



Impact of COVID-19 Lock Down on Quality of Life among Primary Caregivers of Individuals with Schizophrenia in Rural Areas

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Abstract

BACKGROUND: The lockdown would become the primary strategy for facing covid-19 as it quickly mutates which might cause repeated pandemics; however, it negatively affects individuals' quality of life (QOL). The schizophrenia caregivers experience considerable stress. The research on the impact of the COVID-19 lockdown on QOL of schizophrenia caregivers is essential, especially for those who reside in rural areas.

AIM: This study aimed to investigate the impact of lockdown-related COVID-19 on QOL among primary caregivers of schizophrenia patients living in a rural area.

METHODS: This study recruited 204 primary caregivers (15–79 years). This study used the World Health Organization Quality of Life instrument (WHOQOL-BREF) to assess QOL's primary caregiver. Evaluate the possible change in caregivers' QOL before and during the COVID-19 lockdown using paired *t*-test for repeated measures.

RESULTS: The mean age of the caregivers was 46.61 years (SD = 12.79), ranging from 15 to 79 years, with a preponderance of male (54.5%), aged 38–47 years old (29.7%), married (81.2%), employed (57.4%), and had senior high school level of education (34.7%). Majority were parents (26.2%) of the ill relative, and took care of the patients more than 5 years (52.5%). There was a statistical difference ($p < 0.05$) in caregivers' QOL between before and during the COVID-19 lockdown, including in physical health, psychological, social relationships, and environment domain.

CONCLUSION: Implementing a lockdown policy related to COVID-19 has negatively impacted the caregivers' QOL. The degradation of caregivers' QOL showed from before to during COVID-19 lockdown. Further study needs to explore the QOL of other mental illness caregivers regarding COVID-19 lockdown. This finding becomes a reference for a government to modify some policy-related lockdowns to minimize their negative impact.

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Introduction

In early 2020, the central government in most countries used local enforced ties to implement a lockdown to prevent the spread of COVID-19. In Indonesia, the lockdown policy was implemented on March 6 in West Java Province and followed by other provinces afterward [1]. However, the lockdown-related COVID-19 pandemic has negatively affected people's lives. Early tendencies negatively impact employment, livelihood, and income [2]. The Indonesian people face limitations, including in economics, education, literacy, and health access [3]. Almost all people, especially the primary caregivers of schizophrenia patients, suffer from numerous burdens COVID-19 pandemic [4].

The primary caregivers of schizophrenia patients are a vulnerable group with a high risk of physical and mental distress. Some findings reported that they experienced significant distress and had the poorest QOL compared with other caregivers [5]. The evidence suggests that the caregivers of schizophrenia patients tend to have psychiatric distress, anxiety, and psychotic

symptoms due to caregiving responsibilities [6]. A study in a Mental Health Hospital in Saudi Arabia reported that they are prone to a significantly high level of depression [7]. Their life gets worse during COVID-19 pandemic-related lockdown. A recent study reported that they have a high burden and care difficulties during the pandemic of COVID-19 [4].

The negative impact of the COVID-19 lockdown affects the role and attitude of caregivers. It has resulted in numerous adjustments to daily life among schizophrenia patients and their caregivers. Of course, this change in the pattern of relationships leads to a decrease in the quality of care and relationship functioning [8], which can worsen the patient's condition. Some studies found that fewer social networks and satisfying relationships are the primary matter of schizophrenia patients [9], [10].

The implementation of the lockdown may remain the primary strategy to face the Covid-19 pandemic. Research is essential to explore the effect of the implementation of the lockdown related to COVID-19, especially on the quality of life of schizophrenia caregivers. Therefore, this study aimed to identify

the impact of COVID-19 pandemic-related lockdown on QOL among primary caregivers of schizophrenia patients in a rural area.

Methods

Study design

A cross-sectional survey was conducted purposively among primary caregivers of schizophrenia patients living in rural areas of Sumenep district, East Java province of Indonesia.

Sample description

The primary caregiver is an adult relative living with a patient, in the same environment, for at least 12 months and was directly involved in giving care to the patient and most supportive either emotionally or financially, that is, felt most responsible for the patient [11]. We excluded the caregivers with a history of having a mental illness and taking care of schizophrenia patients with comorbid and physical illnesses.

Measures

We use a questionnaire to obtain data such as age, gender, marital status, education level, employment status, the relationship of primary caregiver to patients, number of years of caregiving and number of hours per day providing care, and motivation at care. Other data were collected, including the age of the patient and the patient's suicidal attempts. We use the brief Indonesia version of the World Health Organization Quality of Life instrument (WHOQOL-BREF) to assess the caregiver's QOL [12]. It is a 26-item, self-administered psychometrically cross-cultural instrument. It is a subjective assessment of an individual's perceived QOL in four domains: Physical health, psychological, social relationships, and environment [13]. It has an additional two items for assessing overall QOL and general health. Items constructed variations Likert Scale, with scores from 1 to 5, questioning "how much," "how completely," "how often," "how good," or "how satisfied" the individual felt. The domain scores positively, with higher scores denoting higher QOL except for items 3, 4, and 26, with reversed scores [12]. We use The WHOQOL-BREF because it is familiar among caregivers in Asian countries such as India and Malaysia [11], [14]. The Cronbach's alpha of each domain in this study was as follows – Physical health 0.77, Psychological 0.75, Social relationships 0.74, and Environment 0.85. The overall internal consistency of the WHOQOL-BREF scale in this sample was high (Cronbach's alpha = 0.93).

Data collection

The study was approved by the ethical committee of Wiraraja University (Approval no. 003/KEPK-FIK/UNIJA/VI/2021). Before participating in the study, we informed the participants about the purpose of the research. We assured their right to refuse to participate in the study or withdraw their consent at any stage. Data were collected from July 1 to October 1, 2021, during the lockdown due to the COVID-19 pandemic. We asked The participants twice to complete the questionnaire to describe how they felt immediately before and during the COVID-19 lockdown.

Data analysis

We use statistical analyses using IBM SPSS Statistics 23 (IBM Corporation, New York, USA). The frequencies and percentages described categorical variables, and we used mean and standard deviation to explain continuous variables. We use a paired t-test to evaluate the change and differences in the mean of caregivers' QOL before and during the COVID-19 lockdown. Statistical significance was evaluated at the 0.05 level using two-sided tests.

Results

Participant's and patients' characteristic

Of the 216 primary caregivers participating in this study, 204 completed the questionnaire (94% response rate). The mean age of primary caregivers was 46.61 years (SD = 12.79), ranging from 15 to 79 years. At the same time, the mean age of the patients was 39.34 years (SD = 14.54), ranging from 17–83 years. Around 30% of the primary caregivers were between the age group of 38–47 years, followed by 48–57 years (27.7%). More than half (54.5%) of the caregivers were males. Most primary caregivers were parents (26.2%), married (81.2%), senior high school (34.7%), employed (57.4%), with more than 5 years of duration of caregiving (52.5%), and more than 6 h for providing care in a day (54%). A number of 57% of caregivers said that they have taken care of the patient because they feel having a duty. Table 1 showed a slightly similar QOL in all demographic characteristics of caregivers before and during the COVID-19 lockdown.

The caregivers' QOL in all domains before and during the COVID-19 lockdown

The overall mean score of QOL among caregivers changed from before to during the COVID-19 lockdown (Table 2 and Figure 1). The Physical Health and Environment domain indicated a substantial change

in the mean score of QOL, which were -2.59 ± 4.51 and -2.65 ± 4.43 , respectively. The slightest chance

Table 1: Demographic characteristics of primary caregivers and individuals with schizophrenia

Variable	n (%)	QOL of caregivers (mean ± SD)	
		Before COVID-19 lockdown	During COVID-19 lockdown
Age of caregivers			
15–27	15 (7.4)	87.27 ± 14.74	87.27 ± 14.74
28–37	29 (14.4)	91.62 ± 14.47	91.62 ± 14.47
38–47	60 (29.7)	90.82 ± 13.26	90.82 ± 13.26
48–57	56 (27.7)	87.32 ± 12.78	87.32 ± 12.78
58+	42 (20.8)	87.67 ± 13.55	87.67 ± 13.92
Gender			
Male	110 (54.5)	90.19 ± 13.04	90.19 ± 13.04
Female	92 (45.5)	87.67 ± 14.08	87.67 ± 14.08
Marital status			
Single	16 (7.9)	85.88 ± 12.15	85.88 ± 12.15
Married	164 (81.2)	89.93 ± 13.79	89.93 ± 13.79
Divorced/widowed	22 (10.9)	84.73 ± 11.94	84.73 ± 11.94
Education			
No formal/primary school	49 (24.3)	86.02 ± 13.84	86.02 ± 13.84
Junior high school	45 (22.3)	88.89 ± 9.97	88.89 ± 9.97
Senior high school	70 (34.7)	88.37 ± 13.12	88.37 ± 13.12
University and above	38 (18.8)	94.37 ± 16.36	94.37 ± 16.36
Employment status			
Students and homemakers	71 (35.1)	85.03 ± 13.87	85.03 ± 13.87
Employed	116 (57.4)	91.51 ± 13.18	91.51 ± 13.18
Unemployed	15 (7.4)	89 ± 10.73	89 ± 10.73
Relation to care recipient			
Spouse	34 (16.8)	90.82 ± 11.93	90.82 ± 11.93
Parent	53 (26.2)	89.02 ± 13.81	89.02 ± 13.81
Son/daughter	41 (20.3)	86.9 ± 15.29	86.9 ± 15.29
Sibling	45 (22.3)	89.71 ± 15.09	89.71 ± 15.09
Others	29 (14.4)	89 ± 9.61	89 ± 9.61
Caregiving duration (year)			
5 years and less	96 (47.5)	92.45 ± 11.16	92.45 ± 11.16
>5	106 (52.5)	85.96 ± 14.78	85.96 ± 14.78
Caregiving duration in hour			
6 h and less	93 (46)	89.97 ± 12.51	89.97 ± 12.51
>6 h	109 (54)	88.26 ± 14.38	88.26 ± 14.38
Motivation of caregiving			
Sense of duty	116 (57.4)	90.87 ± 11.15	90.87 ± 11.15
Love and affection	86 (42.6)	86.58 ± 15.98	86.58 ± 15.98
Age of patient			
15–27	43 (21.3)	88.91 ± 12.79	88.91 ± 12.79
28–37	57 (28.2)	87.49 ± 13.84	87.49 ± 13.84
38–47	45 (22.3)	84.24 ± 14.98	84.24 ± 14.98
48–57	25 (12.4)	93.64 ± 11.31	93.64 ± 11.31
58+	32 (15.8)	95.16 ± 10.53	95.16 ± 10.53
Suicidal attempt			
No attempt	155 (76.7)	89.95 ± 13.41	89.95 ± 13.41
Only once	16 (7.9)	89.75 ± 11.89	89.75 ± 11.89
Twice and more	31 (15.3)	84.13 ± 14.36	84.13 ± 14.36

SD: Standard deviation, QOL: Quality of life.

of a mean score of QOL was in the social relationship domain. The statistical analysis using paired *t*-test showed a significant difference in the mean score of QOL before and during COVID-19 lockdown in all domains ($p < 0.05$).

Discussion

The present study investigated the QOL of primary caregivers of individuals with schizophrenia

Table 2: Mean score of quality of life among caregivers before and during COVID-19 lockdown

Domain of QOL	Mean ± SD		Paired t-test	Changes, mean ± SD
	During COVID-19 lockdown	Before COVID-19 lockdown		
Physical health	26.16 ± 5.09	28.76 ± 4.31	0.02	-2.59 ± 4.51
Psychological	20.48 ± 4.34	22.12 ± 3.82	0.02	-1.64 ± 2.95
Social relationships	9.68 ± 2.43	10.55 ± 2.11	0.03	-0.87 ± 2.36
Environment	24.96 ± 6.02	27.61 ± 5.32	0.01	-2.65 ± 4.43

SD: Standard deviation, QOL: Quality of life.

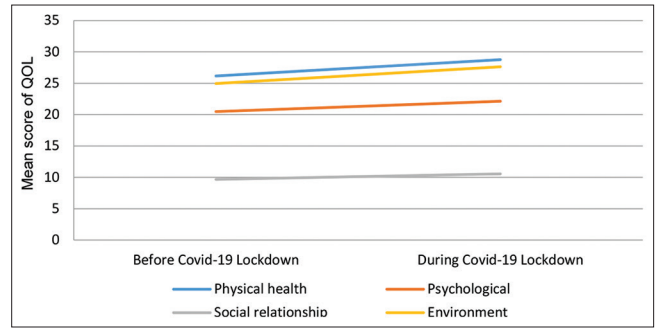


Figure 1: The change in the mean score of QOL among caregivers before and during Covid-19 lockdown

living in a rural area before and during the COVID-19 lockdown. Regarding the demographic characteristic, most caregivers were of productive or working age with a higher QOL than other age groups. It was similar to the previous findings in which caregivers under 50 had a good [15]. It happens because they have an excellent physical and psychological ability to overcome numerous problems arising from themselves or their environment. Male caregivers in the present study reported a better QOL than female. Other studies also found that male caregivers had a well QOL [16], [17]. Male caregivers tend to experience less social pressure to care for relatives compared to female caregivers [17]. Another possible reason is the Indonesian culture, where females have more restrictions on their personal and social activities than males. Married caregivers showed better QOL than unmarried, divorced, or widowed caregivers. It is alike to a prior study in which married caregivers had higher scores of QOL than those with other marital statuses [18]. Even the caregivers who are a spouse of ill relatives in this study reported a better QOL than the parent, sibling, son, or daughter. The presence of a spouse could offer support and share some of the challenges and distress. Another finding of this study showed that the family member dominates as caregivers. These findings mirrored the previous studies that most caregivers were the closest relatives, either parent, sibling, or son or daughter [19], [20]. A previous study reported that Indonesian people typically had a responsibility and obligation to nurse their family members independently with mental illness [17]. Particularly in rural areas, the family of an individual with mental illness rarely hire a paid caregiver because of financial barriers [21]. Besides that, family members with mental illness tend to be covered by others to avoid a negative stigma [22].

Regarding education, the caregivers who had university and above revealed a better QOL than those at other levels. Similarly, a study suggested that caregivers with higher education had higher QOL [23]. It could be explained that a higher level of education could give the caregivers a better understanding and knowledge about the role of giving care to patients with schizophrenia. Some previous studies found that higher education complements caregivers with a better ability

to deal with caregiving tasks and thus accounts for a lower perception of burden and higher QOL [24], [25]. Most participants in this study were employed, meaning they had another job except as a caregiver. The employed caregivers had a better QOL than those who are unemployed, students, and homemakers. This discovery was in line with studies that consider working as a distraction that enables caregivers to escape the caregiving burdens [14], [23].

Most caregivers have been caring for patients for more than 5 years. Interestingly, they had a poorer QOL than those who have been giving care for 5 years or less. The previous study found that the longer the duration of caregiving, the higher the burden experienced [17]. In the present study, caregivers providing care for more than 6 h a day had a poorer QOL than those caring for 6 h or less. A prior study suggested that caregiving more than 6 h a day was positively associated with depression [26]. The caregivers motivated by a sense of duty in caregiving had a better QOL than those motivated by love and affection. In contrast, another study discovered that caregivers most disadvantaged are those who indicate a reason for care as a sense of duty rather than affection [27]. The possible reason is that the sense of duty in caring arises from moral responsibility and commitment, so they could cope with the problem and not consider it a burden.

The present study found that caregivers caring for patient aged 48–57 and 57 years above tends to have a good QOL. A study consistently reported that caring for patients older than 47 correlated with physical problems [26]. The result explains that older patients have non-destructive symptoms of schizophrenia due to weakened physical and psychological functions, thereby reducing the burden of care. In addition, the caregivers' QOL of patients who have never had a history of suicidal attempts was better than those who cared for patients with one or more suicidal attempts. One study discovered that giving care to patients who had two or more episodes of suicidal attempts was positively associated with depression among primary caregivers [26]. The possible reason is that they have a high burden and difficulties caring for a patient because they invariably have to observe and keep the patient safe.

The result shows a significant change in QOL between before and during the COVID-19 lockdown over each domain. The caregivers experienced a worsened QOL during the COVID-19 lockdown. In this study, the most significant change of QOL was in the physical health domain. The caregivers of schizophrenia patients might have more difficulties and challenges in carrying on their care routine and be more physically stressed due to government restrictions. For instant, the caregivers should spend much more time and energy getting along with patients as compensation due to the restriction in associating with their surroundings outside the home, reducing their quality of rest and sleep. In addition, if the caregivers are sick, they tend not to go to

the doctor because of fear of being considered to have Covid-19. The people who live in rural areas have a low level of knowledge and perceive a negative stigma toward COVID-19. The previous research found that, generally, the Indonesian people lack an understanding of COVID-19, particularly in the beginning stage of its outbreak [28]. However, the physical health domain displayed the highest mean score compared with other domains. Some caregivers can maintain their physical activity and health even within some boundaries.

The second substantial change in caregivers' QOL is in the environment domain. Closely related to restrictions on various social access and demands to carry out their daily activities at home, mainly to get health services where the hospital and public health center were overwhelmed by treating many COVID-19 sufferers. The caregivers also prefer to do activities inside the home for fear of being infected with COVID-19.

In regard to the psychological domain, the caregivers experienced a decrease of QOL from before to during the COVID-19 lockdown as well. It is also found that the psychological domain had a lower QOL score compared to the physical and environment domain both before and during COVID-19 lockdown. Numerous research reported that caregivers of schizophrenia patients tend to undergo a psychological distress [29], [30], [31], [32]. The present study found that the caregivers encountered worse psychological distress during the COVID-19 lockdown. The possible reason was that the COVID-19 lockdown compelled the caregivers to encounter some economic burdens and a lack of time for socialization which caused distressing feelings.

The social relationship domain showed the lowest change from before to during the COVID-19 lockdown in this study. The result indicated that caregivers of schizophrenia patients perceived social relationship problems as an aspect that is indeed a problem that is already commonplace. Hence, the implementation of lockdown slightly affects their caring pattern. However, the present study found that it became the worst domain of QOL either before or during the COVID-19 lockdown. The social relationship merged as a prominent matter among schizophrenia caregivers. A study suggested that over one in ten caregivers avoided being a member of social some felt shame or embarrassment about the patients' illness [33].

Conclusion

The overall QOL score in each domain showed a notable derivation from before to during the COVID-19 lockdown. Indicated that implementing lockdown-related COVID-19 negatively impacts the

QOL of schizophrenia caregivers in rural areas. The physical health and environment domain held the significant score change. However, they scored high before and during the COVID-19 lockdown. On the other hand, the psychological and social relationship domain showed a low score change, but they had a poor score either before or during the COVID-19 lockdown. This discovery becomes the anvil for the government and related parties to optimize the socialization of maintenance and improvement of physical health when implementing lockdown related to COVID-19 or other infectious diseases. Furthermore, an exigent solution is required to overcome caregivers' psychological and social relationship problems to prevent other distress, especially in the context of quality of life. The present study recruited schizophrenia caregivers living in rural areas.

Further study needs to investigate the effect of lockdown related to COVID-19 in the urban area. Moreover, the participants in this study were caregivers of schizophrenia patients. Therefore, inviting the caregivers of other mental illness patients is suggested for subsequent research.

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