



Care difficulties and burden during COVID-19 pandemic lockdowns among caregivers of people with schizophrenia: A cross-sectional study

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Abstract

Aims: The purpose of this study was to retrospectively investigate care difficulties experienced by caregivers of people with schizophrenia during COVID-19 pandemic lockdowns in Japan (April 7-May 25, 2020) and examine associations between these care difficulties during lockdowns and daily caregiver burden.

Methods: Data were collected from 132 participants of the LINE Schizophrenia Family Association using an online survey.

Results: Caregivers were mostly concerned about who would care for people with schizophrenia if caregivers become infected with COVID-19. A significant association was found between higher daily caregiver burden and more difficult care experiences during COVID-19 pandemic lockdowns ($B = 0.58$, 95% confidence interval, 0.40-0.75, $P < .01$, adjusted R -squared = .34).

Conclusions: Further studies and supports for caregivers of people with schizophrenia are needed.

KEYWORDS

caregiver, COVID-19, lockdown, schizophrenia

1 | INTRODUCTION

The COVID-19 outbreak has created many public mental health concerns in the general population.¹ The COVID-19 pandemic and associated lockdowns also appear to have negatively impacted the lives of vulnerable populations, including people with schizophrenia and their caregivers. Despite urgent research needs,^{2,3,4} only a few studies have focused on people with schizophrenia. For example, people with schizophrenia have experienced higher stress, anxiety, depression, and paranoia compared to general

population.⁴ However, no studies have examined the social impact of the COVID-19 pandemic on caregivers of people with schizophrenia, a topic requiring urgent attention⁵ because they may have a variety of burdens such as physical, mental, or financial problems during the COVID-19 pandemic.⁵ The purpose of this study is to retrospectively investigate care difficulties experienced by caregivers of people with schizophrenia during COVID-19 pandemic lockdowns in Japan (April 7 – May 25, 2020) and examine associations between care difficulties during lockdowns and daily caregiver burden.

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2 | METHODS

2.1 | Study design and participants

An online cross-sectional survey was conducted during August 1-31, 2020. Participants were recruited from the LINE Family Association of Schizophrenia, which had 238 registered members as of August 1, 2020. The association offers a platform for information exchange and peer support for caregivers of people with schizophrenia using the "LINE" online software. Eligibility criteria were as follows: (a) caregiver of people with schizophrenia and (b) age over 20 years. For example, a caregiver can be someone who cares for a family member with schizophrenia and look after his or her daily living needs. Respondents were invited to participate on a voluntary basis. Participants gave fully informed consent through the internet. The study protocol was approved by the Research Ethics Committee of the National Center of Neurology and Psychiatry (No. A2020-036).

2.2 | Measures

2.2.1 | Care difficulties during COVID-19 pandemic lockdowns (April 7 – May 25, 2020)

To measure care difficulties during COVID-19 pandemic lockdowns, we developed 10 original items based on discussions and collaborations among members of the Family Association of Schizophrenia and a multidisciplinary team that included psychiatrists, psychiatric nurses, clinical psychologists, and mental health social workers (Table 2). These items were based on a five-point Likert scale: (1) strongly disagree, (2) disagree, (3) neither agree nor disagree, (4) agree, and (5) strongly agree. Participants responded to the 10 items by recalling care difficulties during COVID-19 pandemic lockdowns. The validity of this measurement has not been fully evaluated.

2.2.2 | Japanese version of the Zarit burden interview, short version (J-ZBI_8)

J-ZBI_8 was used to measure caregiver burden⁶ (Appendix 2). It consists of eight items scored on a five-point Likert scale from 0 (never) to 4 (nearly always). The total score ranges from 0 to 32, with higher scores indicating higher burden. J-ZBI_8 has high test-retest reproducibility and internal consistency. Concurrent validity and construct validity have also been confirmed.⁶ Caregiver burden was assessed during the study period of August 1-31, 2020.

2.3 | Statistical analysis

We first calculated descriptive statistics for the items about care difficulties. Next, multiple linear regression was used to examine the relationship between daily caregiver burden and the total number of care

TABLE 1 Demographic characteristics of caregivers and people with schizophrenia (N = 132)

	N (%) or Mean (SD)
Caregivers	
Age, years	52.7 (7.9)
Gender	
Male	11 (8.3)
Education	
Junior high school	2 (1.5)
High school	21 (15.9)
Some college	54 (40.9)
University or higher	55 (41.7)
Annual household income	
<2.5 million yen	19 (14.4)
<5 million yen	25 (18.9)
<7.5 million yen	29 (22.0)
≥ 7.5 million yen	48 (36.4)
Unknown	11 (8.3)
Relationship to person with schizophrenia	
Parent	111 (84.1)
Spouse	9 (6.8)
Sibling	6 (4.5)
Child	6 (4.5)
Care time	
≤5 y	82 (62.1)
≤10 y	24 (18.2)
≤15 y	16 (12.1)
≤20 y	3 (2.3)
≥21 y	7 (5.3)
Japanese version of the Zarit burden interview, short version (J-ZBI_8)	15.4 (7.9)
People with schizophrenia	
Age	27.7 (11.6)
Gender	
Male	63 (47.7)
Duration of illness	
≤5 y	82 (62.1)
≤10 y	20 (15.2)
≤15 y	18 (13.6)
≤20 y	3 (2.3)
≥21 y	9 (6.8)
Lifetime hospitalization	1.6 (1.6)

experiences during COVID-19 pandemic lockdowns. In this model, we adjusted for age, gender, education, household income, and care time since previous studies have pointed out that these variables are potential confounders.⁷ Statistical significance was set at the 5% level. All analyses were conducted using SPSS, Windows version 26.

TABLE 2 Care difficulties experienced by caregivers of people with schizophrenia during COVID-19 pandemic lockdowns (April 7 – May 25, 2020) (N = 132)

Care difficulties experienced by caregivers of people with schizophrenia during COVID-19 pandemic lockdowns	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1 I was worried or actually in trouble that the medical institution would not accept people with schizophrenia if they became infected with COVID-19 because they have a mental illness.	14 (10.6)	31 (23.5)	10 (7.6)	38 (28.8)	39 (29.5)
2 I was worried or actually in trouble that people with schizophrenia might not be able to receive psychiatric outpatient or inpatient treatment due to COVID-19.	20 (15.2)	36 (27.3)	15 (11.4)	32 (24.2)	29 (22.0)
3 I felt that the burden of housework increased because people with schizophrenia stayed at home due to COVID-19.	43 (32.6)	32 (24.2)	16 (12.1)	24 (18.2)	17 (12.9)
4 I felt that financial burdens increased because people with schizophrenia stayed at home due to COVID-19.	43 (32.6)	34 (25.8)	28 (21.2)	17 (12.9)	10 (7.6)
5 I was worried or actually in trouble about who would take care of people with schizophrenia if I became infected with COVID-19.	7 (5.3)	18 (13.6)	10 (7.6)	30 (22.7)	67 (50.8)
6 I was worried or actually in trouble that I might not be able to use local consulting services such as from a hospital, city hall, or family association due to COVID-19.	22 (16.7)	34 (25.8)	6 (4.5)	40 (30.3)	30 (22.7)
7 I felt that my relationship with people with schizophrenia was getting worse as I spent more time at home with them due to COVID-19.	48 (36.4)	33 (25.0)	27 (20.5)	19 (14.4)	5 (3.8)
8 I was worried or actually in trouble about worsening schizophrenia due to COVID-19.	34 (25.8)	24 (18.2)	24 (18.2)	28 (21.2)	22 (16.7)
9 I was worried or actually in trouble about whether or not people with schizophrenia could adopt new behaviors such as wearing a mask during the COVID-19 pandemic.	45 (34.1)	38 (28.8)	8 (6.1)	34 (25.8)	7 (5.3)
10 I felt that my leisure time had decreased because people with schizophrenia could not go to work due to COVID-19.	48 (36.4)	26 (19.7)	26 (19.7)	20 (15.2)	12 (9.1)

3 | RESULTS

A total of 132 participants completed the online self-reported questionnaire. Participant characteristics are presented in Table 1. Participants were mostly middle-aged mothers with a care duration of less than 5 years. Table 2 shows care difficulties experienced by caregivers of people with schizophrenia during COVID-19 pandemic lockdowns.

More than half of caregivers were worried about who would care for a family member with schizophrenia if caregivers became infected with COVID-19 [Item #5] (agree, 22.7%; strongly agree, 50.8%). In addition, if a family member with schizophrenia were to become infected with COVID-19, caregivers were worried whether a family member with schizophrenia would be refused appropriate medical care services because of their mental illness [Item #1] (agree, 28.8%; strongly agree, 29.5%). Furthermore, caregivers were worried about restrictions on the use of community mental health-care resources (agree, 30.3%; strongly agree, 22.7%). Less than half

of caregivers were worried about deterioration of relationships with people with schizophrenia due to staying at home together for a long time during COVID-19 pandemic lockdowns [Item #6] (disagree, 25.0%; strongly disagree, 36.4%).

Regression analysis showed that daily caregiver burden was significantly and positively associated with total number of care difficulties during COVID-19 pandemic lockdowns (Unstandardized regression coefficient (B) = 0.58; 95% confidence interval, 0.40–0.75; $P < .01$; adjusted R-squared = 0.34). Daily caregiver burden was also significantly associated with each item about care difficulties (Appendix 1).

4 | DISCUSSION

This is the first study to describe care difficulties experienced by caregivers of people with schizophrenia during COVID-19 pandemic lockdowns in Japan and its association with daily caregiver burden.

Caregivers in the LINE Family Association had often experienced anxiety about caring for family members with schizophrenia, and the level of such difficulties was associated with daily caregiver burden.

Participants tended to be concerned about care for a family member with schizophrenia if caregivers were to become infected with COVID-19, rather than about the relationship with a family member with schizophrenia. In Japan, caregivers are likely to feel a deep sense of responsibility for the care of people with schizophrenia⁸, while community mental health supports and emergency services for caregivers are often lacking.⁹ These situations may affect participants' responses.

Daily caregiver burden was significantly and positively associated with care difficulties during lockdown in this study. There are two potential assumptions. First, participants with high daily care burden might have been more likely to feel anxious about caring for family members with schizophrenia during lockdowns. Second, participants who faced many difficulties while caring for a family member with schizophrenia during the COVID-19 pandemic may feel higher daily care burden. Previous studies support both assumptions. One study found that high caregiver burden often occurs with comorbid anxiety and depression.¹⁰ Another study with a longitudinal design also reported that caregivers who experienced many difficulties associated with care were likely to feel high care burden.¹¹ Since this study had a cross-sectional design, causal inferences and the direction of causality cannot be determined. Further studies with a longitudinal design are needed to examine this finding.

There were several study limitations. First, selection bias may have occurred because our study participants were recruited from only the LINE Family Association of Schizophrenia. This indicated that participants were able to use online software. Not surprisingly, some caregivers, particularly elder caregivers, may be unfamiliar with such software, which might limit the generalization of the results. Second, recall bias may have occurred since the participants had to remember care experiences during lockdowns. Third, the validity for measurements of care difficulties during COVID-19 pandemic lockdowns used in this study has not been fully evaluated. The reliability of participants' responses about care experiences may be insufficient.

While this study presented the caregivers' concerns during the lockdown, comparisons of the availability of healthcare services and caregivers' concerns under and out of lockdown with longitudinal studies are needed in the future to examine the adverse effects of COVID-19. In addition, quantitative evaluation of care difficulties and psychological burden during lockdown in caregivers remains an issue for future research.

5 | CONCLUSION

We identified several caregivers' worries during COVID-19 pandemic lockdowns in Japan. We found an association between higher daily caregiver burden and more difficult experiences while caring

for family members with schizophrenia. Further studies and supports for caregivers are needed.

CONFLICT OF INTEREST

None.

AUTHOR CONTRIBUTIONS

NY wrote the first draft of the manuscript, and other authors critically revised the manuscript. All authors approved the final manuscript.

APPROVAL OF THE RESEARCH PROTOCOL BY AN INSTITUTIONAL REVIEWER BOARD

The study was approved by the Research Ethics Committee of the National Center of Neurology and Psychiatry (No. A2020-036).

INFORMED CONSENT

Informed consent was obtained from all subjects.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy and ethical restrictions. We did not explain to the participants about the public access to the data in the informed consent process. When we receive a reasonable request, the data will be made available after approval by the ethics committee of the National Center of Neurology and Psychiatry.

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APPENDIX 1

Multiple regression analysis results about caregiver burden and care difficulties experienced by caregivers of people with schizophrenia during COVID-19 pandemic lockdowns (April 7 – May 25, 2020) (N = 132)

	1			2			3			4			5		
	B	95% CI	p	B	95% CI	p	B	95% CI	p	B	95% CI	p	B	95% CI	p
J-ZBI_8	0.04	0.01-0.07	<.01**	0.04	0.01-0.07	.01*	0.07	0.04-0.10	<.01**	0.05	0.02-0.07	<.01**	0.05	0.02-0.07	<.01**

Unstandardized regression coefficient (B) for one-point increase in the score is shown. Sociodemographic variables (age, gender, education, household income) and care time were adjusted. * $P < .05$, ** $P < .01$

APPENDIX 2

Japanese version of the Zarit burden interview, short version (J-ZBI_8)

Japanese version of the Zarit burden interview, short version (J-ZBI_8)		Mean (SD)
1	Do you feel embarrassed over your relative's behaviour?	2.42 (1.22)
2	Do you feel angry when you are around your relative?	1.55 (1.11)
3	Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	2.01 (1.29)
4	Do you feel strained when you are around your relative?	1.99 (1.32)
5	Do you feel that your social life has suffered because you are caring for your relative?	1.74 (1.33)
6	Do you feel uncomfortable about having friends over because of your relative?	1.92 (1.53)
7	Do you wish you could leave the care of your relative to someone else?	1.57 (1.28)
8	Do you feel uncertain about what to do about your relative?	2.24 (1.17)



6			7			8			9			10		
B	95% CI	p	B	95% CI	p	B	95% CI	p	B	95% CI	p	B	95% CI	p
0.05	0.02-0.08	<.01**	0.09	0.07-0.11	<.01**	0.06	0.03-0.09	<.01**	0.06	0.03-0.09	<.01**	0.07	0.05-0.10	<.01**