Care burden and depression in caregivers caring for patients with intractable neurological diseases at home in Japan

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A B S T R A C T

Objectives: The aims of this study are to describe the care burden on caregivers of individuals with intractable neurological diseases and to clarify the prevalence of depression in caregivers and factors related to the presence of depression.

Methods: A cross-sectional survey was conducted among caregivers who provide home care to patients with neurological diseases such as Parkinson disease (PD), spinocerebellar degeneration (SCD), multiple system atrophy (MSA), and amyotrophic lateral sclerosis (ALS), using a mailed, self-administered questionnaire. We used the Burden Index of Caregivers to measure multi-dimensional care burden and the Center for Epidemiologic Studies Depression scale to determine the presence of depression among caregivers.

Results: A total of 418 questionnaires were analyzed. Although several domains of care burden for caregivers were significantly different among the four diseases, the intensity of caregiving and hours spent caregiving were the main definitive variables. In addition, we described different aspects of the care burden using the multi-dimensional care burden scale. The prevalence of depression in caregivers was high (PD, 46%; SCD, 42%; MSA, 63%; ALS, 61%). Hours required for close supervision of the patient (P=0.015), intensity of caregiving (P=0.024), and low household income (P=0.013) were independently-related variables for depression in caregivers.

Conclusions: The care burden of caregivers was mainly explained by the intensity of caregiving and hours spent caregiving per day, not only according to the disease. The high prevalence of depression indicates the need for effective interventions, especially for caregivers of patients with MSA and ALS.

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1. Introduction

The concept of burden of care was defined in 1980 by Zarit, an American gerontologist, as the physical, psychological, financial, and social discomfort and disruption experienced by the principal caregiver of an older family member [1]. In 1999, Shultz showed in a prospective study in the United States that care burden is an independent risk factor for mortality among elderly spousal caregivers [2]. Since then, many studies focusing on care burden have been conducted and numerous instruments measuring care burden have been developed [1,3–12]. In addition, it has been shown that many caregivers experience depression during the caregiving period and care burden is correlated with depression in caregivers [13–20].

Japanese health policy now provides various preferential treatment conditions to patients with certain neuromuscular diseases, including Parkinson disease (PD), spinocerebellar degeneration (SCD), multiple system atrophy (MSA), and amyotrophic lateral sclerosis (ALS), under the framework of “intractable diseases.” Despite increased subsidization of costs, however, the heavy burden of home care for these patients has remained [21,22]. However, a quantitative evaluation of the care burden and depression among caregivers of individuals with intractable neurological disease has not been conducted in Japan. In addition, although the care burden and quality of life of caregivers for patients with PD [13,14,23,24] and ALS [25–29] have been well investigated worldwide, little research has been conducted to date in Japan.

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been done on caregivers for patients with SCD and MSA until now [30,31].

Therefore, we conducted a cross-sectional study using a multi-dimensional instrument to clarify the care burden and depression among caregivers of patients with intractable neurological diseases including PD, SCD, MSA, and ALS in Japan. The aims of this study are (1) to clarify the care burden of caregivers of patients with such intractable neurological diseases, (2) to explore factors related to the multiple dimensions of the care burden of caregivers, (3) to clarify the prevalence of depression in caregivers of such intractable neurological diseases, and (4) to explore factors related to depression in caregivers.

2. Methods

2.1. Participants and procedures

Participants were caregivers providing home health care to patients with intractable neurological diseases between November 2003 and May 2004. A self-rating questionnaire was mailed to all caregivers of patients registered as having PD, SCD, MSA, and ALS in Miyazaki Prefecture, Japan. The participants were asked to complete the questionnaire and return the answer sheets.

2.2. Measurements

2.2.1. Burden Index of Caregivers (BIC-11) [32]

The BIC-11 is a multi-dimensional scale that measures the care burden on caregivers. The BIC-11 was developed through qualitative research and a validation study in accordance with Japanese cultural characteristics. The BIC is composed of 10 questions with 5 domains, “time-dependent burden,” “emotional burden,” “existential burden,” “physical burden,” and “service-related burden.” Each domain consisted of two questions. Each question was assessed using a 5-point Likert scale (0: never, 1: almost never, 2: sometimes, 3: often, 4: always). The validity and reliability of the BIC-11 have been confirmed [32].

Table 1

<table>
<thead>
<tr>
<th>Participant characteristics (N=418)</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient age, years (mean+/− SD)</td>
<td>70+/−9</td>
</tr>
<tr>
<td>Patient gender (female)</td>
<td>218 (52)</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
</tr>
<tr>
<td>Parkinson disease</td>
<td>273 (65)</td>
</tr>
<tr>
<td>Spinocerebellar degeneration</td>
<td>77 (18)</td>
</tr>
<tr>
<td>Multiple system atrophy</td>
<td>39 (9)</td>
</tr>
<tr>
<td>Amyotrophic lateral sclerosis</td>
<td>29 (7)</td>
</tr>
<tr>
<td>Intensity of caregiving</td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>117 (30)</td>
</tr>
<tr>
<td>1</td>
<td>90 (23)</td>
</tr>
<tr>
<td>2</td>
<td>84 (22)</td>
</tr>
<tr>
<td>3</td>
<td>77 (20)</td>
</tr>
<tr>
<td>4</td>
<td>54 (14)</td>
</tr>
<tr>
<td>5</td>
<td>56 (14)</td>
</tr>
<tr>
<td>Caregiver age, years (mean+/− SD)</td>
<td>65+/−11</td>
</tr>
<tr>
<td>Caregiver gender (female)</td>
<td>253 (61)</td>
</tr>
<tr>
<td>Relationship to patient (spouse)</td>
<td>315 (76)</td>
</tr>
<tr>
<td>Caregiver’s chronic illness</td>
<td>331 (80)</td>
</tr>
<tr>
<td>Working caregivers</td>
<td>103 (25)</td>
</tr>
<tr>
<td>Household income (yen, millions)</td>
<td></td>
</tr>
<tr>
<td>&lt;=3</td>
<td>186 (47)</td>
</tr>
<tr>
<td>&lt;=5</td>
<td>113 (29)</td>
</tr>
<tr>
<td>&lt;=7</td>
<td>46 (12)</td>
</tr>
<tr>
<td>&lt;=9</td>
<td>29 (7)</td>
</tr>
<tr>
<td>&gt;9</td>
<td>21 (5)</td>
</tr>
<tr>
<td>Duration of caregiving, years (mean+/− SD)</td>
<td>5.61+/−4.6</td>
</tr>
<tr>
<td>Hours spent caregiving per day (mean+/− SD)</td>
<td>5.4+/−5.7</td>
</tr>
<tr>
<td>Hours required for close supervision of the patient (mean+/− SD)</td>
<td>4.8+/−6.3</td>
</tr>
<tr>
<td>Number of other persons who help with caregiving (mean+/− SD)</td>
<td>11+/−10</td>
</tr>
</tbody>
</table>

* Japanese intensity of caregiving grading for the long-term care insurance system.

Table 2

| Care burden among caregivers of patients with intractable neurological diseases (Burden Index of Caregivers) |
|---------------------------------------------------------------|---------------------------------------------------------------|
| PD                            | SCD                            | MSA                | ALS                |
| Mean | SD   | Mean | SD   | Mean | SD   | Mean | SD   | Mean | SD   | P value |
|--------------------------------|--------------------------------|--------------------|--------------------|
| Time-dependent burden          | 2.4 (1.0) | 2.2 (1.1) | 2.5 (1.0) | 2.4 (1.2) | 0.356 |
| Emotional burden               | 1.4 (1.0) | 1.2 (1.0) | 1.6 (1.4) | 1.6 (1.2) | 0.153 |
| Existential burden             | 1.4 (1.0) | 1.3 (1.0) | 1.7 (1.1) | 1.9 (1.2) | 0.046 |
| Physical burden                | 1.6 (1.1) | 1.2 (1.0) | 1.6 (1.1) | 1.9 (1.2) | 0.017 |
| Service-related burden         | 0.9 (0.9) | 0.9 (0.9) | 1.1 (1.0) | 1.2 (1.0) | 0.489 |
| Total care burden              | 2.0 (1.1) | 1.6 (1.0) | 2.2 (1.2) | 2.0 (1.1) | 0.047 |
| BIC total                      | 1.6 (0.8) | 1.3 (0.8) | 1.8 (0.9) | 1.8 (1.0) | 0.015 |

Each question was rated 0: never, 1: almost never, 2: sometimes, 3: often, or 4: always. P values were calculated by analysis of variance.

PD: Parkinson disease; SCD, spinocerebellar degeneration, MSA, multiple system atrophy; ALS, amyotrophic lateral sclerosis.

2.2.2. The Center for Epidemiologic Studies Depression scale (CES-D) [33,34]

The CES-D, developed by the National Institute of Mental Health, USA, is a self-report scale to identify individuals at risk for depression. It has been translated into Japanese by Shima. It is a self-assessment of 20 symptoms associated with depression. The responses to the questions indicate the number of days per week the subject is affected by the symptoms (0 days with a score of 0, 1 to 2 days with a score of 1, 3 to 4 days with a score of 2, and 5 or more days with a score of 3). Scores can range from 0 to 60, with a higher score representing a stronger tendency toward depressive feelings. A score of 16 or higher indicates depression [34].

2.2.3. Participant demographics

Regarding demographic factors, we collected information on patient’s age, gender, diagnosis, intensity of caregiving, caregiver’s age, gender, relationship to patient, presence of chronic illness, working status, household income, duration of caregiving, hours spent caregiving per day, hours required for close supervision of the patient, and number of other persons who help with care. The intensity of caregiving score was determined according to the Japanese intensity of caregiving grading for the long-term care insurance system (0: none or needs only social support, 1: needs part-time caregiving, 2: needs slight caregiving, 3: needs moderate caregiving, 4: needs frequent caregiving, and 5: needs constant caregiving). The intensity of caregiving score was determined by local authorities in accordance with the needs of caregiving and the opinion of the primary physician. In the Japanese long-term care insurance system, the medical and welfare services, including financial support, were defined by the intensity of caregiving score.

2.3. Statistical analysis

We first described the mean values of the BIC and compared them among diseases by analysis of variance. Second, we explored factors related to each domain of the BIC using multiple regression analysis. The dependent variables were the mean score of each domain of the BIC, total care burden, and the total BIC score (mean of 11 questions); explanatory variables were participant characteristics. The multiple regression analyses were conducted with a backward variable selection method (P<0.05). We included the diagnosis in the models. Third, we calculated the prevalence of depression among caregivers and compared its presence among the four diseases by the chi-square test. Finally, we explored factors related to the prevalence of depression by logistic regression analysis. The dependent variable was the presence of depression in caregivers and explanatory variables were participant characteristics. Logistic regression analysis was also conducted with the backward variable selection method (P<0.05). We included the diagnosis in the model. The significance level was set at 0.05 and two-sided tests were conducted. All analyses
were carried out with the statistical package SAS Version 9.1 (SAS Institute, Cary, NC).

2.4. Ethical considerations

Before implementing this study, the ethical and scientific validity was approved by ethics committees at Mie University Hospital in accordance with the Helsinki Declaration. Each subject was informed in writing that participation in the study was voluntary and that privacy would be strictly protected.

3. Results

3.1. Participant characteristics

The questionnaire was sent to all 1577 families of patients with intractable neurological diseases and answer sheets were received from 785 (50%). The 1577 families included caregivers of patient who did not need caregiving. Therefore, we asked families to return the questionnaire only if the patient needed caregiving. Therefore, the nominal response rate was underestimated. The number of total respondents (analysis set) who provided valid final responses was 418 (PD, 273; SCD, 77; MSA, 39; ALS, 29).

We show participant characteristics in Table 1. The mean age of the patients was 70+/-9 years and 52% were female. As for level of caregiving, 48% was equal to or greater than grade 3. The mean age of caregivers was 65+/-11 years and 61% were female. The proportion of caregivers who were spouses was 76%. Annual household income was less than 3 million yen (US $25,000) for 47% of the respondents. Average duration of caregiving was 5.6+/-4.6 years, and average time spent on care was 5.4+/-4.7 h daily.

3.2. Care burden among caregivers of patients with intractable neurological diseases (BIC-11)

We show the care burden among caregivers of patients with intractable neurological diseases according to the BIC-11 score in Table 2. The time-dependent burden was high for all the diseases (PD, SCD, MSA, ALS). As for comparison among diseases, the existential burden (P=0.046), physical burden (P=0.017), total care burden (P=0.047), and BIC total (P=0.015) were significantly different. The existential and physical burdens tended to be higher for MSA and ALS compared to PD and SCD. In addition, the total care burden and BIC total were higher for PD, MSA, and ALS compared to SCD.

3.3. Factors related to the domains and total score of the BIC-11

In Table 3, we show factors related to each domain and total score of the BIC-11. The intensity of caregiving and hours spent caregiving per day were related to the care burden domains. In addition, all participant characteristics were related to the different domains. As for the BIC total, hours spent caregiving per day (P=0.0001), intensity of caregiving (P=0.0001), and caregiver’s gender (male, P=0.025) were significant variables affecting care burden. Moreover, after adjustment for participant characteristics, the diagnoses were not related to domains of the BIC-11 and total score of the BIC-11.
4. Discussion

The prevalence of depression among caregivers for all the intractable neurological diseases measured by the CES-D. The prevalence of depression was high for caregivers of patients with all diseases surveyed (PD, 46%; SCD, 42%; MSA, 63%; ALS, 61%). But there were no statistically significant differences among diseases (P = 0.129).

3.4. Depression among caregivers of patients with intractable neurological diseases (CES-D)

In Fig. 1, we show the prevalence of depression among caregivers of patients with intractable neurological diseases measured by the CES-D. The prevalence of depression was high for caregivers of patients with all diseases surveyed (PD, 46%; SCD, 42%; MSA, 63%; ALS, 61%). But there were no statistically significant differences among diseases (P = 0.129).

3.5. Factors related to depression in caregivers

We show factors related to depression in caregivers of patients with intractable neurological diseases in Table 4. Hours required for close supervision of the patient (odds ratio [OR] = 1.06, P = 0.015), intensity of caregiving (OR = 1.26, P = 0.024), and household income (OR = 0.76, P = 0.013) were significant independently-related variables for depression in caregivers. The R² was 0.127 and max-rescaled R² was 0.169.

4. Discussion

This is the first large-scale quantitative study to investigate the care burden among caregivers of patients with intractable neurological diseases in Japan. This study is unique due to the use of the multi-dimensional care burden scale (BIC-11)[32]. We examined different features of the care burden according to the domains of the BIC-11. In addition, we showed that there is a high prevalence of depression in home caregivers of patients with intractable neurological diseases and we explored the factors related to depression in these caregivers.

Although several care burden domains of the BIC-11 were significantly different among diseases, we found that there were no significant differences after adjustment for participant characteristics (Table 3). The care burden of caregivers was mainly due to the intensity of caregiving and hours spent caregiving per day, not only by the diseases. The results indicated that the intensity of caregiving is different among diseases. Therefore, it is reasonable that the long-term care insurance system is dependent on the intensity of caregiving.

As for emotional and existential burden, the R²'s were low. The personality of caregivers, which was not measured in this study, might affect these two domains [6]. The caregiver’s age was significantly related to the existential care burden. As for the physical burden, the caregiver’s age, duration of caregiving, and patient’s gender (male) significantly increased the care burden, whereas the relationship to the patient (spouse) significantly decreased the burden. These results were easily interpretable. The multi-dimensional approach to measuring the care burden revealed these different features of caregiving.

We found a high prevalence of depression in caregivers for all the diseases. Although statistically not significant, the prevalence of depression in caregivers for MSA (63%) and ALS (61%) was very high. Interventions to alleviate depression are needed especially for caregivers of patients with these two diseases. In addition, we showed the factors that were related to depression in caregivers. The significant variables were the hours required for close supervision of the patient, intensity of caregiving, and household income. This is concordant with the results of Edwards’s report [24]. The results of multiple logistic regression analysis were adjusted according to the intensity of caregiving and the availability of social financial support by the health authority. Low income is an independent risk factor for depression in caregivers.

The R² for the logistic regression exploring factors related to depression was low. This result might be linked with the low R²s obtained for the results of multiple regressions to the emotional and existential burdens. The caregiver’s personality or depressive characteristics might be related to these outcomes [6,7]. Further research is needed to explore factors related to depression among caregivers.

In addition, previous research has reported on problem behavior, such as delirium, in patients with PD [23], the emotional effect of the heritability of SCD [30], the multitude of different symptoms of MSA DEL id="del69" orig="", [31], and respirator-dependent patients and burden of caregiving [27]. Further study including these disease-specific topics would be beneficial.

4.1. Limitations and future perspectives

The limitations of this study are as follows. First, the response rate was low (50%). We suspect that this is related to the patient register used, which included a considerable number of people who do not require care. Thus, the true response rate might be greater than the nominal value. However, it is a fact that there is a lack of external validity in this study. Therefore, we compared the patients’ characteristics between participants and non-participants. The mean age of non-participants was 67 compared to participants’ mean age of 70. In addition, the proportion of females among non-participants was 55% compared to 52% among participants. The participants were slightly older and had a higher proportion of males. Therefore, we assume that older patients require more care and that males could receive care at home from female caregivers. Moreover, we consider that in comparison with the non-participating caregivers, the participating caregivers are slightly older and comprise a higher proportion of females. However, the difference between participants and non-participants was so small that the non-responder bias is not considered to be a serious limitation. Second, we should note that participants in this study were the caregivers in the homes of patients with certain neurological diseases. The results of this study are not generalizable to institutional caregivers of patients or to caregivers of patients with other intractable neurological diseases.

5. Conclusion

We concluded that although several domains of care burden for caregivers of patients with intractable diseases were significantly different among diseases, the intensity of caregiving and hours spent caregiving were the main variables related to the care burden. In addition, the multi-dimensional approach to exploring care burden is effective. The prevalence of depression in caregivers of patients with intractable neurological disease was high. The significant independently-related variables related to depression were hours required for close supervision of the patient, intensity of caregiving, and low household income.

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