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Factors affecting the quality of life of caregivers of children with disabilities during the COVID-19 pandemic

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Abstract

This study aimed to investigate the impact on the quality of life of caregivers of children with disabilities during the COVID-19 pandemic. This study was conducted among 255 caregivers of children with disabilities who attended a disability family support center. Data were collected between February 4 and February 11, 2022. The collected data were analyzed using hierarchical multiple regression analysis. The diagnosis of Hepatitis B, the caregiver's relationship with the child, social support, and depression significantly affected the quality of life of caregivers of children with disabilities during the COVID-19 pandemic. The model's explanatory power was 53%. Among the aforementioned factors, depression had the greatest effect ($\beta = -.61$). To improve the quality of life of caregivers of children with disabilities, it is important to develop nursing interventions and educational programs that reduce depression and improve social support. The results suggest that it is necessary to explore the quality of life of primary caregivers of children with disabilities during pandemics and develop and implement appropriate programs.

Keywords: Caregivers, Depression, Disabled children, Quality of life, Social support.

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1. Introduction

The World Health Organization (WHO) declared COVID-19 a pandemic in March 2020 [1]. This brought extensive changes, such as increased responsibilities, financial burdens, social isolation, and reduced access to healthcare services, particularly among caregivers of children with disabilities [1, 2]. By restricting medical appointments and access to medical equipment and facilities, the pandemic severely affected the health and well-being of children with disabilities, their caregivers, and their families [3]. Given the anxiety induced by the pandemic, research is needed on how support can be provided to the primary caregivers of children with disabilities during such crises [4].

Research has shown that caregivers of children with disabilities are at heightened risk of experiencing mental health issues during pandemics [4, 5]. The parents of children with disabilities are a demographic that is highly likely to suffer from mental health problems such as depression and anxiety [4]. By adding stress and psychological burden, a pandemic can exacerbate these mental health issues [6].

The COVID-19 pandemic significantly affected the health and quality of life (QOL) of caregivers of children with disabilities [7]. Several potential health issues that caregivers may face during a pandemic need consideration [4-6]. First, caregivers are already more susceptible to mental health problems such as depression and anxiety. The additional stress and burden of coping with the pandemic can further exacerbate these issues and affect their QOL [4, 8]. As a disease that caused global fear, the COVID-19 pandemic heightened anxiety among the general population [1]. However, it particularly heightened anxiety among the caregivers of children with disabilities, who can find communication with their children challenging [3, 9].

Furthermore, the COVID-19 pandemic impacted the physical health of the caregivers of children with disabilities [10]. First, the caregivers of children with disabilities are at a high risk of experiencing severe physical health problems [11]. Being the primary person responsible for the child’s well-being, they are prone to physical fatigue and depression [12]. Additionally, they often prioritize the child’s health over their own and dedicate themselves entirely to the child’s care. This can cause them to neglect their health [3, 11, 12] and for their health to become compromised [10, 11]. Before the pandemic, these caregivers could utilize welfare service facilities, attend medical appointments, and engage in health maintenance activities [13]. However, the pandemic led to the closure of such facilities and restricted outdoor activities. Consequently, the caregivers spent all their time with their children, which led to significant physical and mental health burdens [1, 13]. Second, the caregivers of children with disabilities were more likely to experience sleep disorders due to the increased stress caused by the pandemic’s sudden onset [2]. Elevated stress levels can disrupt sleep patterns and hamper sleep quality. This can lead to physical and mental impairment [14], considering that sleep is essential for maintaining physical and mental health [4]. Finally, the caregivers of children with disabilities tend to reduce contact with the community because of concerns about exposure to infectious diseases [1-3]. Children with disabilities have weaker immunity than other children [15], which puts them at higher risk of developing infectious diseases [1]. Additionally, COVID-19 has a high transmission rate, and younger children with disabilities are more vulnerable to infectious diseases [16]. This study aimed to identify the factors that affected the QOL of caregivers of children with disabilities during the COVID-19 pandemic. The results of this study are expected to serve as foundational data in the development of interventions that prevent the spread of infectious diseases and nursing interventions that help caregivers maintain a healthy QOL.

2. Methods

2.1. Design, Study Population, and Sample Size

This was a descriptive study that targeted caregivers of children with disabilities who attended a disability family support center in D City. Individuals who were primary caregivers of children with disabilities attended the disability family support center, could understand and answer the survey questions, understood the purpose of the study, and provided written informed consent were included in the study.

The required sample size was determined using the G*Power 3.1.9.4 program based on Cohen's [17] study. We required a sample of 189 individuals for a power of .95, effect size of .15, significance level of .05, 13 predictor variables, and a hierarchical multiple regression analysis. Considering a dropout rate of 20%, the minimum sample size was adjusted to 237. Anticipating a higher dropout rate and the potential for insincere responses, which are characteristic of online surveys, a sample of 279 individuals was considered appropriate.

2.2. Data Collection

The participants were informed that the collected data would be used only for research purposes and would be stored for three years after the end of the study in accordance with the Bioethics Act. They were also informed that personal information would be destroyed in accordance with Article 16 of the Enforcement Decree. The questionnaire link was distributed to 279 individuals, and the questionnaire could be completed between February 4 and 11, 2022. It took approximately 20 to 30 minutes to complete the questionnaire. The participants received a small gift for their participation.

2.3. Measurement Tools

2.3.1. Social Support

The degree of social support was measured using an instrument developed by Park [18] and restructured by Kim [19]. The questionnaire was modified and supplemented to determine the degree of support received from different parties: family, peers, and healthcare professionals. With 25 items for each provider, the tool comprised a total of 75 items. The items were rated on a 4-point Likert scale, and higher scores indicated higher levels of social support. The Cronbach's α value of the tool was 0.96 at the time of its development and 0.97 in this study.

2.3.2. Depression

The degree of depression was measured using the Korean version of the Beck Depression Inventory. This inventory was originally developed by Beck, et al. [20] and adapted into Korean by Kim, et al. [21]. We used the inventory after obtaining permission from the developers. The inventory consists of 21 questions that are rated on a 4-point scale. The total score ranges from 0 to 63, with higher scores indicating a higher degree of depression. The Cronbach’s α value of this inventory was .86 at the time of its development and .93 in this study.

2.3.3. QOL

Participants’ QOL was evaluated using the QOL scale developed by Yang [22]. This scale assesses one’s subjective QOL and comprises 33 items. All items are rated on a 5-point Likert scale, with 5 indicating "very satisfied," 4 indicating "generally satisfied," 3 indicating "neutral," 2 indicating "generally dissatisfied," and 1 indicating "very dissatisfied." Higher scores indicate a better QOL. The Cronbach's α value of this scale was .91 in Yang’s study and .97 in this study.

2.4. Data Analysis

All statistical analyses were performed using the SPSS software (version 27.0; IBM Corp.). Descriptive statistics were determined to summarize information on participants’ general and health-related characteristics, social support, depression, and quality of life (QOL). Differences in QOL based on participants’ characteristics were determined using t-tests and analyses of variance (ANOVA), and the Scheffé test was used as a post-hoc test. We determined correlations between social support, depression, and QOL using Pearson’s correlation coefficients. Finally, a hierarchical multiple regression analysis was conducted to determine the impact of social support and depression on participants’ QOL.

2.5. Ethical Considerations

This study obtained ethical approval from the Keimyung University Institutional Review Board (IRB No. 40525-202111-HR-069-02) to ensure participants’ protection. Before data collection, the participants were informed about the study’s purpose and procedures, as well as the approximate time required to complete the questionnaire. They were also assured of anonymity and the confidentiality of their data, that there would be no disadvantages to participating in the study, and that they could discontinue participation at any time. Data collection commenced after the participants had voluntarily signed the consent form. The collected data were coded and processed directly on the researcher’s laptop, which was secured with a password to ensure confidentiality. The research data will be stored in a locked facility for three years and then destroyed to maintain participants’ privacy.

3. Results

3.1. Characteristics of the Participants

After excluding 24 responses due to missing data or insincere responses, we used the responses of 255 individuals in the data analysis. Table 1 presents the characteristics of the participants. The participants were mostly mothers (230 participants, 90.2%), while the rest were fathers and grandparents (25 participants, 9.8%). The average age of the participants was 44.2 ± 6.1 years, with the largest age group being 41–50 years (138 participants, 54.1%). Most participants had a college or lower level of education (132 participants, 51.8%), while the rest had a university or higher level of education. Regarding children with disabilities, most were male (140 children, 54.9%). The largest age group was the 11–20 age group (120 participants, 47.1%), followed by the 10 or younger age group (108 participants, 42.3%), and the 21 or older age group (27 participants, 10.6%). Children with Grade 2 disability were the highest in number (103 participants, 40.4%), followed by those with Grade 3 or greater disability (90 participants, 35.3%), and those with Grade 1 disability (62 participants, 24.3%). Regarding participants’ health-related characteristics, most had not been diagnosed with COVID-19 (247 participants, 96.9%), whereas the rest had been diagnosed. Twenty-three participants (9%) underwent self-quarantine due to COVID-19, and ten participants (3.9%) had been diagnosed with Hepatitis B. The rest did not undergo self-quarantine or get diagnosed with Hepatitis B. Furthermore, most participants did not smoke (89.8%) or consume alcohol (67.8%). The rest had experiences of smoking or reported monthly alcohol consumption.

Table 1.
Participants' General Characteristics.

Characteristic	Category	Mean ± SD	N (%)
General characteristics	Caregivers		255(100)
	Mother		230(90.2)
	Father, Grandparents		25(9.8)
	Caregivers' age	44.2±6.1	
	>40		79(31.0)
	≥40~<50		138(54.1)
	≥50		38(14.9)
	Caregivers' education		
	Technical college graduation		132(51.8)
	University graduation		123(48.2)
	Disabled child age	13.2±6.7	
	>10		108(42.3)
	≥10~<20		120(47.1)
	≥20		27(10.6)
	Disabled child gender		
	Men		140(54.9)
	Women		115(45.1)
	Disabled child grade		
	1 grade		62(24.3)
	2 grade		103(40.4)
	3 grade or above		90(35.3)
Health-related characteristics	COVID-19 diagnosis		
of caregivers	No		247(96.9)
	Yes		8(3.1)
	Self-quarantine experience		
	No		232(91.0)
	Yes		23(9.0)
	Hepatitis B infection		
	No		245(96.1)
	Yes		10(3.9)
	Smoking history		
	No		229(89.8)
	Yes		26(10.2)
	Drinking history(months)		
	No		173(67.8)
	Yes		82(32.2)

Table 2.
Participants' Level of Social Support, Depression and Quality of Life.

	Mean±SD	Minimum	Maximum	Range
Social support	2.23±0.51	1.0	3.7	1-4
Depression	15.52±10.83	0.0	48.0	0-63
Quality of life	3.12±0.62	1.0	4.9	1-5

Table 3.
Differences in Quality of Life According to Participants' General Characteristics.

Characteristic	**Category**	**QOL**		
		Mean±SD	**t or F**	***p* (Scheffe)**
General characteristics	Caregivers			
	Mother	2.79±0.71	-2.86	.005
	Father, Grandparents	3.16±0.61		
	Caregivers' age			
	>40	3.17±0.58	0.99	.374
	≥40~<50	3.12±0.63		
	≥50	3.00±0.70		
	Caregivers' education			
	Technical college graduation	3.24±0.54	3.14	.002
	University graduation	3.00±0.69		
	Disabled child age			
	>10	3.20±0.53^{a}	4.30	.015*
	≥10~<20	3.12±0.67^{b}		(a>c)
	≥20	2.81±0.67^{c}		
	Disabled child gender			
	Men	3.16±0.59	0.81	.422
	Women	3.09±0.65		
	Disabled child grade			
	1 grade	2.94±0.68^{a}	5.00	.007*
	2 grade	3.11±0.60^{b}		(a<c)
	3 grade or above	3.26±0.58^{c}		
Health-related characteristics	COVID-19 diagnosis			
of caregivers	No	3.13±0.62	1.43	.153
	Yes	2.81±0.61		
	Self-quarantine experience			
	No	3.15±0.60	2.74	.007
	Yes	2.79±0.74		
	Hepatitis B infection			
	No	3.14±0.61	2.11	.037
	Yes	2.72±0.81		
	Smoking history			
	No	3.12±0.60	-0.29	.769
	Yes	3.15±0.83		
	Drinking history(months)			
	No	3.15±0.62	1.11	.273
	Yes	3.06±0.64		

Note: QOL= Quality of life, * Scheffe' test

Table 4.
Correlations between Participants' Social Support, Depression, and Quality of Life.

	Social Support	**Depression**	**QOL**
	r (*p*)	**r (*p*)**	**r (*p*)**
Social Support	1		
Depression	-0.14 (*p*<0.001)	1	
QOL	0.28 (*p*<0.001)	-0.69 (*p*<0.001)	1

Note: QOL= Quality of life.

3.2. Level of Social Support, Depression, and QOL

Table 2 presents the levels of social support, depression, and quality of life (QOL) reported by the participants. The mean score for social support was 2.23 ± 0.51 on a 4-point scale. The mean score for depression was 15.52 ± 10.83 out of a maximum of 63 points. The mean score for QOL was 3.12 ± 0.62 on a 5-point scale.

3.3. Differences in QOL Based on Participants' Characteristics

Table 3 presents the results of determining differences in QOL based on participants' general characteristics. The QOL differed based on the relationship of the participant with the child ($t = -2.86$, $p = .005$), the participant's education level ($t = 3.14$, $p = .002$), the child's age ($F = 4.30$, $p = .015$) and disability level ($F = 5.007$), the experience of self-isolation ($t = 2.74$, $p = .007$), and the diagnosis of Hepatitis B ($t = 2.11$, $p = .037$).

3.5. Correlation Between Social Support, Depression, and QOL

Table 4 presents the results of examining correlations among social support, depression, and QOL. QOL was significantly correlated with both social support ($r = .28$, $p < .001$) and depression ($r = -.69$, $p < .001$). Additionally, social support and depression were significantly correlated ($r = -.14$, $p < .001$).

3.6. Factors Affecting QOL

Table 5 presents the results of identifying the factors that affected the quality of life (QOL) of caregivers of children with disabilities during the COVID-19 pandemic. A hierarchical multiple regression analysis was conducted with QOL as the dependent variable. The independent variables included the relationship with the child, education level, age of the child, disability level, experience of self-isolation, six variables measuring the diagnosis of Hepatitis B, social support, and depression. Among them, categorical variables included the primary caregiver caring for children with disabilities (under college graduates), the education level of the primary caregiver (under the age of 10), the age of children with disabilities (under the age of 10), the level of disability of children with disabilities (under the age of 10), the level of disability of children with disabilities (under the age of the standard), the self-isolation experience of the primary caregiver due to COVID-19 infection (standard: Yes), and the primary caregiver's diagnosis of Hepatitis B (standard: Yes). Tested using the Durbin-Watson test, the autocorrelation of the errors was 1.51, which was larger than the test statistic. Thus, there was no autocorrelation. The tolerance limit was less than 0.1, and the variation inflation factor was 1.009–1.169, which was not greater than 10. Thus, there were no concerns about multicollinearity.

Table 5.
Impact on Participants' Quality of Life.

Characteristic	**Variable**	**Model I**			**Model II**			**Model III**		
		B (95% CI)	**β**	**p**	**B (95% CI)**	**β**	**p**	**B (95% CI)**	**β**	**p**
General	Caregivers†	0.39(0.141 0.628)	0.18	0.002	0.48(0.240 0.709)	0.23	<0.001	0.19(0.006 0.377)	0.09	0.043
characteristics	Caregivers' education†	-0.17(-0.318 -0.024)	-0.14	0.023	-0.19(-0.327 -0.046)	-0.15	0.010	-0.11(-0.215 0.003)	-0.09	0.056
	Disabled child age†	-0.01(-0.021 0.002)	-0.10	0.091	-0.01(-0.020 0.001)	-0.10	0.087	-0.00(-0.009 0.007)	-0.01	0.814
	Disabled child grade†	0.13(0.028 0.225)	0.16	0.012	0.10(0.005 0.193)	0.12	0.040	0.06(-0.016 0.130)	0.07	0.126
Health-related	Self-quarantine experience†	-0.34(-0.59 -0.086)	-0.16	0.009	-0.31(-0.546 -0.064)	-0.14	0.013	-0.11(-0.297 0.078)	-0.05	0.252
characteristics of caregivers	Hepatitis B infection†	-0.41(-0.786 -0.036)	-0.13	0.032	-0.37(-0.726 -0.010)	-0.12	0.044	-0.34(-0.618 -0.067)	-0.11	0.015
	Social support				0.35(0.215 0.488)	0.29	<0.001	0.24(0.136 0.349)	0.20	<0.001
	Depression							-0.04(-0.04 -0.03)	-0.61	<0.001
Adj. R^2		0.13			0.21			0.53		
F(*p*)		7.22(<0.001)			10.49(<0.001)			36.81(<0.001)		

Note: †Dummy variable: Caregivers (Mother=1, Father, Grandparents=0), Caregivers education (Technical college graduation=1, University graduation=0), Disabled child age(>10=1, ≥10~<20=0, ≥20=0), Self-quarantine experience(Yes=1, No=0), Hepatitis B infection(Yes=1, No=0)

The regression model was statistically significant (F = 36.81, p < .001). In Model I, the primary caregiver caring for a disabled child, the primary caregiver's education level, the disabled child's age, the disabled child's disability grade, and the primary caregiver's COVID-19 infection experience, as well as self-quarantine due to COVID-19, the primary caregiver's diagnosis of hepatitis B, and the primary caregiver's experience of self-isolation due to COVID-19 infection, significantly affected QOL. Social support was added in Model II. As a result, the disability grade, the experience of self-quarantine, the diagnosis of hepatitis B, social support, and the caregiver's education level and standard of living significantly affected QOL. In Model III, depression was added, and depression ($\beta = -.61$, $p < .001$), social support ($\beta = .20$, $p < .001$), diagnosis of hepatitis B ($\beta = .11$, $p = .015$), and relationship with the child ($\beta = .09$, $p = .043$) significantly impacted QOL. The adjusted coefficient of determination (adjusted R^2), which represents the explanatory power of the model, was 13%, 21%, and 53% in Models I, II, and III, respectively. Changes in the adjusted R^2 significantly increased the explanatory power.

4. Discussion

This study was conducted to determine social support, the degree of depression, and QOL among the caregivers of children with disabilities during the COVID-19 pandemic, identify the relationship between these variables, and the impact on their QOL. We obtained several insightful results. First, the mean score for QOL was 3.12 ± 0.62 out of a score of 5. This score is higher than those reported in previous studies. One study assessed QOL with the same tool as the one used in this study. The mean score for the QOL of the caregivers of children with mental disabilities was 2.80 ± 0.43 points [12]. Only a few studies have examined the QOL of caregivers of children with disabilities. Therefore, it is difficult to compare caregivers' QOL based on the type of disability, and there are limitations in generalizing the results. However, primary caregivers of children with disabilities are responsible for the children's overall care throughout their lives. Consequently, they are continuously exposed to physical fatigue and stress [4, 12] and do not have time to take care of their health. This can deteriorate their physical health. Thus, it is necessary to identify and analyze the factors that affect their QOL.

Second, depression had the greatest impact on the QOL of caregivers of children with disabilities during the COVID-19 pandemic. This result corresponds with the results of a previous study involving primary caregivers of children with ADHD. In that study, depression was found to affect caregivers' QOL [4]. Depression increases psychological stress and anxiety in primary caregivers and lowers their overall QOL [23]. If the primary caregiver is suffering from depression, it may be difficult for them to exert the energy required to provide care to the child with a disability. This can negatively impact the QOL of the caregiver and the child [12, 14]. This makes it necessary to understand the needs of primary caregivers of children with disabilities and provide interventions that improve their QOL.

Third, social support significantly affected the QOL of caregivers of children with disabilities during the COVID-19 pandemic. This result aligns with the results of another study involving caregivers of children with disabilities [2]. Social support is an important resource that can be obtained from various parties, such as one's family, colleagues, and experts [18, 19]. When families form positive roles through their child with a disability, family cohesion is strengthened, and social support increases [2]. When it comes to colleagues, synergistic effects can be achieved if one interacts daily with colleagues who support the care of children with disabilities, such as interactions in self-help groups [9, 12]. When it comes to experts, they play an important role in providing accurate and reliable information on infectious diseases [8, 18]. To reduce the difficulties faced by primary caregivers in caring for children with disabilities during pandemics, medical professionals should provide information in an easy-to-understand manner, for instance, by using visual materials and simple language [1, 2]. Overall, the findings suggest that it is essential to establish a social support system to respond effectively to future pandemics.

Fourth, the diagnosis of Hepatitis B significantly impacted the quality of life (QOL) of primary caregivers of children with disabilities during the COVID-19 pandemic. Hepatitis B is an acute hepatitis disease and a class 3 statutory infectious disease [24]. It can be transmitted by exposure to infected blood or the wounds of an infected person. To avoid the spread of the infection, individuals with Hepatitis B must keep their blood, body fluids, and saliva away from others. This also means keeping one's eating utensils away and disinfecting them before use [24, 25]. Therefore, if the primary caregiver is infected with Hepatitis B, there is concern and fear about the possibility of infecting the child, considering that children with disabilities have weak immune systems. This concern and fear are thought to affect caregivers' QOL. Because of the lack of research on the QOL of primary caregivers diagnosed with Hepatitis B, it is difficult to compare and analyze their QOL across studies. It is also difficult to generalize the results. However, primary caregivers of children with disabilities are expected to face difficulties in managing their health and preventing infection, because their priority is to provide care to the child with a disability. Therefore, it is important to explore nursing interventions for Hepatitis B and prepare strategies to protect the health of primary caregivers [24, 25]

Fifth, the caregiver's relationship with the child had a significant impact on the QOL of caregivers of children with disabilities during the COVID-19 pandemic. Additionally, the primary caregivers were mainly mothers, aligning with the results of previous studies [3]. These findings suggest that being the child's mother has a greater impact on the QOL of primary caregivers of children with disabilities than being the child's father or grandparent.

This is because mothers primarily take care of their children among their other roles in the family [9, 26] and this affects their QOL. The government is implementing support measures for mothers raising children with disabilities. However, similar measures must also be implemented at the community level.

This study is significant because it examined the quality of life (QOL) of primary caregivers of children with disabilities and provided foundational data for the development of measures that improve their QOL. The results of this study suggest that medical professionals should explore and provide healthcare programs and social support resources to the primary caregivers of children with disabilities. Furthermore, this study provides the following suggestions. First, we propose that the QOL tool used in this study be employed to specifically investigate the QOL of primary caregivers by using a tool that matches the disability grade and disease characteristics of the disabled child. Second, the participants in this study were caregivers who attended a disability family support center in one region, which limits the generalizability of the results. Therefore, future studies should include primary caregivers from different regions. Third, we propose conducting concrete research. Finally, to comprehensively assess the QOL of caregivers of children with disabilities, we propose to analyze the sub-domains of QOL in detail.

5. Conclusions

Depression, social support, the diagnosis of Hepatitis B, and the caregiver's relationship with the child significantly affected the quality of life (QOL) of caregivers of children with disabilities during the COVID-19 pandemic. These results suggest that, during pandemics, primary caregivers must manage depression by utilizing social support resources. The community must establish a system that allows these caregivers to receive continuous support from families, colleagues, and medical personnel. The results also suggest that it is necessary to explore the QOL of primary caregivers of children with disabilities during pandemics and develop and implement appropriate programs. In addition, we propose the development of QOL tools tailored to the characteristics of the disability. Overall, the results of this study are expected to help improve the physical and mental health of caregivers of children with disabilities by helping them lead meaningful lives.

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