



## **FAMILY EXPERIENCE WHILE CARING FOR COVID-19 PATIENTS DURING HOME QUARANTINE**

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### **ABSTRACT**

Coronavirus Disease 2019 (COVID-19) is concerning health issue that the world, particularly Indonesia, deals with. The number of COVID-19 cases in Indonesia is growing. The role of the family in providing care to the COVID-19 patient with mild and moderate symptoms during home quarantine should be given a serious concern to prevent virus transmission to other family members. This study aims to into the family's experience in Medan while caring for a family member infected with COVID-19 during a home quarantine. The purposive sampling technique is employed to select the 10 participants for this qualitative with phenomenological design research. And indepth interview is conducted as a data collection method, and then the data are analyzed using the Collaizzi method. The findings address six issues that the family experiences while providing health care to the COVID-19 infected family member during home quarantine : family burdens, family healthcare, support, the impact on families of COVID-19 patients, family barriers and family expectation. The family caring for the COVID-19 patient experiences several challenges and seeks support from other family members to obtain information for the patients recovery.

Keywords: covid-19; isolasi mandiri; pengalaman keluarga

### **INTRODUCTION**

COVID-19 has become a serious health problem worldwide and was declared a pandemic in March 2020. Novel Coronavirus 2019 (2019-nCoV) or Severe Acute Respiratory Syndrome Corona virus-2 (SARS\_CoV-2) (Wang, 2020). Corona Virus Disease (COVID-19) is an infectious disease caused by the Corona virus which was newly discovered in Wuhan City, China (WHO, 2020). According to a report from the National Health Commission of the People's Republic of China, COVID-19 is highly contagious and spreads mainly through contacts, droplets and people who are susceptible to disease. Families are one of the most important modes of transmission of SARS-CoV-2 in China (Zhang et al., 2020). According to the World Health Organization (WHO) globally until February 3, 2021, there were 103,362,039 confirmed cases of positive COVID-19 and 2,224,713 people who died from COVID-19, the number of confirmed cases of positive COVID-19 and the number of deaths due to infection. Corona virus (COVID-19) continues to increase every day (WHO, 2020).

In Indonesia, the incidence of positive confirmed cases of COVID-19 reached 1,123,105 cases of COVID-19 until February 2021 and there was an increase in confirmed cases of positive COVID-19 reaching  $\pm 2000$  cases of COVID-19 every day, while the number of deaths caused by COVID-19 was positive. as many as 31,001 people, with a Case Fatality Rate (CFR) of 2.8% (Kemenkes RI, 2021). The role of the family in caring for a sick family is an obligation and family carers in certain cultures are considered a shared responsibility and family members are interdependent in providing various types of supportive care (Dumit et al, 2015). The decision to treat COVID-19 patients at home can be considered for adults or children with suspected

COVID-19 or confirmed COVID-19 who have no symptoms or mild/moderate symptoms without risk factors and if hospitalization is not available or not sufficient to meet the demand for health care services. Caring for an infected person at home will increase the risk of transmitting the virus to other family members at home, but isolation of people infected with SARS-CoV-2 that causes COVID-19 can make an important contribution in breaking the chain of virus transmission (OMS, 2020).

Based on research findings about patients infected with COVID-19 and family members who are in close contact with patients, they must have the awareness to follow the instructions given to patients and family members while quarantined at home is one of the keys to controlling the transmission of COVID-19 to reduce the source of infection, and transmission through the community (Elgendy et al, 2020). Based on interviews conducted with three families in Ghana about the experience of families living among families infected with COVID-19, it was noted that the most common fear felt by families were dying from COVID-19, community stigma, and the fall of the family business, in addition to the family feeling lonely, grief and families feel alienated (Ayisi-Boateng et al., 2020). In Indonesia, there is a lot of social stigma and discrimination and is shunned by the community towards people who are considered to have a relationship with the COVID-19 disease, especially in the families of COVID-19 patients (Dai, 2020). This paper aims to explore the experience of families in caring for COVID-19 patients during self-isolation at home during the COVID-19 pandemic in Medan City.

## METHOD

This study used qualitative with descriptive phenomenology design. This study aims to explore indepth information and experience of families caring for COVID-19 patients during self-isolation at home. It was conducted from April until June 2021 in Medan. *Purposive sampling technique* is used in this study. There are 10 participants in this research. The data is collected until data saturation is reached. Data was collected with indepth interview via phone and live interview during 60 minutes. There are 8 participants interviewed by phone and 2 participant lived interviewed. The inclusion criteria in this study were willing and agreed to be participants in this study, family members who cared for COVID-19 patients with no symptoms and mild symptoms during self-isolation at home, COVID-19 examination evidenced by PCR, participants were able to articulate how they feel experience.

The data collection process is conducted in three stages. The first stage is preparation stage. This stage the researcher submit a letter of ethical clearance and a research permit for Universitas Sumatera Hospital. Then the researcher searched for participants through the patient's medical records and then the researcher contacted the participants via smart phones and build a trusting relationship between researchers and participants one week. After the participants agreed to be interviewed and participant signed the informed consent. The second stage is implementation. Data was collected by conducting in-dept and semi-structured interviews, namely the researcher used an interview guide to ensure that quations had been delivered by the researcher.as for data collection tools in tjis study used smart phones, voice recorders, and interview guides containing a list of quations, and field notes. Last stage is the termination stage, the validation stage or member checking.

After conducting in-depth interviews, the researcher conducted data analysis. Data analysis was used the Collaizi method. Typing interview transcripts and re-reading interview transcripts that have been made in verdatim and listening to interview recordings over. Extracting data on significant statements or statement that are in accordance with the research objectives. Then explain the meaning of each statement significant value to make it easier to analyze the data,

the meanings that have been formulated are grouped into groups of themes or sub-themes and then integrate and describe the phenomenon under study as whole and describe the fundamental structure of the phenomenon or research findings and the last is validation stage or member checking. Ethical approval in this study was obtained from the Ethics Commission of the University of North Sumatera with the number 252/KEP/USU/2021 the ethical principle in this research is to respect human dignity, where the researcher gives informed consent as a form of participant approval that the participants understand the research activities. Validity of the data carried out in this study are credibility, dependability, transferability, confirmability, and authenticity.

## RESULTS

### Characteristics

There are 10 participants and 1 male participant (10%) and female 9 participants (90%). Participants' ages ranged from 24-52 years. There are 3 (30%) participants with undergraduate education, 5 (10%) participants with D-III education, and 2 (10%) participants with high school education. There are 1 (10%) participants who work as Civil Servants (PNS), 3 (30%) participants work as Honorary Employees, 2 (20%) participants work as Private Employees, and 4 (40%) participants as Housewives (IRT), 10 (100%) Muslim participants. The family relationship with the patient is husband 1 (10%) participant, wife 6 (60%) participant, child 1 (10%), sister 1 (10%) participant. With confirmed mild COVID-19 there were 8 (80%) participants and moderate COVID-19 there were 2 (20%) participants. Meanwhile, none of the participants had comorbidities.

### Theme

This study are presented by 6 themes and 16 subthemes, namely family burdens while caring for COVID-19 patient during self isolation at home with sub-themes physical burden, economic burden, psychological burden, societal stigma. Family healthcare during self isolation at home with sub-themes the efforts made by the family to increase the patients body immunity, the family's efforts to prevent the transmission of COVID-19 at home, and the family's efforts to seek information about the patients treatment. Support while caring for COVID-19 patient at home with sub-themes of family support and social support. The impact on families of COVID-19 patients with sub-themes of closer family relationships, families adapting to COVID-19, spiritual improvement while caring for patients COVID-19. Family barriers while caring for COVID-19 patients at home with the sub-theme of not being able to treat directly and family expectation while caring for COVID-19 patients at home with sub-themes of community stigma do not exist, the COVID-19 pandemic ended quickly, and no one in the family was affected by COVID-19.

### Theme 1 : Family Burdens While Caring for COVID-19 Patient During Self Isolation at Home

The results of the analysis show that on the theme of family burden while caring for COVID-19 patients during self-isolation at home, there are sub-themes of physical burden, economic burden, psychological burden and community stigma.

#### a. Physical Burden

The analysis show that the family in caring for the patient COVID-19 during isolation at home feels fatigue, lack of sleep, stomach acid disorders due to stress, and experiences weight loss while caring for COVID-19 patients who are self-isolating at home. This statement is in accordance with the expressions of some of the participants below:

*"...Sometimes Feeling tired of dealing with COVID-19 and feeling like being imprisoned and experiencing gastric acid disease due to stress" P1*

*"..Feeling tired from lack of sleep and experiencing weight loss body while treating COVID-19 patients" P6*

*"..Feeling tired because there is no one to take care of patients" P7*

#### **b. Economic Burden**

The analysis show that the family in caring for the patient COVID-19 during self-isolation at home, participants experienced material difficulties due to the business not running and spending a lot of money to buy medicines, fruits and other vitamins to increase the immunity of the patient and family. This statement is in accordance with the statements of several participants below:

*"..Having experienced material difficulties since my husband was sick and hoping that COVID 19 will pass quickly, so that our business can return to normal" P3*

*"It costs a lot to buy fruits, honey and other vitamins" P5, P7, P9, P10*

#### **c. Psychological Burden**

The analysis show that the family in caring for the patient COVID-19 during self-isolation at home experiences a psychological burden, namely families express fear because the virus is very dangerous as a result many victims, families are also afraid of contracting COVID-19 and transmitting it to their children and others, afraid that others will know that family members are confirmed COVID-19, the family also feels sad because they can't get together with other families. This statement is in accordance with the expressions of some of the participants below:

*"..The first time I heard my son, I screamed there, ma'am, I don't know anymore, I ran, his father happened to be asleep because it was 11 o'clock at night" P1*

*"... "Fear of interacting with other people and being overshadowed by fear" P1'*

*"..The first time I knew it was positive, I was surprised, I didn't think it could happen, right, I immediately checked, Alhamdulillah, it was negative, while we were at home sleeping in the same dining room at home, how come I was negative, he was positive, didn't expect it. P5*

#### **d. Society Stigma**

The analysis show that the family while caring for the patient COVID-19 during self-isolation at home feels the stigma of society. Participants revealed that they felt sad because their neighbors shunned them. One of the participants also said that he was afraid that his son would be ridiculed by his friends because his father had COVID-19. This statement is in accordance with participant's expression below:

*"We feel sad because our neighbors cornered us" P6*

*"I'm afraid of the children, children play outside, I'm afraid you know that fellow children don't understand, later they will mock each other like that, the victim is the same as my child, we are parents, dealing with children everyday is like that" P4*

### **Theme 2 : Carrying out the Family Health Care Function**

The analysis show that the theme performs the function family health care, there are several sub-themes, namely: carried out by the family to increase the patient's immune system and efforts families in preventing the transmission of COVID-19 at home.

#### **a. Efforts Made by Families to Boost Immunity**

**Patient's Body** The results of data analysis show that families in caring for COVID-19 patients during self-isolation at participants' homes make efforts to increase the body's immunity of patients and other family members by providing fruits, herbal drinks, namely

ginger water, herbal medicine such as habbatussauda', honey, feeding boiled eggs three times a day, and milk. This statement is in accordance with the participants' expressions below:  
*"...One more thing, we must continue to subsidize fruits, juices, honey, Black Seed." P1*  
*"...He eats three times a day so it's rice food, right if for example in the morning for breakfast, oh it's a cooked egg and then he drinks the same honey drink bearbrand milk" P6*  
*"...Drinking vitamins is the same as drinking honey, I bought that person too honey, people say that sis Clover honey is good" P10*

#### **b. Family Efforts in Preventing the Transmission of COVID-19 at Home**

The analysis show that families in caring for COVID-19 patients during self-isolation at home try to prevent transmission of COVID-19 at home by implementing health protocols.  
*"...I washes it with a mask and then I soak it in detergent first before washing it, soak it in a pack of detergent with soap so that the germs die, right?" P5*

#### **c. Family Efforts in Finding Information about Patient Health**

The results of data analysis show that families in caring for COVID-19 patients during self-isolation at home seek information about patient treatment from health workers such as doctors, nurses, midwives, and nutritionists and seek information via telehealth. This statement is in accordance with the expression of several participants below:  
*"If it's a drug problem, I'm asking, Sis, because a friend at the hospital at work also has Covid..." P10*  
*"...Asking a friend happens to be a midwife" P8*  
*"...I'm not satisfied either, so the last time I had a brother, I called, I talk about this, then by chance, doctor retno I know" P1*

### **Theme 3: Support while Caring for COVID-19 Patients**

#### **a. Support from family**

Families in caring for COVID-19 patients during isolation at home receive support from families by praying for patients and giving encouragement to patients and families. This matter according to the participant's expression below:  
*"If your family gives you encouragement..." P7*

#### **a. Social Support**

The analysis show that families who are caring for COVID-19 patients during self-isolation at home receive support from the patient's friends and neighbors in the form of materials, fruits. This statement is in accordance with the expressions of some of the participants below:  
*"...Coincidentally we have neighbors..." P1*

### **Theme 4: Impact on Families of COVID-19 Patients**

Families who care for COVID-19 patients during self-isolation at home have a good impact on families, namely families can adapt to COVID-19, family relationships closer, and spiritual improvement while caring for COVID-1 patients

#### **a. Families Adapt To COVID-19**

The family revealed that the family was more concerned about maintaining health protocols while at home and outside the home and families also reminded each other of other family members to maintain health protocols. This is in accordance with the expression participants below:  
*"I'm used to it, for example, at the beginning of work, at the beginning of COVID-19, it's lazy to wear a mask, even though you meet people now who are guarding wearing masks, taking care of your brother more" P6*

*"It's more important to take care of this process, Sis, it's important to take care of yourself, not every time we can remind that person, not every time I can call that person, it has to be ourselves too" P10*

#### **b. Closer Family Relations**

As long as family members are infected with COVID-19 and participants take care of COVID-19 patients during self-isolation, family relationships are getting closer to each other and to take care of and remind each other among family members to avoid the corona virus. The statement is in accordance with the participant's expression below:

*"..We have to strengthen each other, the lesson is, even though Eko has been quiet all this time, that's where he finally appears, dear, sometimes our children are indifferent.."P1*

*"...Indeed, after that incident, the communication got better, close, communication, reminding each other, taking care of each other" P2*

*"It's good that the more harmonious our family relationship is" P9*

#### **c. Spiritual Improvement while Caring for COVID-19 Patients**

Participants revealed that participants prayed more, tried and surrendered, participants also said that the COVID-19 suffered by the family was a test given by God to be better. Self-introspection and is God's destiny. This is in accordance with the respondents' statements below:

*"The most visible wisdom when we get closer to Allah" P1*

*"Just think positively, maybe it's fate that you will have a disaster like this" P5*

*"...Keep praying and keep on wheeling" P4*

#### **Theme 5: Family Obstacles During Caring for COVID-19 Patients**

The family revealed that in caring for patients during self-isolation at home, they experienced difficulties when caring for patients because families minimized direct contact with patients. patients and cannot linger with patients during self-isolation. participants also revealed that participants could not comfort patients directly. This statement is in accordance with the participants' expressions below

*"The difficulty is that we can't directly touch him, we can't immediately entertain him, the communication is far away." P2*

*"..At least maybe because you can't do this, you can't just meet, Sis, you can't meet beside him, you can't speak the language freely" P6*

#### **Theme 6 : Family Expectations During Caring for COVID-19 Patients**

The analysis show that the family hopes that while caring for COVID-19 patients at home there is no family stigma, the COVID-19 pandemic is fast ended and no family was affected by COVID-19

##### **a. No Stigma Society**

The results of data analysis indicate that the family hopes that there is no society stigmatizes families because they have experienced how to treat COVID-19 patients. Participants also said this according to the participant's statement below:

*"....not if there are people who get COVID, because of me, I've experienced it, if someone or their family gets it, I see that my mother's neighbor has been kicked out" P1*

##### **b. The COVID-19 Pandemic Ends Fast**

The results of the data analysis showed that participants hoped that the COVID-19 pandemic would end quickly and the death toll would decrease. Participants also hope that things will return to normal. This is in accordance with the statements expressed by the participants below:

*"...Hopefully in 2022, hopefully this covid will be over, even though we are still hearing that in other countries the second phase is starting to attack, which is said to be sunammi covid, a new covid appears.." P2*

*"...Of course, let this COVID pass quickly..."P5*

### **c. No Other Families Affected By COVID-19**

The results of data analysis show that the family hopes that there is no families affected by COVID-19 so that they can gather with other families. This is in accordance with the statements expressed by the participants below:

*"..Hopefully this corona will pass quickly, even our names are not free to go outside, be active, it's enough what has been done, no one else feels like this.." P4*

*"..Hopefully my brother doesn't get hit again, sis hmhm., it's not too much, don't let family members get hit.." P6*

## **DISCUSSION**

Families felt tired due to lack of sleep and there was no substitute for caring for patients, and participants also experienced acid reflux disease due to stress and experienced weight loss while treating COVID-19 patients. The research of Rahimi et al (2021) stated that some caregivers experience physical problems such as sleep disturbances, anorexia, and allergies due to excessive use of disinfectants. Fatigue and insomnia are physical symptoms that are often found in families caring for COVID-19 patients at home (Rahimi et al., 2021). The family experiences an economic burden during treating COVID-19 patients, namely participants experiencing material difficulties due to business not running and spending a lot of money to buy medicines, fruits and other vitamins to increase the immunity of the patient and family. Based on research conducted by Rahimi et al (2021) Regarding the caregiver experience of patients with COVID-19, they experienced financial problems for their needs during quarantine and stated that on the one hand their income was reduced and on the other hand medical expenses and other expenses (Rahimi et al, 2021).

Families experience a psychological burden while caring for COVID-19 patients at home, namely families express fear because the virus is very dangerous as a result many victims, families are also afraid of contracting COVID-19 and transmitting it to their children and other people, afraid of other people knowing family members confirmed COVID-19, the family also felt sad because they could not gather with other families. Research conducted by Jafari-Oori, M et al (2020) that of 77, 5% of caregivers experiencing depression, 75% experiencing anxiety, and 80% experiencing stress and 69% of caregivers experiencing fear with moderate to high severity due to caring for families with COVID-19 and making direct contact with the virus. every day, this virus is also new with high morbidity and mortality and limited knowledge about COVID-19 (Jafari-Oori M et al, 2020).

Families in caring for COVID-19 patients during self-isolation at home experience societal stigma. Participants revealed that they felt sad because their neighbors shunned them. And one of the participants also said that he was afraid that his son would be ridiculed by his friends because his father had COVID-19. This is in line with the qualitative research conducted by Akbarbegloo, M et al (2021) in Iran on the experience of psychological treatment patients with COVID-19 at home that they experience social rejection, namely other people avoid and do not communicate with families who care for patients. Families hide illness to prevent misjudgment of those around them and fear that other people around them are infected (Akbarbegloo, M et al,2021).

Family provides fruit, herbal drinks, namely ginger water, herbal medicines such as habbatussauda', honey, feeds boiled eggs three times a day, and milk. Based on research conducted by Mansoor et al (2020) that family members seek treatment using home remedies, such as the most frequently used medicines, namely kalwanji, hot water, green tea, gargle with haldi using warm water, warm lemon, multivitamins, cough syrup, honey, and breadneem (Mansoor et al., 2020). Family in caring for the patient feels responsible for the patient, family does not have the heart to leave the patient alone at home, and will continue to care for the patient until he recovers. This is in line with the research of Zahed et al (2019) that raising a family is an honorable task and loyalty and commitment to their love and care for their partner (Zahed et al, 2019).

Families in caring for COVID-19 patients during self-isolation at family homes trying to find information about the treatment of patients from symptoms that arise due to COVID-19 Based on research conducted by Mansoor et al (2020) that family members seek treatment using drugs. The COVID-19 pandemic (Coronavirus disease 2019) and social distancing have accelerated the implementation of telehealth programs in hospital systems around the world (Hirko, K. A et al, 2020). Research has been conducted that social contact and support can help reduce stress, depression, anxiety and isolation, as well as increase self-esteem, normal life, well-being and quality of life (Santoso, 2020). social support from family and friends. Studies in various countries have shown positive effects of social support, and poor social support has been associated with a more than twofold increased risk of death (Chen D et al, 2020).

Families caring for COVID-19 during self-isolation at home hope that no family is kicked out by his own neighbour. The negative stigma of society towards COVID-19 patients is removed with various optimal health literacy from various parties. And support from various parties is needed to increase the immunity of COVID-19 patients (Abudi et al., 2020). Families who care for COVID-19 patients during self-isolation at home experience spiritual improvement while caring for COVID-19 patients at home, namely the relationship with God is getting closer and COVID-19 is a test given by God. Participants try and pray for the healing of the patient. Asgari's research (2020) that the families of COVID-19 patients are trying to fight the pressure of the COVID-19 disease by carrying out religious practices and problem solving. However, due to the nature of the disease and its severity, families sometimes feel ashamed and lonely and fear losing their loved ones (Asgari., (2020).

## CONCLUSION

The findings address six issues that the family experiences while providing health care to the COVID-19 infected family member during home quarantine : family burdens, family healthcare, support, the impact on families of COVID-19 patients, family barriers and family expectation. The family caring for the COVID-19 patient experiences several challenges and seeks support from other family members to obtain information for the patients recovery.

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