

Factors Affecting Burden of Family Caregivers of the Home-bound Elderly Disabled

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Abstract. [Purpose] The purpose of this study was to clarify the factors affecting the burden of family caregivers of home-bound disabled elderly persons. [Subjects] Data were collected for 66 home-bound disabled elderly persons (mean age of 81.4 ± 9.7) and their 66 family caregivers (mean age of 62.4 ± 11.5) who were living at home in Kobe city, Hyogo. [Method] Capacity to perform ADL was assessed using the Barthel Index for the home-bound disabled elderly persons. The care burden and health status of their family caregivers were also evaluated. [Results] There was no significant correlation between ADL, the grade of care required for home-bound disabled elderly persons and family caregivers' burden. It was also revealed that the family caregivers' burdens were determined by their state of depression. [Conclusion] These results suggest that social and psychological supports are necessary to reduce the burden of family caregivers.

Key words: ADL, Home-based care elderly disabled, Burden of family caregivers

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INTRODUCTION

According to the 2011 White Paper on the Aging Society, Japan's aging shows no sign of slowing down. The elderly population (65 years and over) increased to 29,580,000 people in 2010 compared to 29,010,000 people in 2009. The population aging rate, which is the proportion of the total population aged 65 years old or over, was 23.1% in 2010 compared to 22.7% in 2009¹⁾. In addition, the Ministry of Health, Labour and Welfare's interim report on the Long-Term Care (LTC) Insurance program issued in February 2011 states that 5,030,000 people are recognized as needing care, and this figure is expected to continue increasing²⁾. At the same time, looking at families, changes in social structure, including fewer children living with their aged parents, have taken place resulting in an increase in nuclear families and more women entering the workforce. These changes have weakened family care and support capacity, making it difficult for families to care for aged members. For Japan, which has become an aged nation in such a social environment, successfully providing home care for the disabled elderly is a key challenge.

Given the circumstances, the Long-Term Care (LTC) Insurance was started in April 2000. One purpose of the establishment of LTC was lightening the burden imposed on family caregivers. This, combined with maintaining family caregiver quality of life (QOL), should improve the QOL of the entire family, including elderly disabled care recipients. To achieve this, the family and society must clarify the division of their responsibilities and functions and continue to assume their responsibilities during the process

of families surrendering their care responsibilities to society. To achieve this, determining caregivers' caregiving burden and clarifying factors relating to this burden, in addition to understanding care recipient conditions, and working to reduce caregivers' caregiving burden, are important. Some studies have addressed the caregivers' burden imposed on people taking care of home-bound disabled elderly persons, including Kawamoto's study that examined the relationships between activities of daily living (ADL) and the psychological states of home-bound disabled elderly persons and the burden felt by family caregivers³⁾. Such studies, however, are scarce.

In order to discover how family caregivers taking care of home-bound disabled elderly persons can maintain the quality of care life, we researched home-bound disabled elderly person's physical conditions and caregivers' physical and psychological conditions, particularly the caregiver's burden. We analyzed and examined the current caregiving burden felt by family caregivers caring for home-bound disabled elderly persons and the factors that affect this burden.

SUBJECTS AND METHODS

The subjects were 66 home-bound disabled elderly persons (20 males and 46 females, mean age of 81.4 ± 9.7 years old) who were receiving day-care services at welfare facilities for the elderly requiring long-term care in Kobe City and their 66 family caregivers (14 males and 52 females, mean age of 62.4 ± 11.5 years old). Home-bound disabled elderly subjects had no obvious dementia symptoms

Table 1. Characteristics of the caregivers

Mean age	62.4 ± 11.5 years (mean ± SD)	
Total points on the ZBI	Mean value (mean ± SD)	36.1 ± 18.4
	Male (mean ± SD)	29.8 ± 15.7
	Female (mean ± SD)	37.5 ± 18.8
Total points on the GDS-15	Mean value (mean ± SD)	4.5 ± 3.1
	Normal (n %)	29 (44%)
	Depression (n %)	37 (56%)
Subjective health condition*	Yes (n %)	41 (62%)
	No (n %)	25 (38%)

*Did you impair health by nursing?

and were capable of answering the questionnaire. The research covered the home-bound disabled elderly subjects' physical conditions and caregiver subjects' psychological conditions and caregiver's burden.

In advance, we approached the elderly disabled and caregiver subjects through staff at the welfare facilities and asked them to participate. When handing over the questionnaire form, we explained the purpose of this study and asked the subjects to participate in writing. All the subjects all agreed. Considering ethics, we explained to the subjects that information obtained from the questionnaire survey would only be used for this study, and that the information learned would be confidential and would not be disclosed to any third parties.

We gave the questionnaire form to facility users who agreed to participate in the study. They returned the form on their next visit to the facilities.

We asked the disabled elderly subjects their age, gender, activities of daily living (ADL), care need level, and if they had any problematic behaviors. We asked the caregiver subjects their age, gender, their relationships to the home-bound elderly disabled they were caring for, the caregiving burden they felt, and their psychological and subjective health conditions.

To assess the basic ADL of the disabled elderly subjects, we used the Barthel Index (BI) modified pursuant to Isogoda's method in a questionnaire requiring respondents to answer yes or no^{4, 5)}. BI is widely used throughout the world because of its convenience, accuracy and comprehensiveness. BI consists of the following items: feeding, transfer (bed to chair and back), grooming, toileting, bathing, mobility (gait / wheelchair), stairs climbing, dressing, bowel and bladder continence. Each item is assessed with scores of 0 to 15 points with a possible total score of 100 points. A higher total score indicates that subject is more independent.

The Zarit Caregiver Burden Interview (ZBI)⁶⁾ was used to assess the caregiving burden felt by the caregiver subjects. Zarit, an American gerontologist, defines caregiving burden as "Emotional, physical, social and financial problems experienced by caregivers as a result of providing care to their family members"⁷⁾. There were 22 questionnaire items, and each was assessed on a scale of 0 to 4. Scores were from 0 to 88 points. A higher score indicates that the caregiver subject feels a greater burden.

The Geriatric Depression Scale (GDS-15)^{8, 9)} was used to assess caregiver subject depression. The GDS-15 was developed to assess depression. The total score ranges from 0 to 15 points. A total score of 0 to 4 indicates normal, 5 or more depressive tendencies or depression.

Regarding the subjective health conditions of caregiver subjects, we asked if they had ever felt ill due to providing care, and the subjects answered yes or no.

From the results obtained, we examined factors that affect the caregiving burden felt by caregivers. We divided the caregivers into two groups by their burden level, gender and if they had misgivings about their physical health, and conducted the Mann-Whitney U Test on these groups. To assess the relationships between the burden felt by caregivers and care recipient age, ADL independence, care need level, caregiver age and GDS-15 scores, we calculated Spearman's rank correlation coefficient. For statistical analysis, we used Stat Soft's statistical analysis software, STATISTICA. Values less than 5% were considered statistically significant.

RESULTS

The 66 home-bound disabled elderly persons consisted of 20 males and 46 females. Their average age was quite high: 81.4 ± 9.7 years old. As for the disabled elderly persons' ADL independence, their average BI score was 62.2 ± 27.1 (15 to 100 points). Some required care and some were independent. As for their care need level, 14 subjects (21.2%) were classified as level I, 21 subjects (31.8%) as level II, 14 subjects (21.2%) as level III, 6 subjects (9.1%) as level IV, and 11 subjects (16.7%) as level V.

Regarding caregiver relationships with care recipients, the caregivers consisted of 17 wives (25.8%), 26 daughters (39.4%), 9 daughter-in-laws (13.6%), 10 husbands (15.2%), 2 sons (3.0%), and 2 other relatives (3.0%). Female caregivers accounted for 79% of all caregivers. The average age of caregivers was 62.4 ± 11.5 years old, indicating that the caregivers themselves were not young. Spouse caregivers, wives taking care of husbands or vice versa, accounted for 41%, indicating the current situation of roro-kaigo, one elderly person caring for another.

The caregivers' average GDS-15 score, which indicates their psychological functions, was 4.5 ± 3.1. When classifying the GDS-15 score of 0 to 4 as normal and 5 or more

as depressive tendencies or depression, 29 subjects (43.9%) were classified into the normal group and 37 subjects (56.1%) were classified into the depression group. More than half of the subjects showed tendencies of depression. As for the subjective health of caregivers, 41 subjects (62.1%) answered yes to the question asking if they had ever felt ill due to providing care, indicating that more than half of all caregivers experienced ill health due to providing care (Table 1).

The average caregiving burden score was 36.1 ± 18.4 (4 to 73 points). The caregiving burden showed no statistical correlation or difference with care recipient age, caregiver age and caregiver gender. A weak correlation ($r = -0.23$, $p < 0.05$) was observed between the caregiving burden and care recipients' total ADL independence score. Although there was a tendency for the caregiving burden to reduce when care recipients' ADL independence was high, the impact of care recipients' ADL independence on the caregiving burden felt by caregivers was not strong. As for the relationships between the caregiving burden and ADL items, the caregiving burden was moderately or weakly correlated with grooming ($r = -0.33$, $p < 0.01$), dressing ($r = -0.34$, $p < 0.01$), and bladder continence ($r = -0.43$, $p < 0.01$) (Table 2). No statistical correlation was observed between the caregiving burden and care recipients' care need level ($r = 0.21$).

A moderate positive correlation was observed between the burden felt by caregivers and their GDS-15 scores ($r = 0.54$, $p < 0.01$), indicating that caregivers felt a greater caregiving burden when they became more depressed.

DISCUSSION

According to the 2010 Comprehensive Survey of Living Conditions of the People on Health and Welfare conducted by the Ministry of Health, Labour and Welfare, spouses accounted for the largest percentage, 25.7%, of family caregivers living together with care recipients, and they were followed by children, 20.9%, and children's spouses, 15.2%⁽¹⁰⁾. The survey also reported more female caregivers than male caregivers. Females accounted for 69.4% of caregivers and males for 30.6%. Yokoyama et al.⁽¹¹⁾ reported that caregivers aged sixty years or older tend to have some health problems. Murayama⁽¹²⁾ indicates that caregiver aging and their health create problems. The average age of caregivers in our research was 64.0 ± 13.7 years old, which is not young, with spouses accounting for 35% of all caregivers. These figures clearly indicate the *roro-kaigo* situation. Female caregivers accounted for 79% of all caregivers, and female caregivers provided most home care. Sixty percent of caregivers had misgivings about their health, and 56% of caregivers show depressive tendencies. We fear that these background circumstances may make continuing family care impossible in the future. Medical professionals typically tend to place first priority on the person requiring care. They tend to consider such person's family members as caregivers for the person, often expecting family members to act as ideal caregivers. Medical professionals, however, should consider the entire family, including the person requiring care, as one functional unit. Professionals working

Table 2. Correlation between the burden of caregivers (ZBI) and independence in ADL (Barthel Index) of elderly disabled persons

Barthel Index	ZBI (r)
Feeding activity	-0.16
Transfer activity	-0.13
Grooming	-0.33**
Toileting	-0.16
Bathing	-0.23
Gait / Wheelchair	-0.05
Stairs climbing	-0.03
Dressing	-0.34**
Bowel continence	-0.24
Bladder continence	-0.43**
Total	-0.24*

* < 0.005 , ** < 0.001

for home-bound disabled elderly persons must look at family caregivers, as well as care recipients, assessing caregivers' physical and psychological health correctly and approaching them appropriately.

In this research, the average caregiving burden score was 36.1 points. Saito et al.⁽¹³⁾ and Washio et al.⁽¹⁴⁾ reported 29.6 and 37.1 points, which are similar to our results. Caregivers feel a burden. Concerning the relationship between care recipient age and the caregiving burden, Maeda et al.⁽¹⁵⁾ reported that caregivers caring for older care recipients feel a greater caregiving burden. Tanigaki et al.⁽¹⁶⁾ reported that older caregivers feel a greater care-giving burden. Obviously, care recipients are able to do less when they age, making caregiving more burdensome. It is also obvious that caregiving becomes more burdensome when caregivers get older. Our results showed no statistical significance in the relationships between the age of care recipients and caregivers and caregiving burden felt by caregivers. Such relationships, however, require further study.

Concerning the relationship between care recipients' ADL independence and caregiving burden, researcher opinion is divided. Some studies report significant relationships and some do not⁽¹⁷⁾. In our results, a weak correlation was observed between the caregiving burden and care recipients' total ADL independence score. Although the caregiving burden tended to be lower when care recipients' ADL independence was high, the impact of care recipients' ADL independence on the caregiving burden felt by caregivers was not strong. This suggests that care recipients' ADL independence is a factor, albeit a not very important one, in reducing the caregiving burden. Increase in care recipients' ADL independence does not necessarily reduce the caregiving burden. As for the relationships between the caregiving burden and ADL items, the caregiving burden moderately or weakly correlated with grooming, dressing and bladder continence, indicating that the caregiving burden is reduced when care recipients are more independent in these activities. The elderly disabled subjects in our research are day-care service users. Helping

elderly disabled subjects' self-care activities in the limited time before they leave home for day-care services may increase the caregiving burden felt by caregivers. This suggests that, in order to encourage disabled elderly persons to go out, establishing disabled elderly person's self-care independence and reducing caregiver burden are important. For this purpose, self-help devices and welfare equipment may be used.

Shigenobu et al.¹⁸⁾ and Makizako et al.¹⁹⁾ reported that care recipients' care need level is not reflected in caregivers' caregiving burden. Also in our results, no positive correlation was observed between caregiving burden and care needs level. Although it is not clear from our results, this may suggest, as indicated by Shigenobu et al.¹⁸⁾, that some care recipients' care need level is too low. Despite the great caregiving burden they cause, care assistance services their families receive do not sufficiently compensate the caregiving burden. The current recognition system assesses the care need level based on the time theoretically required for care and fails to consider the caregiving burden. Closely studying factors affecting the caregiving burden imposed on family caregivers, and improving the recognition system so that it also considers factors making the caregiving burden greater will be important, because one of the reasons for establishing the Long-Term Care Insurance System was lightening the burden imposed on family caregivers.

Asami et al.²⁰⁾ reported that depressive tendencies are observed in caregivers feeling greater caregiving burden. Our results agree with those of Asami et al., indicating that caregivers with greater caregiving burden have a greater tendency to become depressed. Listening carefully to caregivers to understand what they think is burdensome in caregiving, adjusting caregiver relationships with patients so that they can establish and preserve good relationships, and assisting caregivers by reducing their psychological and physical caregiving burden are required.

REFERENCES

- 1) Ministry of Health, Labour and Welfare: Aged social white paper in 2011. http://www8.cao.go.jp/kourei/whitepaper/w-2011/zenbun/23pdf_index.html (Accessed Nov. 18, 2011).
- 2) Ministry of Health, Labour and Welfare: Nursing insurance business report. <http://www.mhlw.go.jp/topics/kaigo/osirase/jigyo/m11/1103.html> (Accessed Nov. 18, 2011).
- 3) Kawamoto R, Okamoto K, Yamada A, et al.: A study of the degree of burden and subjective sense of well being in car-givers involved in home care. *Nippon Ronen Igakkai Zasshi*, 1999, 36: 35–39 (in Japanese). [Medline] [CrossRef]
- 4) Mahoney FI, Barthel D: The Barthel Index. *Md State Med J*, 1965, 14: 61–65. [Medline]
- 5) Isagoda A: Prediction of functional state in stroke patients living at home. *Sogo Rehabil*, 1998, 26: 1119–1125 (in Japanese).
- 6) Arai Y, Kudo K, Hosokawa T, et al.: Reliability and validity of the Japanese version of the Zarit caregiver burden interview. *Psychiatry Clin Neurosci*, 1997, 51: 281–287. [Medline] [CrossRef]
- 7) Zarit SH, Todd PA, Zarit JM: Subjective burden of husbands and wives as caregivers, a longitudinal study. *Gerontologist*, 1986, 26: 260–266. [Medline] [CrossRef]
- 8) Yesavage JA, Brink TL, Rose TL, et al.: Development and validation of a geriatric depression screening scale. – A preliminary report-. *J Psychiatry Res*, 1983, 17: 37–49.
- 9) Kasahara Y, Kada H, Yanagawa Y: Measure to evaluate depression state (1). *Japan J Geriatr Psychiatry*, 1995, 6: 757–766 (in Japanese).
- 10) Ministry of Health, Labour and Welfare: National life base investigation in 2010. <http://www.mhlw.go.jp/toukei/saikin/hw/k-tyosa/k-tyosa10/4-2.html> (Accessed Nov. 18, 2011).
- 11) Yokoyama Y, Shimizu T, Hayakawa K, et al.: Health conditions of caregivers of elderly living at home and the influence of factors present in the home care environment. *Nippon Koshu Eisei Zasshi*, 1992, 39: 777–783 (in Japanese). [Medline]
- 12) Murayama M: Help service for disabled patients at home and their family caregivers. *Koshu Eisei*, 1992, 56: 394–398 (in Japanese).
- 13) Saito E, Kunisaki C, Kanagawa K: Positive perceptions encouraging continued caregiving at home among family caregivers. *Nippon Koshu Eisei Zasshi*, 2001, 48: 180–189 (in Japanese). [Medline]
- 14) Washio M, Arai Y, Izumi H, et al.: Burden on family caregivers of frail elderly persons one year after the introduction of public long term care insurance service in the Onga District, Fukuoka Prefecture. *Nippon Ronen Igakkai Zasshi*, 2003, 40: 147–155 (in Japanese). [Medline] [CrossRef]
- 15) Maeda D, Shimizu Y: Factor analysis of subjective difficulty of family who nurses disabled elderly. *Soc Gerontol*, 1984, 19: 3–17 (in Japanese).
- 16) Tanigaki S, Miyabayashi I, Miyawaki M, et al: Examination of factors affecting of the efficacy and burden of caregivers. *Kousei no Shisin*, 2004, 51: 8–13 (in Japanese).
- 17) Arai Y: Assessment of family caregiver burden in the context of the LTC insurance system. *Nippon Ronen Igakkai Zasshi*, 2005, 42: 195–198 (in Japanese). [Medline] [CrossRef]
- 18) Shigenobu K, Ikeda M, Tanabe Y: Relationship between the burden of family caregivers and the needing care level in long-term care insurance system. *Nichii Zasshi* 2000, 124: 1074–1078, 2000 (in Japanese).
- 19) Makizako H, Abe T, Abe K, et al.: Factors burdening the caregiving relatives of community-dwelling disable Japanese people. *Nippon Ronen Igakkai Zasshi*, 2008, 45: 59–67 (in Japanese). [Medline] [CrossRef]
- 20) Asami T, Washio M, Arai Y, et al.: Burden among caregivers of elderly patient with osteoarthritis-tis of hip joint. *Fukuoka Acta Med*, 2002, 93: 96–103. [Medline]