairs	0.02	–0.05
Comprehension	0.10	–0.02
Expression	0.38	0.21
Cooperation	0.02	–0.35
Problem solving	–0.07	–0.26
Memory	–0.24	–0.61**

Spearman's rank correlation coefficient was used. *$p<0.05$, **$p<0.01$.
N.S.: not significant; MMSE: Mini-Mental State Examination; FIM: functional independence measure;
J-ZBI_8: The short version of the Japanese version of the Zarit Caregiver Burden Interview.

Table 5. Relationship between caregiver factors

Variable	Correlation coefficient	*P* value
Age	–0.24	N.S.
Gender	-	N.S.
Relationship	-	N.S.
Difference between expected and actual amount of care provided	0.68	0.000
Time spent on caregiving	0.29	N.S.
Sleeping hours	–0.71	0.000
Frequency of observation of rehabilitation	0.25	N.S.
Frequency of visits	0.16	N.S.

Spearman's rank correlation coefficient and the chi-square test were used.
N.S.: not significant.

Table 6. Multiple regression analysis with J-ZBI_8 as the dependent variable

	B	*β*	*P* value
Variable			
Sleeping hours	–1.95	–0.47	0.00
Difference between expected and actual amount of care provided	–2.71	–0.46	0.00
R^2	0.57		0.00

J-ZBI_8: The short version of the Japanese version of the Zarit Caregiver Burden Interview.

our analysis identified a significant correlation between J-ZBI_8 and FIM scores for bowel management at one month after discharge, suggesting that helping with defecation and bowel movements at night places an additional burden on caregivers and reduces their sleeping hours.

No previous studies have focused on the difference between the expected and actual amount of care provided. Numerous studies have reported that the care receivers' degree of ADL affects caregiver burden, and that improving ADL with a focus on being independent is an aim of rehabilitation. However, improving ADL among care receivers with severe primary disease, complications, and a detailed medical history can be difficult. The results of the present study suggest that even when care receivers cannot improve their ADL, it is possible to avoid placing an additional burden on caregivers by providing them with an accurate assessment of the actual amount of care that will be required after discharge.

Based on the result of this study which the frequency of caregivers observed the rehabilitation of care receivers were 1.5 ± 1.4 times showing an insufficiency despite the visiting per week was 3.1 ± 1.2 times. If the insufficiency may be improved, with more adequate knowledge of care receiver condition and the caregiving techniques, the actual and expected difference of amount of care may be lessen. However, considering the age (average 62.6 years), sex (75% female) and the working time, an arrangement should be made by the therapist with the caregivers.

This study did have some limitations. First, the data regarding sleeping hours, which influences caregiver burden, and the difference between the expected and actual amount of care provided were limited. Collecting more information on the factors associated with decreased sleeping hours and differences between the expected and

actual amount of care provided would enable more detailed instructions to be given to family caregivers before discharge. Lastly, we cannot clearly state that predicting the actual amount of care provided after discharge with more accuracy would help improve caregiver burden for all potential stressors. These are challenges that need to be addressed in future studies.

The result of this study showed a relevance between caregiver sleeping hours and burden of caregiving. However we did not investigate whether the caregiver were insomnia or compare the difference of sleeping hours before the caregiving started. Besides, care receivers' bowel management also relevance to the caregiving burden. As a further research, we should also investigate the presence of digestive organ failure, frequency of defecation and the shape of defecate.

Acknowledgements

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