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KUWAHARA, Yuichi
Keichiku Public Health Center

WASHIO, Masakazu
Department of Preventive Medicine, Graduate School of Medical Sciences, Kyushu University

ARAI, Yumiko
Research Unit for Nursing Caring Sciences and Psychology, National Institute of Longevity Sciences

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Burden among Caregivers of Frail Elderly in Japan

Yuichi KUWAHARA[1),*], Masakazu WASHIO[2)], Yumiko ARAI[3)]

[1)]*Keichiku Public Health Center, Fukuoka 824-0005, Japan,*
[2)]*Department of Preventive Medicine, Graduate School of Medical Sciences, Kyushu University, Fukuoka, 812-8582, Japan,*
[3)]*Research Unit for Nursing Caring Sciences and Psychology, National Institute of Longevity Sciences, Aichi 474-8522, Japan.*
**Present address : Kaho Public Health Center, Fukuoka 820-0004, Japan*

Abstract The present study was conducted in order to investigate the factors related to the feelings of psychological stress, called heavy burden, in caregivers who took care of frail elderly in the eastern part of Fukuoka Prefecture, Kyushu, Japan. Fifty-eight caregivers answered a self-administered questionnaire, involving the Japanese version of the Zarit Caregiver Burden Interview (ZBI) and thus described their own caregiving situation. Compared to caregivers with a light burden, heavily burdened caregivers were less likely to have time to go out without patients, but were more likely to consult physicians. Heavily burdened caregivers spent a longer time on looking after the elderly as well as on physical caregiving, and also used more social services than lightly burdened caregivers. However, the physical disabilities of the patients did not differ between the two groups. Even after controlling for confounding factors, the time spent on looking after frail elderly was found to be a significant factor related to the caregivers' heavy burden (10-24 hrs vs. 0-9 hrs; odds ratio: 5.35, 95% confidence interval: 1.17-25.58). These findings suggest that looking after frail elderly for a long time seems to be an important factor related to caregivers' developing psychological feelings of heavy burden.

Key words: burden, caregiver, frail elderly, look after, Japan

Introduction

Japan is quickly becoming an aged society. Improvements in public health and advances in medicine after the World War II have given Japan the highest life expectancies in the world, which reached 77.2 years old for men and 83.8 years for women as of 1997[16)]. The dramatic increase in the number of the older people in this country is well documented[5)9)10)]. Due to the increased elderly population, the number of elderly in need of care has also increased. It is estimated that the number of elderly in need of care will reach 3.9 million in 2010[9)]. It has been reported that caring for the elderly in need of care tends to induce feelings of psychological burden in the caregivers[17)22)]. There have been many reports which showed that fatigue of caregivers[12)] or a large amount of time spent on caregiving[14)18)] was related to the feelings of burden in such caregivers. There have also been many reports on the relationship between the caregivers' feelings of burden and the time spent on providing physical care. But there

Address for correspondence Yuichi Kuwahara MD. Kaho Public Health Center, 8-1 Shintateiwa, Iizuka City, Fukuoka 820-0004, Japan
Tel: 0948-21-4972 Fax: 0948-24-0883

have so far been few reports on the relationship between the feelings of burden and the time spent on looking after the elderly by such caregivers.

The present study was conducted in the urban and rural communities in our public health center service area (i.e. Keichiku Public Health Center service area). We investigated the relationship between feelings of burden in caregivers and various factors including the time spent on physical caregiving or looking after the elderly based on a Japanese version of the Zarit Caregiver Burden Interview (ZBI).

Methods

Subjects

During the period from October to December in 1999, a questionnaire survey was carried out of seventy-nine pairs of caregivers and disabled elderly who received regular nurse visits from nurse stations located in two districts in the eastern part of Fukuoka Prefecture, Kyushu, in south-western Japan. One was Kanda, a town of automobile industry with a population of 34,000 and the other was Yoshitomi, a country town with a population of 7,500. Both of them had only one nurse station in the district. We invited 79 frail elderly and their caregivers to participate in this study. Seventeen refused, and 4 caregiver gave an incomplete report for ZBI in this study, which thus left us with 58 pairs of disabled elderly and their caregivers as the subjects of this study. The ZBI is one of the most common scales for assessing the burden of caregiving[23]. The Japanese version of the ZBI has been tested for its reliability and validity in both northern[1] and southern Japan[2].

Measurements

The caregivers were asked to complete the following self-administered questionnaires in relation to their burden and caregiving situation, which were (i) a Japanese version of the ZBI, (ii) questions regarding demographic variables of the patients and their caregivers, and (iii) questions regarding the time spent in caregiving, the time used attending the patients and the total duration of caregiving in the same manner as our previous studies[1)2)21)].

The methods of assessing dementia and physical disabilities have been reported elsewhere[1]. In short, the Barthel Index (BI)[7] was employed for physical disability. As reported previously, the patients were divided into the following two groups; (i) severely dependent (BI: from 0 to 10) and (ii) moderately dependent (BI: from 11 to 20). In order to assess whether or not the elderly patients had any behavioral disturbances associated with dementia, we asked the caregivers if the elderly had any behavioral problems listed on the Dementia Behavioral Disturbance (DBD) scale[4)11)]. A diagnosis of dementia was obtained by reviewing medical records of the patients (KY and MW). The physicians in each nursing home made diagnoses based on the DSM-IIIR.

Analyses

The caregivers were divided into the following two groups according to their ZBI score (i.e., the cut-off point of the ZBI being 37 as defined above): (i) those who were heavily burdened (group 1); and (ii) those who were lightly burdened (group 2). Statistical analyses were performed using the Statistical Analysis System package (SAS Institute, Cary, USA)[15]. The Mann-Whitney U-test, the Chi-square test, the Mantel-Haenszel test and the Fisher exact test compared the two groups. A multiple logistic regression analysis was conducted to control for any confounding factors related to the heavy burden of the caregivers. The odds ratio (OR)

and their 95% confidence interval (95% CI) were then calculated for each factor based on the logistic regression coefficient and standard error.

Results

The characteristics of caregivers in our study are shown in Table 1. Fifty-one of the 58 caregivers (88%) were females and their average age was 61.2 years old (SD=11.8). The mean score of the ZBI was 37.4 (SD=20.4). Table 2 shows the characteristics of the patients. Thirty-four of the 58 patients (59%) were females and the average age was 78.5 years old (SD=11.7). Among them, 41% had severe limitations in activities of daily livings (ADL) and 33% were diagnosed to have dementia. As shown in Table 3, compared with the lightly burdened caregivers, the heavily burdened caregivers were less likely to have time to go out without their patients (40% vs. 69%, p=0.03), but were more likely to consult physicians (72% vs. 44%, p=0.04). The heavily burdened caregivers spent a longer time on attending the elderly (14.7h vs. 6.4h, p=0.00) as well as in caregiving (11.4h vs. 6.6h, p=0.04), and also used more social services (5.6 vs. 3.6, p=0.003) than the lightly burdened caregivers. The age, relationship of the caregivers to patients, the duration of caring or the number of family members did not differ significantly between the two groups. The caregivers who lived in Yoshitomi (i.e. a country town), those who had a job, those who had someone to help with care, and those who had experienced life events (i.e., the death of family members, etc.) were similarly observed in the two groups.

Table 4 shows the characteristics of the patients. Compared with the lightly burdened caregivers, the heavily burdened caregivers tended to look after male patients. The proportion of the frail elderly with dementia, behavioral disturbances or the ADL of the elderly in need of care did not differ significantly between the two groups.

Table 5 shows the results of a multiple logistic regression analysis regarding the feelings of heavy burden of the caregivers. The time

Table 1 Characteristics of the Caregivers (n=58)

	number (%) or mean (SD)
Gender	
Male	7 (12.1)
Female	51 (87.9)
Age (years old)	61.2 (11.8)
Relationship of the caregiver to the patient	
Spouse	23 (39.7)
Child	22 (37.9)
Daughter-in-law	10 (17.2)
Others	3 (5.2)
District	
Yoshitomi (a country town)	29 (50.0)
Kanda (a town of automobile industry)	29 (50.0)
No. of family members	3.2 (1.6)
No. of social services used by caregivers	4.5 (2.6)
ZBI #	37.4 (20.4)

ZBI: Zarit Caregiver Burden Interview.

Table 2 Characteristics of the Patients (n=58)

	number (%) or mean (SD)
Gender	
Male	24 (41.4)
Female	34 (58.6)
Age (years old)	78.5 (11.7)
Activities of daily livings (ADL)#	
Severely limited ADL	24 (41.4)
Moderately limited ADL	34 (58.6)
Dementia	
Without	37 (63.8)
With	19 (32.8)

Severely limited ADL: Barthel Index ≦10
Moderately limited ADL: Barthel Index >10

Table 3 Comparison between the heavily burdened caregivers and the lightly burdened caregivers: Caregivers' characteristics

Caregivers	heavily burdened caregivers (group 1; n=25)	lightly burdened caregivers (group 2; n=33)	p-value
Age (years old)	64.1±9.5	59.1±13.0	0.100
Gender Male/Female	3/22	4/29	0.989
Relationship of the caregiver to the patients			
Spouse	13	10	0.213
Child	7	15	
Daughter-in-law	4	6	
Other	1	2	
District Yoshitomi/Kanda	12/13	17/16	0.793
Had a job Yes/No	4/21	11/22	0.139
Had someone to help with care Yes/No	8/17	14/18	0.370
Had time to go out without their patient Yes/No	10/15	22/10	0.031
Had consulted physicians within a month: Yes/No	18/7	14/18	0.035
Time spent in caregiving (h/day)	11.4±8.9	6.6±7.4	0.043
Time spent looking after the elderly (h/day)	14.7±8.4	6.4±8.3	0.001
Duration of care (months)	60.7±80.4	61.4±66.8	0.975
No. of family members	3.4±1.9	3.1±1.4	0.493
No. of social services used by caregivers	5.6±2.5	3.6±2.3	0.003
Life events Yes/No	8/16	9/24	0.625

Each set of values represents the number, or mean ± SD
Life event: an event which may cause depression within 6 months

Table 4 Comparison between the heavily burdened caregivers and the lightly burdened caregivers: Patients' characteristics

Patients	heavily burdened caregivers (group 1; n=25)	lightly burdened caregivers (group 2; n=33)	p-value
Age (years old)	76.6±13.6	79.8±9.9	0.326
Gender men/women	14/11	10/23	0.051
Dementia yes/no	10/14	9/23	0.294
Behavioral disturbance yes/no	5/20	3/30	0.237
Barthel Index	6.4±6.5	9.5±7.9	0.106

Values are expressed as to number or mean ± SD

spent on looking after the patients was a factor related to the heavy burden (10-24 hrs vs. 0-9 hrs: odds ratio: 5.35, 95% confidence interval: 1.17-25.58). Since the time spent for caregiving ($r=0.731$, $p=0.00$) was positively related to the time spent looking after the frail elderly (Data

Table 5 The multiple logistic regression analysis in relation to the caregivers' feelings of heavy burden.

Factors	Odds ratio	95% confidence interval	p-value
Caregivers' characteristics			
Time spent looking after the patients 10-24 vs 0-9 (hours/day)	5.53	1.17-25.58	0.03
Had consulted with physicians within a month Yes vs No	3.87	0.80-19.83	0.09
Had time to go out without their patients Yes vs No	0.38	0.09-1.63	0.19
No. of social services used by caregivers 0-4 vs 5-10	2.59	0.61-11.03	0.20
Patients' characteristics			
Gender Male vs Female	1.55	0.31-7.72	0.59
District Yoshitomi vs Kanda	0.63	0.14-2.76	0.54

not shown in the table), this factor was not used in this analysis.

Discussion

In the present study, the heavily burdened caregivers spent a longer time looking after frail elderly as well as in the physical caregiving. Even after controlling for confounding factors, the time spent on looking after the elderly was a significant factor related to the caregivers' feelings of heavy burden (10-24 hrs vs. 0-9 hrs, odds ratio: 5.35, 95% confidence interval: 1.17-25.58). This finding is consistent with the results of our previous study[1)21)]. Since heavily burdened caregivers tend to be depressed[21)], this finding may be partly explained by the possibilities that the depressed caregivers spent a longer time in both looking after and in physically caring for the frail elderly than the non-depressed caregivers.

In the present study, heavily burdened caregivers were more likely to consult their physicians about their own health. Even after controlling for other factors, they tended to visit physicians. Since the present study was a cross-sectional study, further studies should be performed to answer such questions as whether (i) a heavy burden may worsen the caregivers' health; or whether (ii) ill caregivers may experience an even greater care burden.

Caregiver's burden is frequently assumed to be strongly related to the severity of the patient's disability[22)]. In our previous studies, however, caregivers who took care of the elderly with more limited ADL felt less care burden[2)], and caregivers who look after the elderly with totally limited ADL were less likely to give up caregiving at home than those caring for the elderly with partially limited ADL[3)]. Ogata and her coworkers[13)] reported that family members caring for the elderly with partially limited ADL felt more burden than either the elderly with totally limited ADL or the elderly without limitation in ADL. In the present study, there

was no significant association between the caregivers' burden and the ADL of the frail elderly. Further studies are thus called for to elucidate these aspects.

In the present study, heavily burdened caregivers tended to take care of male patients rather than female patients. This finding may be explained by the following possibilities. First, caring for male patients may be physically harder than caring for female patients. In the present study, 18 (75.0%) of 24 caregivers caring male patients were wives while only 5 (14.7%) of 34 caregivers caring female patients were husbands. Since most of caregivers caring female patients were daughters and daughters-in-law, caregivers of male patients were older than those of female patients. Second, compared with female patients, caregivers taking care of male patients may feel a greater care burden when the elderly have dementia with behavioral disturbances that directly affect the caregivers (e.g. violence, uncontrollable sexual appetite).

George and Gwyther[6] reported that caregivers who need more social support and more help from friends and family, tend to demonstrate more stress symptoms and less self-satisfaction, and also spend less time relaxing, compared with those who do not.

In order to improve the quality of the elderly's life and to reduce the caregivers' feelings of heavy burden, a new public long-term care insurance service started in April 2000[9)10)19)21]. Local governments must endeavor to acquire both a sufficient quality and quantity of social services for the frail elderly and their caregivers, and care-managers (coordinators of social services) are expected to play an important role in this project[9)19]. However, in the present study, the heavily burdened caregivers used more social services than the lightly burdened caregivers. Since the present study was carried out during the period from October to December in 1999, neither the quality nor the quantity of social services were considered to be sufficient. In Fukuoka Prefecture, the supply of services for the elderly in need of care and their caregivers in the community are below average for Japan[8)], and more than 70% of the caregivers answered that they needed more respite services (74%) and more home help services (71%)[20)].

In summary, the present study showed that, in spite of using more social services, the heavily burdened caregivers tended to look after the frail elderly longer than the lightly burdened caregivers although the physical disability of the frail elderly did not differ between the two groups. Even after controlling for confounding factors, the time spent looking after the elderly was a significant factor related to the caregivers' feelings of heavy burden. These findings suggest that looking after frail elderly for a long time seems to be an important factor related to caregivers' developing psychological feelings of heavy burden.

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Zaritの介護負担評価尺度日本語版を用いた要介護高齢者の主介護者の介護負担に関する研究

[1] 福岡県京築保健所,
[2] 九州大学大学院医学研究院予防医学分野,
[3] 国立長寿医療研究センター看護介護心理研究室
桑原裕一[1]・鷲尾昌一[2]・荒井由美子[3]

要介護高齢者の主介護者を対象に，Zaritの介護負担尺度を用いて介護負担感とその関連要因について調査を行った．福岡県京築保健所の管轄内の苅田町（自動車工業の町）と吉富町（田舎町）の訪問看護ステーションを利用している58組の要介護高齢者とその主介護者が調査に参加した．介護負担感が小さな介護者に比べ，介護負担感が重い介護者は要介護高齢者をおいて一人で外出できる者が少なく，医者にかかっている者が多く，要介護高齢者から目が離せない時間や介護をしている時間が長く，社会的サービスを多く利用していた．しかし，要介護高齢者の日常生活動作障害の程度や居住地は両群間で有意差を認めなかった．交絡因子を補正しても，要介護老人から目が離せない時間は重い介護負担感の関連要因であった（10-24時間VS 0-9時間，オッズ比：5.35，95%信頼区間：1.17-25.58）．以上より，要介護高齢者の介護者にとって，要介護高齢者から目が離せない時間が長いことは重要な介護負担の関連要因であると考えられた．