

MOTHERS' EXPERIENCES IN CARING FOR CHILDREN DIAGNOSED WITH COVID-19: A PHENOMENOLOGICAL STUDY

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ABSTRACT

Mothers, as the primary caregivers are most likely affected when children are exposed to the COVID-19 pandemic. A few studies in Eastern countries, particularly in Indonesia, explored how mothers were affected by their children's hospitalization due to COVID-19. Indonesia and most eastern countries applied collectivism, which is essential for togetherness. This study aimed to identify mothers' experiences caring for children diagnosed with COVID-19. A phenomenological approach was used, and the data were collected through in-depth interviews with 15 mothers recruited using a purposive sampling technique. Thematic analysis was performed to analyze the data by compiling mothers' experiences caring for children diagnosed with COVID-19 at home and in hospitals. Five themes were revealed: (1) feeling guilty when the child was confirmed positive for COVID-19, (2) feeling worried about the health of the child but thinking positively and becoming stronger, (3) feeling grateful to be able to do the isolation together with the child, (4) making an effort to help the child become cured of COVID-19 and (5) feeling relieved when their children had relatively mild symptoms during isolation. Mothers faced psychological problems including feeling guilty about their child's condition, but then happy when they were hospitalized and recovering together.

Keywords: *Children; COVID-19; isolation; mother*



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INTRODUCTION

The COVID-19 outbreak has quickly spread to all countries worldwide, causing a rapid increase in confirmed COVID-19-positive cases. Indonesia had the most COVID-19 confirmed cases in Southeast Asia, followed by the Philippines and Myanmar (John Hopkins University & Medicine, 2020; World Health Organization (WHO), 2020). Children diagnosed with COVID-19 might require self-isolation and even intensive care. Of the 171 children treated in Wuhan, China, 1.8% admitted to intensive care (Ludvigsson, 2020). Meanwhile, 20% of children diagnosed with COVID-19 in the United States were hospitalized (Bialek et al., 2020). From March to December 21, 2020, Indonesia has 37,706 confirmed COVID-19 positive cases in children, including 175 deaths. The highest death rate occurred in children aged 10–18 years, i.e. 42 of 159 cases (26%), followed by 36 cases in children aged 29 days–12 months (23%), 36 cases in children aged 1–5 years (23%), 24 cases in children aged 0–28 days

(15%) and 21 cases in children aged 6–9 years (13%) (Pudjiadi et al., 2021).

The most likely life aspect affected by the COVID-19 pandemic in a family is the mother's psychological condition. The prevalence of anxiety in mothers who have children aged 0–8 years increased during the COVID-19 pandemic due to the severity of COVID-19 illness if compared to other illnesses (Cameron et al., 2020). The high number of cases and deaths caused by COVID-19 lead fears of the disease, and women were 1.44 times more likely to develop psychological problems than men (Zhu et al., 2020). A study found that the stress response and anxiety included the worry of being infected, encountering contaminated surfaces, and strangers carrying the infection. (Taylor et al., 2020b, 2020a). Emotional stress and social disorders might be worsened by such conditions, leading to maladaptive coping mechanisms during self-isolation (Taylor et al., 2020a). Parents whose

children were sick experienced additional stress because other family members could not visit them (Meesters et al., 2021). Furthermore, if children were sick, they are still highly dependent on their mothers, therefore, this condition impact on the family in general.

Studies related to the experience of mothers caring for their children diagnosed with COVID-19 have been increasing since the pandemic and post-pandemic era (Jones, et al., 2022; Kracht, et al., 2021; Tamo, 2020). These studies could add new insights to determine the appropriate intervention in nursing care to overcome the difficulties experienced by mothers and children during infection and isolation. However, studies focused on the characteristics of Eastern countries, including Indonesia, were limited. Indonesia has a strong principle of togetherness, where being in the isolation room due to COVID-19 was indeed a challenge. Based on this description, this study aimed to explore meanings from the lived experiences of mothers caring for children diagnosed with COVID-19.

METHOD

Study design

The design used in this study was qualitative, using a phenomenological approach. The phenomenological approach focuses on common meanings of lived experiences from several individuals (Creswell & Poth, 2018). We used this method because it was considered the most appropriate for the research questions, which explored the lived experience of mothers who cared for their children who were diagnosed with COVID-19. This study was conducted in Jakarta, Indonesia, a COVID-19 red zone with the highest percentage of infection cases from all over Indonesia. The characteristics of the families in Jakarta varied in terms of religion, culture, and social life. Therefore, the mothers and families evaluated in this study could have several characteristics of mothers who experienced caring for their children diagnosed with COVID-19 throughout the country.

Informants

The participants were selected purposively from mothers who had completed the form to participate in this study. The inclusion criteria were mothers who had children aged 12–59 months with confirmed COVID-19 infection and who were isolated in the hospital, self-isolated at home, or both. The maximum time interval between data collection and recovery was six months. Mothers were physically and mentally healthy, communicating, reading, and writing well in Indonesian. The exclusion criteria were mothers who felt or were inconvenienced with the procedures, those who could not continue the study, and those whose data could not be analyzed.

In total, 18 mothers were interviewed. However, only 15 interviews were transcribed. The recording of three interviews could have been better, so, the transcription could not be completed. The data saturation was reached when the researcher interviewed the 12th mothers. Three more interviews were conducted to ensure there were no added data.

Data collection

This study was conducted when the pandemic situation in 2021 still occurring. The data might be important as a lesson learned from a similar situation that might happen in the future. The data were collected through online semi-structured, in-depth interviews using Zoom Meeting. After reviewing the literature on mothers' experiences caring for sick children, the interview guide was arranged after

reviewing. The questions were open-ended to help the authors investigate more profoundly the experiences of each participant. The research team conducted the trial and evaluation of the interviews before the data collection. This process was conducted to test the research instrument and questions in the interview guide.

The second author conducted the interviews. The researchers and participants had yet to learn from each other previously. Twenty-two participants were personally approached through messages and phone calls to introduce themselves as researchers and build trust. The researcher explained the objectives and details of the study and the rights of each participant in the study. The data collection began after 18 participants consented to participate. During the interviews, the researcher and participants were in private places, either at home or work, with no one else accompanying them.

The interviews were conducted online once with each participant using Zoom Meeting for 35–60 min, using the interview guide provided in Table 1. The interviews were recorded in the form of audio-visual media. However, three interviews were not appropriately recorded, resulting in low-quality results and, therefore, could not be used in the analysis process. The researcher made field notes related to the interview process, the expressions of the participants, and non-verbal communication during the interviews. The participants were allowed to answer openly and freely without coercion or time constraints. Furthermore, the researcher conducted three additional interviews to ensure that no new information or data was found.

Table 1. Interview Guide

Questions
1. When was your child first confirmed to be positive for COVID-19?
2. How was your reaction when knowing your child confirmed positive for COVID-19?
3. How was your experience during the treatment of your child?
4. Who did help you while caring for your child?
5. How did you care for your sick child?
6. When was your child declared negative?
7. How was your experience with the health workers who helped during the treatment?

Data analysis

The thematic analysis was used in this study. The researchers followed the seven iterative phases of Colaizzi's method described in Polit and Beck (2022). First, the interview recordings were listened to, and transcription was made word by word. Then, the text was read repeatedly to grasp the overall message's meaning. Second, all significant statements from mothers in the transcripts were compiled and interpreted in the third phase. Fourth, all meanings derived from the transcripts were arranged into categories, sub-themes, and themes. In the fifth and sixth phase, a comprehensive picture of mothers' experiences in caring for their children who confirmed COVID-19 positive was integrated from the themes considering the context of the study. The final phase of Colaizzi's method consisted of participants' confirmation related to the final analysis. No new data was found in this member-checking activity.

Trustworthiness

The strategy used to achieve data validity was to follow the standards of credibility. Credibility was achieved by conducting member checking to verify that all participants

had checked the findings and provided feedback. Data validation was carried out by obtaining consent from the participants for the compiled coding. Furthermore, data collection triangulation was also used through interviews and field notes, which complement each other to form the themes for the findings. Dependability in this study was fulfilled by presenting all the processes transparently. Confirmability was fulfilled systematically by compiling all data and documentation, namely, interview recordings and field notes. Transferability was determined by reaching the maximum variation of participants' characteristics. The maximum variation included involving families with a wide-range of children's aged (between 12–59 months), religion, age of the mother, education level of the mother, occupation of the mother, COVID-19 status of the mother, number of children, age of the child the COVID-19 case was confirmed positive and isolation place.

Ethical consideration

This study was approved by the Ethical Committee Faculty of Nursing Universitas Indonesia (SK-36/UN2.F12D1.2.1/ETIK 2021). The participants signed an electronic form sent via message, which contained the objectives, benefits, and risks of the study.

RESULT

This study was conducted during the pandemic period, which was from October 2020 to November 2021. During that time, the number of paediatric cases of COVID-19 increased and was considered high in Indonesia.

Characteristics of the participants

The total of participants in this study was 15 people. All of them used pseudonyms. The ages of the mothers ranged from 28–44 years. Most of them were Moeslim. The occupations consisted of a dentist (one person), nurses (eight people), housewives (four people), and civil servants (two people). There were senior high school graduates (three people), university graduates (six people), bachelor's degree (three people), and nurses (three people) regarding with the education background. The number of children in one family ranged from 1–4 children. The age of the children who tested positive for COVID-19 ranged from 13–57 months. The confirmed period was from December 2020 to July 2021. The number of participants treated in the hospital and self-isolated at home was ten and five, respectively. Fourteen mothers were confirmed positive during the isolation, and one was confirmed negative for COVID-19.

Five themes to describe the experience of mothers while caring for confirmed positive COVID-19 children were revealed in this study. The themes were: (1) feeling guilty when the child was confirmed positive for COVID-19, (2) feeling worried about the health of the child but thinking positively and becoming stronger, (3) feeling grateful to be able to do the isolation together with the child, (4) making an effort to help the child become cured of COVID-19 and (5) feeling relieved when their children had relatively mild symptoms during the isolation. Table 1 provides examples of coding trees for two themes.

Table 2. Example of Coding Tree

Significant Statement	Coding	Categories	Sub-theme	Theme
"... while taking care of my child, I think the feeling of guilt dominates. I mean it's like because of the parents' negligence the child also becomes positive..." (P01)	Feeling guilty due to parents' negligence	-	Feeling guilty due to parents' negligence	Theme 1. Feeling guilty when the child confirmed positive for COVID-19
"I was like, 'Oh, I feel so guilty, I was the first to get the virus'. I was the one who gave it to my child." (P07)	Feeling guilty due to virus transmission	-	Feeling guilty due to virus transmission	
"Oh my God, the child is still small. Will he be healthy or not. I can't stop thinking. Oh my child is hot like this. The nurse said, 'Ma'am, calm down'. 'Sister, look at my child. What's going on?' I was getting worried." (P06)	Worried because the child had fever and parents did not know what happened	Worried the child's condition became worst	Worried about the child's condition	Theme 2. Feeling worried about the health of the child but think positively and become stronger
"Thinking about it [news that many children died due to COVID]. At that time that was what I was afraid of. The fear of dying is really exist." (P02)	Afraid the child would die as many children died due to COVID	Worried the child would die		
"I try to generate positive thoughts, I was told to take a break not to work, so I took advantage of this condition to have some rest. I try to build positive thoughts." (P05)	Think positive in the condition of having COVID	-	Positive thinking	
"So we as adults must be stronger than him [the child]. I have a feeling that I have to be strong for my child, like that." (P15)	Feel that mothers should be stronger than the child	-	Trying to be a strong mother	

Theme 1. Feeling guilty when the child confirmed positive for COVID-19

Mothers felt guilty (n = 5) when their children were confirmed to be positive for COVID-19. They felt guilty because they were neglected in caring for their children. Mothers who worked in health facilities felt guilty because they carried the disease to their children. This theme was described in Scheme 4.2.

... while caring for my child... I dominantly felt guilty... and when caring for them, I felt guilty... I mean, I felt like it was because of my neglect, my child became positive too. (Jane)

... when I knew it was positive, I felt guilty, like, since the beginning, I felt guilty... I only could cry and blame myself

because I did not obey the government to not go travelling, I still went to visit my parents. (Margareth)

The mothers said that they predominantly felt guilty during their experience of caring for their children. They thought they failed to take care of their children and exposed them to the disease. They regretted and blamed themselves because they did not obey the health protocols made by the government related to the travel ban.

Theme 2. Feeling worried about the children's health but thinking positively and becoming stronger

All participants (n = 15) were worried that children exposed to COVID-19 would have more severe symptoms. The mothers were also concerned about the possibility that their children would die.

First time knowing my child was positive... I was sad, confused, and confused what to do. I was Afraid, afraid it'll get worse... Oh, Allah, this COVID was like a burden, like ashamed to have COVID disease, at that time, I was kind of confused what to do, like that basically mental. (Hana)

... my feeling at that time, I was worried because my child was still a baby, still little, I was afraid especially when knowing there was a new variant with a high rate of mortality, and the death rate in my neighborhood was also high. (Valerie).

Mothers felt sad and confused when knowing their children were exposed to and confirmed positive for COVID-19. They were afraid the disease would get worse and even cause death, as mentioned by participants who were a housewife. They said that being exposed to COVID-19 was a heavy burden on their minds. They mentioned that being exposed to COVID-19 made them ashamed and confused about dealing with it. COVID-19, in their opinion, not only affected them physically but mentally.

During the isolation, all participants (n = 15) mentioned that being exposed to COVID-19 made them feel depressed and stressed. All participants realized that they had to put more effort into fighting stress by building coping skills. They have made several efforts to develop coping skills include praying, dhikr (continuously mentioning God's name), thinking positively, being strong, and avoiding stress.

We will recover as long as we always think positively. (Michelle)

Because we're older, we have to be stronger than him (child)... I had a feeling that, yes I had to be stronger than my child. (Madeleine)

The mothers tried to look strong in front of their children, although they felt sad and worried. Being confirmed as positive for COVID-19 made them stressed. However, as mentioned by the oldest participants in this study, they always managed to remain calm and control their stress.

Theme 3. Feeling grateful for being able to do the isolation together with the child

Mothers confirmed positive (n = 14) Mothers confirmed positive (n = 14) expressed gratitude when their children were also confirmed positive for COVID-19, as the mothers and their children could be hospitalized together in the isolation room. They felt more relieved to do the isolation together because they could monitor and care for their children.

Previously, when some mothers confirmed positive, they thought about their children at home.

Yes, I was confused because there was nobody to take care of, I actually also upset, as a parent, how it was our own child, if separated for too long, it will also be sad... so, I, indeed, when knowing my child was positive, I felt happy, I meant happy, so I could take care of my own child, compared to when we're separated, that's it... So, indeed, the hardest blow was when I got separated from my child. (Charlotte)

Mothers expressed that they felt more confused and sadder if their children were negative and separated from them.

"Alhamdulillah [praise to Allah], we were (hospitalized) together. My child was the last person in the family who was hospitalized. I felt more relieved when we were together. (Jennifer)

"...but, Alhamdulillah [praise to Allah]. I felt happy but sad when my children were diagnosed with COVID-19 positive, because they could be with me. (Sophie)

The mothers felt grateful that their children were confirmed as positive because they could stay with them and did not have to think about who would care for their children if their results were negative.

Generally, the mothers said that being separated from their children was a heavy burden. Therefore, when their child was confirmed to be positive, they felt happy.

Theme 4. Making an effort to help children become cured of COVID-19

All participants hoped for the most to have their children cured of COVID-19. Many efforts have been made to help the child recover soon and become cured. In addition to giving them medicine regularly, mothers tried to control their nutrient intake to maintain the immunity of their children. Another effort made by the mothers was to maintain the immunity of their children by giving them toys to keep them happy. Mothers did everything to make their children eat more, including cooking their favorite food and keeping them entertained while eating. others order their children's favorite food via online delivery applications. The mothers invited them to play and let them play as they were pleased to keep their children happy. Some participants (n = 5) gave their children headphones to watch videos on YouTube and play games, although they rarely did so previously.

We gave him vitamin-rich foods, tried everything to help him recover, so returned negative soon ... We tried to give healthy four perfect five, whatever it takes, there should be carbo, protein, vegetables, fruits; all should be included, and vitamin to meet his needs, all multivitamin provided... Fortunately, he wanted it, banana, avocado he wanted, all he wanted, so I gave him chicken, eggs, sometimes rice because he didn't really want rice, so I tried porridge, he wanted it, it was softer... (Barbara)

... She/he declined to take medicine, if it was me, I made a strategy, so if it was only once a day if had been taken this morning, the medicine, for example, curcuma to be consumed in the morning, it should be once a day for example... I made it not always morning... I invited them to play, anything... a messy house, that's fine, let him play accompanied by me... sometimes, he also watched YouTube. (Madeleine)

Mothers tried to give vitamin-rich foods to help their children recover and become cured soon. They ensured that the nutrition requirements were met. They tried to maintain the immunity of their children by giving them vitamins and additional supplements, such as honey. They also made an effort to prevent their children from boredom during isolation. They coaxed them into taking medicine, such as dividing medicine time into several different times. For example, when the child had two medications, they were given at two different times, one in the morning and the other in the afternoon. They said that providing supplements, maintaining the mood of the children to stay happy and giving medicine on a daily basis could retain children's immunity and cure them of COVID-19 sooner.

Theme 5. Feeling relieved when children had relatively mild symptoms

Some participants (n = 5) stated that their children had no COVID-19 symptoms. Some others (n = 7) reported that their children had fevers and mild coughs. The other children (n = 2) had fevers and rashes on their skin. Another child (n = 1) had a fever and sore eyes. These symptoms healed after 1–3 days.

On Monday (July 12, 2021), my child had a fever, and I was suspicious because it was a high fever and a little cold, and, if I'm not mistaken, also cough, but not really, not a cough with phlegm... fever and flu... that time also cold, that's it, fever with cold, the temperature was up to 39.8... the fever, alhamdulillah only two days, Monday and Tuesday, and then Wednesday onwards no more fever alhamdulillah. (Valerie)

My child had no symptoms. He (child) had no symptoms at all... because seeing my child acted normal, so I was just happy... I mean, not happy because he was sick, but thank God, he had no symptoms like that. So, I was not too worried, just normal, I meant sad, sad but happy, the point was happy, I was grateful because indeed there's no complaint. (Lauren)

Based on their stories, children infected by COVID-19 had relatively mild symptoms in this study. Their mothers said that these symptoms mainly disappeared in 1–3 days. Five children did not show any symptoms since they first confirmed positive for COVID-19 until the isolation was over and returned negative. It relieved the mothers because their children looked healthy and active, despite being infected by COVID-19.

DISCUSSION

Mothers expressed guilt when the children were diagnosed with COVID-19. They felt guilty because they did not obey the health protocol related to the travel ban during the pandemic. All mothers had increased guilt if they prioritised their own needs (Reid, 2020). The negative emotions were feeling ashamed and guilty by criticising themselves upon their actions and their effects on others (Cavalera, 2020).

In this study, mothers were shown to feel worried when their children were exposed to COVID-19. The feeling of worry arose when knowing the child was confirmed to be positive for COVID-19, and the child showed symptoms of illness, such as fever (Shteinbuk et al., 2021). They worried that the fever would not decrease and the disease would worsen, causing death. The information about 'the new variant' of COVID-19 and the high mortality rate due to COVID-19 were several factors that increased the concerns of the mothers

about the health condition of their children. During the pandemic, anxiety increased after obtaining information about death cases, increased reports in the media, and an increased number of new cases (Lima et al., 2020). Much false information about the pandemic on social media has contributed to fear (Ren et al., 2020). A study confirmed that mothers experienced psychological stress when their children were exposed to COVID-19, making them experience emotional changes, such as worry, sleeping difficulty, and irritability (Aamer et al., 2020). People infected with COVID-19 and in quarantine felt disturbed by thoughts related to health and death (Horeh & Brown, 2020).

Mothers in this study described that when they were first exposed to COVID-19, they felt confused, sad, afraid, ashamed, worried, panicked, and had various thoughts and feelings that made them stressed and mentally attacked. Although many people worldwide will demonstrate resilience to the loss, stress, and profound fear associated with COVID-19, the virus is likely to exacerbate the existing mental health disorders, contributing to the emergence of new stress-related disorders in many people (Horeh & Brown, 2020). Mothers realized that COVID-19 had made them stressed and tried to build coping mechanisms by praying, dhikr, thinking positively, trying to be strong, and avoiding stress. For religious people, praying is part of the recovery process (Kaakinen et al., 2015). Prayer can comfort in sad situations (Abela et al., 2020). Positive thinking allows a person to better cope with stressful situations, thereby reducing harmful health problems caused by stress (Hassan & Alazzeah, 2020). It was shown in a study that the more people engaged in positive thinking, the lower their stress levels and vice versa (Basith et al., 2020).

Interestingly, mothers felt grateful when they knew their children were diagnosed with COVID-19 so that they could stay together during isolation. Most of the participants in this study were first confirmed to be positive for COVID-19, and tracing was conducted on the whole family, including their children. They were worried that the child was negative because they felt sad about being separated from their children. It was shown in a study that parents were likely to be stressed when they had to separate from their children, being unable to care for them (Dahav & Sjöström-Strand, 2018). One of Indonesian society's philosophy, particularly for Javanese people, it is stated that '*mangan ora mangan, sing penting kumpul*', which means togetherness is important, even though they do not have something to eat (Tandywijaya, 2020). This philosophy relates to the theme that mothers are expected to stay together with their children in any condition. Another similar finding was that separation significantly contributed to stress in the family (Hagstrom, 2017). Working mothers stated that undergoing isolation with their children allowed quality time because they had more time to spend with their children. Mothers with mild symptoms said that experiencing isolation from their children and other family members in the hospital felt like a vacation. It was explained in a study that mothers had more quality time with their children during the pandemic and were able to do more activities together (Sari et al., 2020).

In this study, the efforts made by the mothers to help their children diagnosed with COVID-19 to become cured were described. Building the immune system can be achieved by providing children with a balanced diet, enough sleep, and regular exercise. With these activities, children will tend to develop a more robust immune system to fight disease (National Association of School Psychologists, 2020). During isolation, the mothers tried to medicate their children regularly,

maintaining their nutritional intake in various ways to make the child eat. Mothers also tried to make their children happy during isolation, preventing boredom. Playing is for fun or pleasure (Lai et al., 2018). Young children need to play to release energy and feelings to avoid boredom. Therefore, they do not become fussy (Sari et al., 2020). All of these strategies became possible to happening since most children had relatively mild symptoms of COVID-19.

The findings were related to the experiences of mothers caring for their children diagnosed with COVID-19 during the pandemic. It will be necessary for paediatric nurses to provide infected children with holistic care by giving relevant information and showing empathy concerning the psychological condition of their mothers. If the psychological state of the mothers remained positive, they could provide better care for their children. It was mentioned in some studies that the psychological condition of mothers was critical to the psychological state of children during hospitalization (UNICEF, 2020). The occurrence of COVID-19 in children can increase feelings of affection for family and those closest to them. Finally, information regarding the feelings and expectations of the mothers during COVID-19 treatment was also provided in this study.

The main limitation of this study was that the data were obtained only from mothers whose children had relatively mild symptoms. Therefore, data from mothers whose children had severe COVID-19 symptoms were not gathered. The online data collection might hinder the mothers' expression during the interviews.

CONCLUSION

The psychological conditions of mothers while caring for their children diagnosed with COVID-19 are described here. Specifically, the mothers felt guilty because they neglected and transmitted the disease to their children, and they worried that their children would have severe symptoms and die. When experiencing this feeling, the mothers still tried to build coping skills to prevent them from being stressed. Although they felt sad that their child was exposed to the disease, the mothers felt grateful for undergoing isolation to monitor and care for their child independently. The support the children received from their mothers made them calmer and more spirited to recover. The mothers made many efforts to cure their children of COVID-19. Finally, the mothers were relieved that their children had relatively mild symptoms or even no symptoms at all.

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