

Burden and Health among Japanese Family Caregivers of the Frail Elderly in an Aging Society

Toko Imamura¹⁾, Masakazu Washio^{2,3)}

ABSTRACT

Objectives: To investigate how to reduce burden of family caregivers of the frail elderly and to improve their health.

Design: Cross sectional study.

Subjects and Methods: 101 pairs of the frail elderly and their family caregivers participated in this study. All of them used visiting nursing services. Caregivers completed self-administered questionnaires about their care burden and various factors that may affect their care burden. Caregivers were divided into two groups: (i) heavily burdened group (n = 41) and (ii) less burdened group (n = 60).

Results: More than half of caregivers (57.4%) were 65 years old or older. Heavily burdened caregivers were older than less burdened caregivers. Compared to their counterparts, they were more likely to be depressed and spent more time on physical caregiving and watching their charges. Compared to their counterparts, heavily burdened caregivers were more likely to want to use social services such as regular daytime respite care, regular help for caregiving, and 24-hour home help.

Conclusion: Since old caregivers are at high risk at long-term care, we should support old caregivers so that they will be able to continue caregiving at home as well as to consult with physicians with their own health.

KEY WORDS

burden, health, family caregiver, aging society

INTRODUCTION

The improvement of public health and advances in medicine after World War II has increased the number of older people living longer (i.e., life expectancy at birth in Japan (81.3 years for men and 87.3 years for women in 2018¹⁾) in Japan while the liberation women from the traditional Japanese family system following World War II has given women increased opportunities for higher education and gainful employment outside of home in Japan, which may lead to advancing of late marriage and late birth, which may decrease the net reproduction rate (from 1.50 in 1950 to 0.69 in 2017¹⁾). Due to the combination of increased life expectancy at birth and decreased reproductive rate, the proportion of old people (65 years old and over) increased from 4.9% in 1950 to 28.1% in 2018¹⁾, which means the increased number in disabled elderly who need long-term care in Japan.

Stroke, fracture after fall, physical frailty due to old age, and dementia are main causes of long-term care for old people in Japan²⁾, and more than half of home-visiting nursing users needed medical care by home-visiting nurses³⁾.

Physiological, psychological and cognitive declines occur with aging among older people, and frailty due to multisystem decline makes older adults vulnerable to increased risk of disability, and long-term care⁴⁾.

Informal care for the disabled elderly is a heavy burden and the source of depression of family caregivers^{5,6)}. In an aging society, however, the proportion of elderly caregivers increases although aged family caregivers themselves are at high of long-term care.

Therefore, the present study sought to investigate the way how to reduce burden of family caregivers of the frail elderly and improve their health.

SUBJECTS AND METHODS

During the period from November to December 2012, a questionnaire survey was carried out of one hundred and one pairs of the disabled elderly and their caregivers agreed to participate in this study. All of them received regular nurse visits from nurse stations in an old castle town in Fukuoka Prefecture, southern Japan, whose proportion of older people (65 years old or older) (26.9% in 2010 and 30.5% in 2015⁷⁾ was relatively high compared with that of Japan as a whole (23.0% in 2010 and 26.6% in 2015¹⁾) due to the out-migration of young people to big cities⁷⁾. The caregivers were asked to complete the following self-administered questionnaires in relation to their burden and caregiving situation: (i) a Japanese version of the Zarit Caregiver Burden Interview (J-ZBI)^{8,9)}; (ii) a Japanese version of the Center for Epidemiologic

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1) Fukuoka School of Nursing, International University of Health and Welfare
Fukuoka City, Fukuoka, 814-0001, Japan

2) School of Nursing, St. Mary's College
Kurume City, Fukuoka, 830-8558, Japan

3) Kitakyushu-Wakasugi Hospital
Sasaguri-machi, Fukuoka, 811-2405, Japan

Correspondence to: Toko Imamura.

(e-mail. toko@iuhw.ac.jp)

Table 1: Characteristics of family caregivers

Factors		Heavily burdened group n = 41	Less burdened group n = 60	p-value
J-ZBI		53.5 ± 11.9	22.7 ± 9.0	
Sex	Male	9(22.0)	11(18.3)	0.85
	Female	32(78.0)	49(81.7)	
Age (years old)	40-64	14(34.1)	29(48.5)	0.01
	65-74	12(29.3)	24(40.0)	
	75+	15(36.6)	7(11.7)	
Number of family members in same household	2	20(48.8)	27(45.0)	0.61
	3	10(24.4)	20(30.0)	
	4+	11(26.8)	13(21.7)	
Kinship	Wives	17(41.5)	26(43.3)	0.65
	Husbands	10(24.4)	9(15.0)	
	Daughters	9(22.0)	18(30.0)	
Family members who help in caring for the elderly	Sons	4(9.8)	4(6.7)	0.37
	Daughters-in-law	1(2.4)	3(5.0)	
	Yes	23(56.1)	39(65.0)	
Able to go out without accompanying the elderly	No	18(43.9)	21(35.0)	1.00
	Yes	30(73.2)	43(71.7)	
Have chronic disease under medical treatment	No	11(26.8)	17(28.3)	0.75
	Yes	24(58.5)	32(53.3)	
Feel ill	Never	4(9.8)	12(20.0)	0.40
	Seldom	24(54.8)	36(60.0)	
	Often	11(26.8)	10(16.7)	
Depression#	Frequently	2(4.9)	2(3.3)	< 0.01
	Yes	27(65.9)	19(31.7)	
	No	14(34.1)	41(68.3)	

Values are expressed as number (%) or mean ± SD
 J-ZBI: Japanese version of the Zarit care burden Interview
 Depression: the Center for epidemiologic studies depression scale (CES-D) was 16 or over.

Studies Depression Scale (CES-D)^{10,11} ; (iii) questions regarding demographic variables of the caregivers and their patients; (iv) questions regarding the time spent actually helping their patients to perform daily activities, the time spent only looking after their patients, and the total duration of caregiving; and (v) social services that caregivers wanted to use. The Barthel Index (BI)¹² was employed to assess activities of daily living (ADL), and the Dementia Behavioral Disturbance (DBD) Scale¹³ was used to check whether the elderly had behavioral disturbances associated with dementia.

This study was approved by the Ethics Committee of the St. Mary's College (H20-004).

ANALYSIS

The family caregivers' mean J-ZBI score (± SD) was 35.8 (± 18.4). Caregivers were divided into two groups according to their J-ZBI score: (i) heavily burdened group (J-ZBI = 36 or higher: n = 41) and (ii) less burdened group (J-ZBI = 35 or lower: n = 60).

Statistical analyses were performed using the Statistical Package for Social Science (SPSS, ver. 21). T-test or the Chi-square test was used to compare these two groups. A level of 0.05 was used as the critical level of significance.

Table 2: Characteristics of the elderly in need of care

Factors		Heavily burdened group n = 41	Less burdened group n = 60	p-value
Sex	Male	21(51.2)	32(53.3)	1.00
	Female	20(48.8)	28(46.7)	
Age (years old)	40-64	8(19.5)	11(18.3)	0.95
	65-74	9(22.0)	12(20.0)	
	75+	24(58.5)	37(61.7)	
Barthel index	0-60	30(70.3)	36(60.0)	0.25
	61-100	11(26.8)	24(40.0)	
Dementia	Yes	19(46.3)	35(58.3)	0.33
	No	22(53.7)	25(41.7)	
Behavior disturbances associated with dementia	Yes	15(36.6)	10(16.7)	0.04
	No	26(63.4)	50(83.3)	
Yokaigodo (Government certified need of care)	Need of support	1(2.4)	3(5.0)	0.15
	Grade 1	4(9.8)	11(18.3)	
	Grade 2	3(7.3)	12(20.0)	
	Grade 3	9(22.0)	5(8.3)	
	Grade 4	10(24.4)	13(21.7)	
	Grade 5	14(34.1)	16(26.7)	

Values are expressed as number (%).

RESULTS

The mean (± SD) age of caregivers was 65.1 (± 10.1) years; 58 (57.4%) of 101 caregivers were 65 years old or older, and 22 (21.8%) were 75 years old or older. Among 101 caregivers, 81 (80.2%) were females, 62 (61.4%) were spouses (i.e., 43 wives and 19 husbands), 46 (45.5%) were depressed, 56 (55.4%) had chronic diseases and were under medical treatment, and 25 (24.8%) often or frequently felt ill (not shown in the table).

The mean (± SD) age of their disabled elderly was 75.0 (± 13.7) years. Among 101 disabled elderly persons, all of them (100%) were 65 years or older and 58(57.4%) were 75 years old or older, 48 (47.5%) were females, 66 (65.3%) had impaired activities of daily living (i.e., Barthel Index was 60 or less), 54 (53.5%) were diagnosed as having dementia, and 25 (24.8%) had behavioral disturbances associated with dementia (not shown in the table).

The mean (± SD) duration of caregiving was 69.8 (± 76.8) months; the mean (± SD) time of physical caregiving was 6.0 (± 5.9) hours/day, and the mean (± SD) time of watching their disabled elderly was 8.1 (± 7.3) hours/day (not shown in the table).

Table 1 shows a comparison between the heavily burdened group and less burdened group regarding the characteristics of family caregivers. Heavily burdened caregivers were older and more likely to be depressed than less burdened caregivers.

Table 2 illustrates a comparison between the two groups as regards the characteristics of their disabled elderly. Heavily burdened caregivers were more likely to care for the disabled elderly with behavioral disturbances associated with dementia than were less burdened caregivers.

Table 3 shows a comparison between the two groups in terms of care setting. Heavily burdened caregivers spent more time on physical care for the disabled and watching their charges, and were more likely to pay 10,000 yen or more per month for self-pay cost not covered by LTCIS than less burdened caregivers were. They had tendency to pay 10,000 yen or more for the personal cost of services under the LTCIS than less burdened caregivers although it failed to show statistical significance.

Table 4 shows a comparison between the two groups regarding the social services that family caregivers wanted to use. Compared to their counterparts, the heavily burdened caregivers wanted to use social services such as regular daytime respite care, regular help for caregiving, dental check for the elderly, and 24-hour home help.

Table 3: Care setting

Factors		Heavily burdened group n = 41	Less burdened group n = 60	p-value
Duration of caregiving	months	72.39 ± 78.58	68.03 ± 76.30	0.78
Time of physical care	hours/day	7.84 ± 6.18	4.69 ± 5.38	0.01
Time of watching the elderly	hours/day	10.89 ± 7.18	6.14 ± 6.77	< 0.01
Self-pay cost of care service under the LTCIS	0-9,999 yen/month	5(12.2)	17(28.3)	0.09
	10,000+yen/month	36(87.8)	43(71.7)	
Self-pay cost not covered by LTCIS	0-9,999 yen/month	5(12.2)	21(35.0)	0.02
	10,000+ yen/month	36(87.8)	39(65.0)	
Health welfare services of city/town	Yes	17(41.5)	17(28.3)	0.25
	No	27(65.9)	49(81.7)	
Concern about what others say	No	27(65.9)	49(81.7)	0.07
	Yes	14(34.2)	11(18.39)	

Values are expressed as number (%) or mean ± SD

LTCIS: long term care insurance system

Table 4: Social services that caregivers want to use

Factors		Heavily burdened group n = 41	Less burdened group n = 60	p-value
Class for learning how to care for the elderly	Yes	12(29.3)	25(41.7)	0.29
	No	29(70.7)	35(58.3)	
Respite care during a journey	Yes	35(85.4)	45(75.0)	0.31
	No	6(14.6)	15(25.0)	
Regular daytime respite care	Yes	33(80.5)	35(58.3)	0.05
	No	8(19.5)	25(41.7)	
Regular help for caregiving	Yes	34(82.9)	34(56.7)	0.01
	No	7(17.1)	26(43.3)	
Regular health check-up for the elderly	Yes	35(85.4)	49(81.7)	0.83
	No	6(14.6)	11(18.3)	
Dental check for the elderly	Yes	33(80.5)	35(58.3)	0.03
	No	8(19.5)	25(41.7)	
Regular bathing service	Yes	33(80.5)	40(66.7)	0.19
	No	8(19.5)	20(33.3)	
24-hour home help service	Yes	27(65.9)	19(31.7)	< 0.01
	No	14(34.1)	41(68.3)	
Rehabilitation for disabled elderly	Yes	36(87.8)	49(81.7)	0.58
	No	5(12.2)	11(18.39)	
Meal delivery service	Yes	14(34.1)	23(38.3)	0.83
	No	27(65.9)	37(61.7)	

Values are expressed as number (%).

DISCUSSION

In the present study, more than half (57.4%) of caregivers were 65 years old or older, and 21.8% were 75 years old or older while more than half (55.4%) of family caregivers had chronic diseases under medical treatment and 24.8% of caregivers are ill health (often: 20.8%, frequently: 4.0%). In addition, nearly half of caregivers (45.5%) were depressed in the present study. Furthermore, heavily burdened caregivers were older and more likely to be depressed than less burdened caregivers. Since physiological, and psychological declines make older adults vulnerable to increased risk of disability, and long-term care⁹, we should take care of both disabled elderly and their family caregivers so that family caregivers will not impair their health and can continue care for their relatives at home in our aging population.

Walker *et al.*¹⁴ reported that spending a large amount of time on caregiving was reported to be a risk factor for stress among caregivers.

In the present study, compared with their counterparts, heavily burdened caregivers spent more time on physical care and watching their discharges. In addition, heavily burdened caregivers were more likely to want to use social services (i.e., regular daytime respite care, regular help for caregiving, and 24-hour home help) that give them free time from caregiving than their counterparts in the present study. This result suggests that social services that give caregivers free time from caregiving may not be enough for family caregivers.

Physical frailty due to old age is one of the main causes of long-term care for old people in Japan², and loneliness, depression, muscle disuse and nutritional deficiencies are associated with an increased risk of frailty⁴, home-visiting nurses should watch family caregivers so that they do not take care of their relatives at the cost of their own health. We should support family caregivers to receive public health services and medical care services for their own health.

Dementia is one of the main causes of long-term care for old people in Japan². The relationship between caregiver burden and behavioral disturbances associated with dementia is well documented¹⁵. Hashimoto *et al.*¹⁶ reported that behavioral problems increased the risk of depression among family caregivers of patients with dementia. In the present study, caring for the elderly with dementia and behavioral problems was positively related to the burden of caregivers. However, the proportion of the disabled elderly with dementia did not differ between the heavily and less burdened groups. These findings suggest that the behavioral disturbances of the elderly with dementia (not dementia itself) may increase the risk of heavy burden among family caregivers. Since the prevalence of dementia increased greatly over the past quarter centuries in Japanese elderly population¹⁷, we should provide more public services to support family caregivers of the demented elderly.

Financial burden is also related to the heavy burden of family caregivers¹⁸. Washio *et al.*¹⁸ reported that depressed caregivers wanted more social services than did non-depressed caregivers, but the use of social services did not differ between depressed and non-depressed caregivers. Moreover, compared to non-depressed caregivers, depressed caregivers were less likely to pay 20,000 yen or more per month for social services under LTCIS¹⁸. Some caregivers may restrain from using social services because they cannot afford to self-pay for these services¹⁸. In the present study, compared with less burdened caregivers, heavily burdened caregivers were more likely to personally pay 10,000 yen or more per month for expenses not covered by LTCIS, and they had tendency to pay 10,000 yen or more for the personal cost of services under LTCIS than less burdened caregivers although it failed to show statistical significance. In order to reduce caregiver's burden as well as to prevent caregiver's ill health, municipal public nurses and care-managers should help family caregivers feel free to use free services other than social services under LTCIS (e.g., municipal services for disabled elderly, informal services for the elderly)³.

CONCLUSION

In conclusion, population aging increases not only older people with

chronic diseases but also older people who need care in Japan. Therefore, it is important to prevent the aggravation of chronic diseases as well as to prevent declines in mental and physical function in older people. We should support old caregivers so that they will be able to continue caregiving at home as well as to consult with physicians with their own health because old caregivers are at high risk at diseases which need long-term care such as stroke, fracture after fall, physical frailty due to old age, and dementia²⁾. Healthcare workers should take care of the frail elderly as well as their old caregivers so that old caregivers will not impair their physical or mental health through their caregiving.

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