

ORIGINAL ARTICLE

Changes in family caregivers' sense of caregiving burden resulting from the COVID-19 pandemic

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Abstract

Family caregivers' sense of caregiving burden during the COVID-19 pandemic was investigated using an original self-administered questionnaire, the Japanese version of the Zarit Caregiver Burden Interview (J-ZBI) and the 12-item General Health Questionnaire (GHQ12). Family caregivers who felt that the time involved in caregiving increased during the COVID-19 pandemic tended to strongly feel that the care recipients demanded more care than necessary, and that they themselves had less time for social activities and had poorer mental health. Alongside this, the physical state of care recipients was thought to worsen during the COVID-19 pandemic and this was thought to have a significant impact on the increase in caregiving time and thus the sense of caregiving burden. Refraining from going out during a pandemic can lead to a decrease in physical activity and interruption of treatment, and this may have life-threatening consequences for elderly people. This study highlighted the situation of caregivers of family members of people with dementia in an atypical situation such as a pandemic. Information and communications technology has been shown in previous studies to alleviate some of these problems, and we suggest it might be used to facilitate certain social activities and medical care and to relieve some of the burden on caregivers.

INTRODUCTION

The outbreak of novel coronavirus infection (COVID-19) in December 2019 had a significant impact on the social lives of people worldwide, with effects felt to this day. In Japan, the Ministry of Health, Labour and Welfare promoted preventive measures such as hand washing and wearing masks (Ministry of Health, Labour and Welfare, 2020) and unprecedented restriction of movement and social interaction which resulted in fewer opportunities for people to leave their homes. As a substitute for proximal face-to-face interaction, various online activities were used. Elderly people with dementia living at home were not excepted from these measures and restrictions, and so had reduced access to day care services and fewer conversations with non-family members (Ohno, 2021; Sugawara, 2022). This led to reduced opportunities for physical activity and social participation, and there have been reports of increased frailty and cognitive decline as a consequence (Iijima, 2021; Takai, 2022). A less commonly-reported issue is that people caring for elderly

relatives in their homes with dementia had increased time spent at home with the care recipients and the recipients are highly vulnerable elderly people at high risk of contracting COVID-19. The care givers therefore had to take special infection prevention measures during the pandemic for not only themselves, but also for the care recipients. This reportedly increases the caregiving burden and is thought to be likely to increase psychological stress (Suzuki, 2021).

We hypothesized that people involved in the care of elderly relatives in the home with dementia would feel an increased sense of burden during the pandemic. To assess the sense of burden, we conducted a cross-section survey of caregivers of patients from our hospital. We used a self-administered rating scale and examined the factors influencing these results. A previous study (Arai, 2004) used a self-administered questionnaire to examine the change in caregiving time of family members. We used a similar questionnaire to examine the change in caregiving time, which is thought to be representative of

the change in caregiving burden before and after the COVID-19 pandemic.

METHODS

Subjects and methods

A total of 204 family caregivers who lived with and cared for an elderly person with dementia attending Shin-Abuyama Hospital at home were asked to complete an unadministered questionnaire survey. Of the 103 responses received, 41 results were considered valid for analysis (50.5% recovery rate, 39.8% valid response rate). We excluded the respondents 30 who answered 'no' to the question 'Did you start caring for the person during rather than before the COVID-19 pandemic?', and the 32 correspondents who provided incomplete answers.

The study period was from 1 September 2022 to 30 April 2023, and included an original questionnaire on home care (developed by the authors), the Japanese version of the Zarit Caregiver Burden Interview (J-ZBI), and the 12-item General Health Questionnaire (GHQ12).

The questionnaire on home care included a profile of the study subjects (gender, age, duration of care, and relationship with the care recipients), details on the use of care services during the COVID-19 pandemic, details of changes in the time caregivers spent involved in care before and after the pandemic, details of changes in time caregivers spent on social activity during the pandemic, items on changes in the physical and mental state of care recipients during the pandemic, and items on fear of care recipients contracting COVID-19.

J-ZBI was also used to assess the burden of caregiving among subjects during the COVID-19 pandemic. The original version was developed as a quantitative measure of caregiving burden (Zarit, 1980). J-ZBI is a standardized Japanese language version with confirmed reliability and validity (Arai, 2018, 1997). It has 22 questions, each of which is answered on a five-point Likert scale. The maximum score is 88, with a score of zero representing no caregiving burden at all. Family caregivers were considered to have severe depression if they have > 24 points (Schreiner, 2006).

In addition, to assess the mental health of the subjects during the COVID-19 pandemic, we used GHQ12 (Goldberg, 1972), which has a standardized Japanese version and has been shortened (Nakagawa, 2013). GHQ12 has been found to have high reliability and validity and it provides a convenient

measure of mental health in the weeks prior to testing. The cut-off point used was based on a previous study (Nakagawa, 2013): scores < 3 points were considered better mental health and > 4 were considered poorer mental health. Subjects' scores were obtained using the GHQ scoring method.

Statistical analysis

The subjects were divided into two groups (increased caregiving time group and non-increased caregiving time group) based on their answers to the questionnaire on home care, and the change in the time spent involved in care as a result of the pandemic. Analyses were conducted after classification. Not all variables in both groups were found to be normal and equally distributed, so we employed non-parametric tests for analyses of quantitative variables.

To determine the effect of changes in subjective caregiving time on total J-ZBI scores and scores on each questionnaire and GHQ12, a two-group comparison was conducted using Mann-Whitney's U-test. In addition, a Pearson's chi-square test was used to compare the responses to the questionnaire on home care between the two groups. All statistical analyses were performed using SPSS ver. 27 (IBM Corp., Armonk, NY, USA) and with two-tailed tests. The statistical significance level was set at $p = 0.05$.

Ethical considerations

The study was approved by the Ethics Committee of Shin-Abuyama Hospital, Osaka Institute of Clinical Psychiatry. The study was performed in accordance with the Declaration of Helinski. Prior to the distribution of the questionnaires, family caregivers were given verbal and written explanations of the purpose of the study and were told that the responses were anonymous, that cooperation in the study was voluntary and that refusal would not be detrimental to treatment in any way. All subjects thus participated with opt-in consent.

RESULTS

Details of the subjects are presented in Table 1. The subjects were all the primary caregiver. Of the 41 analyzed, 20 were men and 21 were women. The median age of the analyzed subjects was 74 years overall, 77 years for men and 66 years for women. The median duration of care was 62 months overall, 56.5 months for men and 70 months for women. The care recipients were 24 spouses, 12 parents,

3 parents-in-law, 1 sibling and 1 child. There were 13 people in the increased caregiving time group and 28 people in the non-increased caregiving time group, classified on the basis of their responses to the questionnaire on home care and change in the time caregivers are involved in care as a result of the COVID-19 pandemic.

Results of J-ZBI and GHQ12 in the increased caregiving time group and the non-increased caregiving group are presented in Table 2. No significant differences were found in comparison between the two groups.

Regarding the J-ZBI questions, a significant difference was found between the groups for a question on whether the carer felt that the person under their care asked for more help than they actually needed ($p = 0.047$) and for a question on whether they felt uncertain about what to do about that person. The increased caregiving time group tended to have higher scores than the non-increased caregiving time group ($p = 0.080$).

Regarding increased caregiving time and non-increased caregiving time, the increased caregiving time group tended to have higher GHQ12 scores ($p = 0.075$).

The results of the questionnaire on home care for the analyzed subjects are shown in Table 3. Regarding the use of care services during the pandemic, six respondents replied that it had stopped, five said that it had decreased, 14 said that it was the same as before, four said that it had increased, and 12 reported no use of services.

Regarding changes in time spent on social activity of caregivers during the pandemic, 18 respon-

dents answered that there was a large decrease, 18 answered that there was a small decrease, five answered that it was the same as before, and no respondents answered that there was large or small increase.

Regarding changes in the physical and mental state of care recipients during the pandemic, two respondents answered that their physical state had become much worse, 14 that it was slightly worse, 22 reported that it was the same as before, three answered that it was slightly better, and none answered that it was much better.

Regarding personal mental state, one respondent reported that it had become much worse, 11 reported that it had become slightly worse, 25 reported that it was the same as before, four that it was slightly better, and none said that it was much better.

Regarding fear of the care recipient contracting COVID-19, 12 respondents answered that they were very worried, 21 respondents were reportedly a little worried, three respondents were unsure, five were not very worried, but no respondents stated that they were not worried at all.

A comparison between the two groups showed a significant difference in the changes in the physical state of care recipients during the pandemic ($p = 0.020$), a worsening trend in the group of increased caregiving time in the change in the mental state of care recipients as a result of the pandemic ($p = 0.091$). In the group with increased caregiving time, there was a decreasing trend in changes in the time caregivers spent on social activities during the pandemic ($p = 0.054$).

Table 1. Profile of subjects

	all subjects	men	women
Number of subjects	$n = 41$	$n = 20$	$n = 21$
Age (years)	74(51–88)	77(53–88)	66(51–84)
Duration of care (months)	62(36–159)	56.5(36–159)	70(36–130)
Person responsible for care	Spouses 24	Spouses 15	Spouses 9
	Parents 12	Parents 5	Parents 7
	Parents-in-law 3	Parents-in-law 0	Parents-in-law 3
	Sibling 1	Sibling 0	Sibling 1
	Child 1	Child 0	Child 1

† Age and duration of care are shown as median (range: min-max).

Table 2. Comparison of J-ZBI and GHQ12 between the two groups in the increased and non-increased caregiving time groups

	all subjects <i>n</i> = 41	Increased caregiving time group <i>n</i> = 13	Non-increased caregiving time group <i>n</i> = 28	
J-ZBI total score	31(9–70)	34(9–61)	27.5(12–70)	<i>p</i> = 0.260
J-ZBI Questionnaire (Questions omitted for copyright reasons)				
Q1.	1(0–4)	2(0–4)	1(0–3)	<i>p</i> = 0.047**
Q2.	2(0–4)	2(0–4)	1.5(0–4)	<i>p</i> = 0.353
Q3.	1(0–4)	1(0–4)	1.5(0–4)	<i>p</i> = 0.901
Q4.	1(0–4)	2(1–4)	1(0–4)	<i>p</i> = 0.413
Q5.	1(0–4)	2(0–3)	1(0–4)	<i>p</i> = 0.430
Q6.	1(0–4)	1(0–4)	1(0–3)	<i>p</i> = 0.382
Q7.	2(0–4)	2(2–4)	2(0–4)	<i>p</i> = 0.463
Q8.	3(0–4)	3(0–4)	3(1–4)	<i>p</i> = 0.589
Q9.	1(0–4)	1(0–3)	1(0–4)	<i>p</i> = 0.648
Q10.	0(0–4)	1(0–3)	0(0–4)	<i>p</i> = 0.324
Q11.	0(0–3)	0(0–3)	0(0–3)	<i>p</i> = 0.989
Q12.	1(0–4)	1(0–4)	1(0–4)	<i>p</i> = 0.648
Q13.	0(0–4)	0(0–2)	0.5(0–4)	<i>p</i> = 0.793
Q14.	3(0–4)	2(0–4)	3(0–4)	<i>p</i> = 0.570
Q15.	1(0–4)	1(0–4)	0.5(0–4)	<i>p</i> = 0.413
Q16.	1(0–4)	1(0–3)	1(0–4)	<i>p</i> = 0.989
Q17.	2(0–4)	2(0–4)	2(0–4)	<i>p</i> = 0.750
Q18.	1(0–3)	1(0–3)	1(0–3)	<i>p</i> = 0.226
Q19.	1(0–3)	2(0–3)	1(0–3)	<i>p</i> = 0.080*
Q20.	1(0–4)	1(0–4)	1(0–3)	<i>p</i> = 0.688
Q21.	0(0–3)	1(0–1)	0(0–3)	<i>p</i> = 0.609
Q22.	2(0–4)	2(1–4)	2(0–4)	<i>p</i> = 0.772
GHQ12 score	2(0–12)	3(1–10)	2(0–12)	<i>p</i> = 0.075*

† J-ZBI : Japanese version of the Zarit Caregiver Burden Interview, GHQ12 : General Health Questionnaire12

‡ J-ZBI, GHQ12 scores indicate median (range: min-max).

* : *p* < 0.10, ** : *p* < 0.05

Table 3. Results of questionnaire on home care in the increased and non-increased caregiving time groups

Use of care services during the COVID-19 pandemic ($p = 0.710$)					
	stopped	decreased	same as before	Increased	no use of services
all subjects $n = 41$	6	5	14	4	12
Increased group $n = 13$	2	2	5	2	2
Non-increased group $n = 28$	4	3	9	2	10
Changes in time spent social activity of caregivers during the COVID-19 pandemic ($p = 0.054^{**}$)					
	decreased a lot	decreased a little	same as before	increased a little	increased a lot
all subjects $n = 41$	18	18	5	0	0
Increased group $n = 13$	9	4	0	0	0
Non-increased group $n = 28$	9	14	5	0	0
Changes in the physical state of care recipients during the COVID-19 pandemic ($p = 0.020^{**}$)					
	much worse	slightly worse	same as before	slightly better	much better
all subjects $n = 41$	2	14	22	3	0
Increased group $n = 13$	2	7	3	1	0
Non-increased group $n = 28$	0	7	19	2	0
Changes in the mental state of care recipients during the COVID-19 pandemic ($p = 0.091^{*}$)					
	much worse	slightly worse	same as before	slightly better	much better
all subjects $n = 41$	1	11	25	4	0
Increased group $n = 13$	1	6	5	1	0
Non-increased group $n = 28$	0	5	20	3	0
Fear of care recipients contracting COVID-19 ($p = 0.312$)					
	very worried	a little worried	unsure	not very worried	not worried at all
all subjects $n = 41$	12	21	3	5	0
Increased group $n = 13$	6	4	1	2	0
Non-increased group $n = 28$	6	17	2	3	0

* : $p < 0.10$ ** : $p < 0.05$

DISCUSSION

During the COVID-19 pandemic, elderly people with dementia were faced with an unprecedented situation. As well as general effects, there was also the potential for lack of understanding of the need for infection prevention measures, and major changes in their living situation and environment, such as voluntary restraint from activities. These changes in the environment are thought to accelerate deterioration in the physical and cognitive functions of elderly people with dementia, and can lead to a decline in activities of daily living (ADL) and behavioral and psychological symptoms of dementia (BPSD; Osa-

wa, 2021). The decline in ADL and the appearance of BPSD reportedly affect family caregivers' sense of caregiving burden (Arai, 1999). In addition, caregiving time, which is widely used as an indicator of the amount of caregiving, is significantly correlated with caregiving burden (Arai, 2004).

This study considered changes in family caregivers' caregiving time as a result of the COVID-19 pandemic as a representation of change in caregiving burden. We examined the association between these changes and changes in family caregivers' daily life and the physical and mental state of elderly people with dementia during this especially dif-

difficult period. The median total J-ZBI scores of the caregivers in the study exceeded the cut-off point in both the increased and non-increased caregiving time groups. This suggests that caregivers felt especially burdened by caregiving during the pandemic. The J-ZBI questionnaire also showed that family caregivers with increased time involved in caregiving strongly felt that the person under their care required more care than necessary, and the results of the GHQ12 showed that their mental health tended to worsen. On the other hand, the results of the self-administered questionnaire showed no difference in the use of care services by care recipients between the two groups. Presumably, few care recipients had care services were stopped or reduced, and this did not affect the caregiving burden. However, family caregivers who felt that the time involved in caregiving had increased felt that the physical and mental state of the care recipients had worsened. It was assumed that the worsening physical state in particular had an impact on the increased caregiving burden. Furthermore, about 80% of family caregivers were found to be concerned that they might transmit COVID-19 to the care recipients. The caregiving environment in the home was suggested by these results to have changed dramatically during the pandemic. Family caregivers were suggested to have spent more time at home with the people under their care and less time on their own social activities during the pandemic, and they were forced to deal with the care recipients' reduced ADL and infection prevention measures.

In a previous report, the isolation policy during the COVID-19 pandemic in Italy was shown to have resulted in a decline in ADL, in cognitive decline and in worsening of BPSD in elderly people with dementia, and there was increased stress among caregivers (Vernuccio, 2022). In Japan too, it has been suggested that elderly people in the community have been less likely to attend medical examinations (Ichinohe, 2021), and there has been an increase in frailty and pre-frailty (Iijima, 2021). The need for geriatric care in Japan is increasing year by year (Ministry of Health, Labour and Welfare, 2022), so there is concern that both elderly people with dementia and family caregivers may have a decline in motor and cognitive functions.

In a widespread crisis such as the COVID-19 pandemic, vulnerable groups, including elderly people, are most likely to be affected. Refraining from leaving their homes as a means of preventing

infection can lead to a decrease in physical activity and interruption of treatment, which can be life-threatening for elderly people. As a result of the 2011 Great East Japan Earthquake, for example, there was a decline in motor function among elderly people affected by the disaster (Murakami, 2014). A recent study reported that 'having people and places to support each other promotes resilience in the process of rebuilding the lives of affected elderly people' (Enomoto, 2023). As a countermeasure for some of the social problems associated with restriction of activities during the COVID-19 pandemic, online-based activities became commonplace. Online activities can facilitate social participation and physical activity, including the development of apps for elderly people with a focus on health promotion (National Centre for Geriatrics and Gerontology, 2022). There may be problems regarding the online environment and digital literacy of elderly people. Nonetheless, to prevent elderly people with dementia and family caregivers from being isolated, we suggest that the government should take the lead in collecting and providing information using online resources, encouraging people to monitor their health status. As in the case of the subjects in this study, if the care recipients are being cared for in a medical institution, active use of information and communication technology (ICT) is recommended, for example, medical institutions and pharmacies could provide online medical treatment and guidance on medication, and the ability to see or talk with friends and family members who would not be able to visit in person.

Limitations and future directions

A limitation of this study is that the results cannot be easily generalized because it targeted to elderly people with dementia and their caregivers that would usually visit a hospital in a single region, and the influence of multiple caregivers within the family cannot be excluded. In addition, the results of this study were no doubt affected by the infection status and social situation at the time of the study- it was conducted some time into the COVID-19 pandemic, in a period in which caregivers were able to retrospectively reflect on the period with the most severe social restrictions and fear. Our results suggest it is necessary to more widely investigate the use of digital devices by family caregivers caring for elderly people with dementia at home, and how ICT resources might be utilized by carers to relieve some of their burden in times of disaster.

CONCLUSION

According to this survey, during the COVID-19 pandemic, the physical and mental states of elderly people with dementia deteriorated due to changes in the care environment in the home. This appeared to increase the caregiving burden on family caregivers. Active use of ICT by governments and medical institutions could be used to prevent elderly people with dementia and family caregivers from becoming isolated during disasters, including during pandemics.

This study reports some of the findings from the cross-sectional study on the relationship between caregivers and mental health as affected by COVID-19 pandemic, conducted at Shin-Abuyama Hospital between 2022 and 2023.

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