Psychological Distress in Caregivers for People With Dementia: A Population-Based Analysis of A National Cross-Sectional Study

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Abstract

Background: Informal caregivers (CGs), also called family caregivers, play an important role in supporting the well-being of and providing care to older people with dementia. However, taking care of patients with dementia is often stressful and exhausting. To facilitate the sustainable provision of care to people with dementia at home, it is crucial to reduce the burden placed on CGs. The aim of this study was to evaluate the psychological distress experienced by CGs for care recipients with dementia (CRDs) and identify the sociodemographic factors affecting that distress.

Methods: We utilized the 2013 Comprehensive Survey of the Living Conditions for CRDs and CGs. Linked data from 643 pairs of CRDs and CGs were extracted. The psychological distress experienced by CGs was measured by Kessler's Psychological Distress scale (K6) with a cutoff point of 13. Factors predictive of psychological distress were evaluated using multivariable logistic regression analysis with the forward selection method.

Results: Overall, the mean age of the CGs was 63.5 ± 11.6 years, and 5.3% (34/643) experienced serious psychological distress. Male sex of CRDs, knowing how to access consulting services, spending almost all day for nursing care, and having subjective symptoms within a few days were associated with having serious psychological distress, while older age, participating in shopping as part of the nursing, and having their own house were related to freedom from serious psychological distress.

Conclusions: Clinicians should be aware of the risk factors for psychological distress in CGs and consider providing support to reduce the burden imposed by modifiable factors. Further studies are warranted to examine whether such efforts would improve the mental health of CGs for CRDs.

Background

Informal caregivers (CGs), who are individuals caring for their relatives, usually without payment, play an important role in supporting the well-being and health of older people with disabilities [1]. With the rapid increase in the number of elderly individuals in Japan, dementia has become a leading cause of the need for long-term care (LTC) [2]. Caring for care recipients with dementia (CRDs) has often been regarded as stressful and exhausting [3]. In fact, the CGs burden may adversely affect their emotional, social, financial, physical, and spiritual functioning [4], making it a major concern in an aging society.

In Japan, the public LTC insurance system was started in 2000 to relieve the burden on CGs [5]. In 2012, the Ministry of Health, Labor, and Welfare (MHLW) launched the Orange Plan for the early detection and care of elderly people with dementia and the provision of support to CGs [6]. At present, most CRDs are taken care of by family members in Japan, and more than 70% of LTC is provided at home [7]. Although most elderly Japanese people want to continue to live in their house and community [8], a heavy burden on the CGs has been found to predict the admission of care recipients to a nursing care institution [9, 10]. Therefore, it is crucial to reduce the burden on CGs to facilitate the sustainable provision of care to CRDs at home [11].

To date, several interventions targeting psychological distress in CGs have been tested. However, a recent meta-analysis investigating the usefulness of educational interventions found only a small effect on the psychological burden experienced by CGs [12]. Given the increasing numbers of CRDs, it is necessary to clarify the social factors that predict psychological distress in CGs.

The purpose of this study was to evaluate psychological distress in CGs of CRDs and identify the associated sociodemographic factors. Accordingly, we conducted an analysis of cross-sectional data from the 2013 Comprehensive Survey of Living Conditions (CSLC). These data were collected nationwide by the MHLW and are representative of the Japanese population [13].

Methods

Participants

The 2013 CSLC targeted 295,367 households based on 5,530 randomly selected enumeration districts (EDs) of the 2010 Population Census, and 234,383 households (79.4%) completed the 'household questionnaire' and the 'health questionnaire' in June-July 2013 [13]. All household members, except for those who did not live at home during the survey period, responded to the questionnaires. The 'LTC questionnaire' was distributed (n=7,270) to 2,500 randomly selected EDs from the original 5,530 EDs, and 6,342 questionnaires were collected from households with a member who was officially certified as needing LTC at the time of the survey.

The flowchart showing the process of extracting the data for our quantitative analysis is presented in Figure 1. Among the 6,342 responses to the LTC questionnaire, we identified the nursing care recipients whose main reason for receiving care was dementia (n = 1,042). Based on the household questionnaire, the main CGs for the abovementioned household members were identified, and 683 CRDs with family CGs were extracted. We then excluded CGs who lacked data on age, sex, and psychological distress. The remaining 643 dyads of CRDs and their main CGs were included in the analysis.

This study was approved by the ethics review committee of the National Center of Neurology and Psychiatry (approval number: A2017-001) and it conformed to the provisions of the Declaration of Helsinki, and Japanese Ethical Guidelines for Medical and Health Research Involving Human Subjects. We obtained permission to use certain data from the 2013 CSLC for purposes other than those originally intended by the MHLW according to the Statistics Act, Article 33. Because we did not use any personally identifiable information, the requirement for written informed consent was waived by the Ethics Committee and the Statistics Act since the study involved record review only.

Measures

Kessler's Psychological Distress scale (K6) was used to measure psychological distress in the CSLC. The K6 scale was developed as a brief screening tool for nonspecific psychological distress in adults and consists of 6 questions asking about psychological symptoms in the previous month [15, 16]. In line with

the recommended K6 cutoff point, we defined serious psychological distress according to a K6 score ≥ 13 [17].

As independent variables of the CRDs, we included data on levels of LTC needs as well as demographics (age, and sex). Regarding the main CGs, we extracted data from the 2013 CSLC on the following variables: age, sex, relationship with the CRD, marital status, educational attainment, having someone to consult with, knowing how to access consulting services, time spent on nursing care (almost all day, other), participation in 16 nursing activities, the presence or absence of subjective symptoms within the last few days, paid work, and regular visit of hospitals. With respect to household factors, we used data concerning the number of family members at home, total household monthly expenditures, the presence or absence of other family members in need of nursing care, and house ownership.

Statistical Analysis

Analyses were conducted using SAS version 9.4 (SAS Institute Inc., Cary, NC, USA). To describe the sociodemographic characteristics of participants stratified by the presence or absence of serious psychological distress, we conducted unpaired Student's t-tests and chi-square tests for continuous variables and categorical variables, respectively. Continuous variables are presented as the means $\pm$ SDs.

To examine the association between CGs' psychological distress ($K6 \geq 13$) and factors related to CRDs, CGs, and households, we conducted multivariable logistic regression analysis using a forward selection method based on the score test (selection criteria: $p < 0.05$). In that analysis, the dependent variable was CGs' psychological distress, and the independent variables were factors related to the CRDs (age, sex, and level of LTC required), CGs (age, sex, relationship with CRD, marital status, educational attainment, having someone to consult with, knowing how to access consulting services, time spent on nursing care, participation in 16 nursing activities, having subjective symptoms within a few days, and regularly visiting hospitals), and household (number of family members at home, house ownership, total household monthly expenditures, and other family members in need of nursing care). The C statistic and Hosmer-Lemeshow test were employed to evaluate the goodness-of-fit of the estimated logistic model. We considered a value of $P < 0.05$ to be significant.

Results

Overall, the mean age of the CGs was 63.5 ± 11.6 years, and the proportion of CGs with serious psychological distress was 5.3% (34/643). Analysis of the influence of sociodemographic data on psychological distress (Table 1) showed that CGs with serious distress were significantly younger, having male CRDs, having someone to consult with, to know how to access consulting services, spending almost all day for nursing care, and to have had subjective symptoms within a few days. In addition, CGs who participated more in cleaning up and shopping when providing nursing care and had their own house were less likely to have serious psychological distress.

To evaluate the predictors of psychological distress in CGs, we performed a multivariable logistic regression analysis with the forward selection method (Table 2). In that analysis, having male CRDs, knowing how to access consulting services, spending almost all day for nursing care, and having subjective symptoms within a few days were associated with having serious psychological distress. Being older, participating in shopping as a form of nursing care, and having their own house were related to the absence of serious psychological distress. The C statistic and Hosmer-Lemeshow test yielded a C of 0.840 and p of 0.728, respectively.

Discussion

This study evaluated potential associations between psychological distress in CGs and caring for a CRD at home in Japan. Twenty-four percent (154/643) of CGs were found to spend most of their time on nursing CRDs, and 44.5% (286/643) of the CGs had their own health problems. Approximately 5% (34/643) of CGs reported that they experienced serious psychological distress. Multivariable logistic regression analysis revealed the association between serious psychological distress and male sex of the CRDs, younger age of the CGs, knowing how to access consulting services, spending almost all day for nursing care, not participating in shopping as part of nursing, having subjective symptoms within a few days, and not owning a house.

In our study, CGs who nursed male CRDs had greater psychological distress than those who nursed female CRDs, which is not consistent with some previous studies [18-21]. A possible explanation for this discrepancy is the difference in kinship between CGs and CRDs. In Japan, the majority of (*informal*) CGs at home are spouses, offspring, and spouses of offspring of CRDs [8]. A recent study showed that female CGs who were spouses of the offspring of male CRDs experienced greater psychological distress than CGs with other relationships to the CRDs [22]. Another explanation is that sex-based differences in the behavioral and psychological symptoms of dementia (BPSD) could affect psychological distress in CGs. Specifically, men with dementia have been reported to exhibit aggressive behaviors and diurnal rhythm disturbance more frequently than their female counterparts [23, 24]. These considerations are in line with the suggestion that the sex of CRDs would affect physical and financial distress among their CGs [18].

Social support for the CGs of CRDs has been regarded as an important intervention because support programs could improve the psychological status of CGs as well as their ability to take care of the CRDs [25-27]. However, data from our study indicate that participants who knew how to access consulting services still experienced serious psychological distress. We cannot completely explain these conflicting results. It may be that a number of CGs might be reluctant to use social support services or receive adequate support, in spite of their knowledge of helpful resources [28].

Our results showed that spending almost all day on nursing care was associated with serious psychological distress in CGs. Nursing CRDs requires more time than nursing elderly people without dementia [29], and spending substantial time caring for CRDs has been associated with the heaviness of the burden imposed on CGs [29, 30]. Specifically, caring for CRDs at home involves a variety of tasks,

such as changing clothes, washing, toileting, assisting with eating, or helping with medication, producing subjective burden experienced by CGs [31]. Although we did not identify specific tasks that could elevate their distress, the findings in our study might be explained by a lack of data concerning the time spent on each task.

Spending almost all day engaged in nursing, which indicates an absence of relief, could accelerate the social isolation of CGs [32, 33]. A recent study in Japan reported that participation of CGs in social activities may protect their mental health [34]. In that context, shopping as a form of nursing care may serve as a form of the social engagement for CGs. In fact, our results indicate that participating in shopping was related to freedom from serious psychological distress.

Our results demonstrated that subjective symptoms of CGs were associated with their psychological distress. CGs have been shown to be at a higher risk of mental and physical health problems, even after adjusting for confounders [35, 36]. Specifically, subjective symptoms of CGs have been shown as risk factor of harmful behavior for care recipients [37]. As the burden on CGs is associated with adverse health outcomes in care recipients [10, 38], it is important for clinicians to consider ways to reduce the burden on CGs imposed by the need to provide nursing care to CRDs.

Previous studies have reported the relationship between house ownership and nursing care at home [39-41]. For example, the lack of house ownership has been shown to accelerate the institutionalization of CRDs [39, 40]. In addition, a recent study found protective effects of house ownership against psychological distress in CGs, consistent with our results [41]. In Japan, more than half of the households own their homes [42]. CGs who own their houses may be able to more easily prepare safer and more feasible environments in which to provide care. On the other hand, we did not find an association between monthly expenditures and psychological distress. Therefore, house ownership may provide a better indicator of household wealth than expenditures [43].

The current study has several limitations. First, its cross-sectional nature does not allow for causal conclusions to be drawn with regard to care-related stress factors and serious psychological distress in the CGs studied here. Further studies with longitudinal designs are needed to investigate these associations. Second, BPSDs, such as hallucinations, delusions, agitation, disinhibition, apathy, anxiety, and changes in sleep or appetite, were not included in the CSLC dataset, although they could have impacted adversely on the mental health of CGs [44]. Finally, the CSLC lacks data on some characteristics of CRDs, such as cognitive function, although it included the levels of LTC based on the Japanese insurance scheme. In the Japanese scheme, the levels of LTC are decided not by cognitive function but by the intensity of cares needed.

Conclusion

Spending a substantial amount of time nursing CRDs may be associated with the psychological burden imposed on CGs. To facilitate the sustainable provision of care to people with dementia at home, effective support programs are needed for CGs who are engaged in providing care almost all day long

and/or have their own health problems. Further studies are warranted to develop interventions targeting the psychological distress experienced by CGs.

Abbreviations

CGs, Caregivers, K6, Kessler's Psychological Distress scale, CRD, Care Recipients with Dementia, LTC, Long-Term Care, MHLW, Ministry of Health, Labor, and Welfare, CSLC, Comprehensive Survey of Living Conditions, BPSD, Behavioral and Psychological Symptoms of Dementia.

Declarations

Ethics approval and consent to participate

This study was approved by the ethics review committee of the National Center of Neurology and Psychiatry (approval number: A2017-001). We obtained permission to use certain data from the 2013 CSLC for purposes other than those originally intended by the MHLW according to the Statistics Act, Article 33. Because we did not use any personally identifiable information, consent to participate was not required.

Consent for publication

Not applicable.

Availability of data and material

The datasets used in this study are available from the MHLW (contact via <https://www.mhlw.go.jp/toukei/sonota/chousahyo.html>) for researchers who obtain approval to use the anonymous data in accordance with Statistics Act, Article 33.

Competing interests

The authors report no conflicts of interest related to this work.

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Author contributions

N.S., N.Y.F., K.M., K.S., and T.S. contributed to study design, interpretation, and writing/review of this publication, including approval of the final manuscript. K.M. performed the statistical analyses. N.S., N.Y.F., K.M., K.S., and T.S. read and approved the final manuscript.

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Tables

Table 1. Sociodemographic characteristics stratified by serious psychological distress.

	K6 score <13		K6 score ≥ 13		p value
Nursing care recipients					
Age	85.6 ± 5.8	(n=609)	82.9 ± 6.2	(n=34)	0.010
Sex (being male)	29.1%	(177/609)	55.9%	(19/34)	0.001
Levels of LTC required					
Support Level 1 or 2, or LTC Level 1	37.1%	(224/607)	29.4%	(10/34)	0.230
LTC Level 2 or 3	45.0%	(272/607)	41.2%	(14/34)	
LTC Level 4 or 5	17.9%	(108/607)	29.4%	(10/34)	
Family caregivers					
Age	63.6 ± 11.5	(n=609)	61.6 ± 12.7	(n=34)	0.339
Sex (being male)	28.9%	(176/609)	26.5%	(9/34)	0.761
Relationship with nursing care recipients					
Spouse	25.0%	(152/609)	32.4%	(11/34)	0.714
Offspring	40.4%	(246/609)	38.2%	(13/34)	
Offspring spouse	30.2%	(184/609)	23.5%	(8/34)	
Others	4.4%	(27/609)	5.9%	(2/34)	
Marital status					
Married	79.6%	(485/609)	67.6%	(23/34)	0.132
Never Married	10.0%	(61/609)	20.6%	(7/34)	
Divorced/ Widowed	10.3%	(63/609)	11.8%	(4/34)	
Educational attainment					
Vocational college or above	18.7%	(114/609)	11.8%	(4/34)	0.308
Having someone to consult with	3.4%	(21/609)	14.7%	(5/34)	0.009
Knowing how to access consulting service	0.5%	(3/609)	11.8%	(4/34)	<0.001
Spending almost all day for nursing care	23.2%	(141/609)	38.2%	(13/34)	0.045
Participation of nursing activities					

Face washing	17.7%	(108/609)	14.7%	(5/34)	0.652
Brushing teeth	18.4%	(112/609)	11.8%	(4/34)	0.328
Bed bath	14.1%	(86/609)	17.6%	(6/34)	0.613
Shampoo	12.3%	(75/609)	20.6%	(7/34)	0.182
Changing clothes	31.2%	(190/609)	38.2%	(13/34)	0.390
Bathing	11.8%	(72/609)	20.6%	(7/34)	0.172
Changing body position/ daily living	11.5%	(70/609)	8.8%	(3/34)	0.787
Helping with toilet	17.2%	(105/609)	20.6%	(7/34)	0.617
Fixing meals and cleaning up	53.0%	(323/609)	41.2%	(14/34)	0.178
Assistance with eating	18.4%	(112/609)	29.4%	(10/34)	0.111
Helping with medication	55.2%	(336/609)	50.0%	(17/34)	0.555
Walking	19.0%	(116/609)	17.6%	(6/34)	0.839
Cleaning up	52.7%	(321/609)	35.3%	(12/34)	0.048
Laundry	62.4%	(380/609)	50.0%	(17/34)	0.148
Shopping	59.8%	(364/609)	35.3%	(12/34)	0.005
Conversation	38.8%	(236/609)	35.3%	(12/34)	0.687
Having subjective symptoms within a few days	43.0%	(260/605)	76.5%	(26/34)	<0.001
with paid work	45.0%	(270/600)	29.4%	(10/34)	0.075
visiting hospitals regularly	57.9%	(351/606)	73.5%	(25/34)	0.072
Households					
Number of family members at home	3.5 ± 1.4	(n=609)	3.5 ± 1.5	(n=34)	0.939
Other family members in need of nursing care	12.2%	(74/609)	20.6%	(7/34)	0.178
Having own house	93.9%	(572/609)	79.4%	(27/34)	0.006
Total household monthly expenditure	31.9 ± 63.3	(n=592)	24.0 ± 13.2	(n=32)	0.479

Table 2. Factors associated with serious psychological distress of family caregivers for people with dementia.

	Odds ratio (95% Confidence interval)			Z value	p value
Nursing care recipients					
Sex (being male)	2.83	(1.20	- 6.69)	5.59	0.018
Family caregivers					
Age	0.95	(0.92	- 0.98)	8.72	0.003
Knowing how to access consulting service	34.22	(5.40	- 217.10)	14.05	<0.001
Spending almost all day for nursing care	2.41	(1.20	- 5.51)	4.36	0.037
Participation of nursing activities					
Shopping	0.26	(0.11	- 0.61)	9.48	0.002
Having subjective symptoms within a few days	5.56	(2.15	- 14.33)	12.57	<0.001
Households					
Having own house	0.19	(0.06	- 0.58)	8.59	0.003

Figures

Figure 1

Flow chart of study sample