ISSN 2354-8428 e-ISSN 2598-8727 **IVRNAL KEPERAWATAN INFORMATION COMPREHENSIVE NURSING JOURNAL**



Sekolah Tinggi Ilmu Keperawatan PPNI Jawa Barat

Vol. 8 No. 4, October 2022

- Psychosocial Status Equality between Familial and Non-Familial Breast Cancer Patients
- Response, Emotional Impact and Expectation of Family Caregiver in Caring For Family Member with Covid-19: A Qualitative Study
- Preceptorship Program and Recruitment Process on Improving the Behavior of Professional Nurses in the Inpatient Room of Hospital C Jakarta
- The Effect of Five-Finger Hypnosis Relaxation Educational Videos as Psychosocial Support on Reducing Anxiety Levels in Student Chronotype during Distance Learning during the COVID-19 Pandemic
- Conflict Management Strategies on the Learning Process of Nursing Undergraduate Students During the Covid-19 Pandemic
- Factor Affecting Treatment Compliance in TB Patients
- The Effect of Murottal Al-Quran Therapy on Anxiety Level of Chronic Kidney Disease Patients Undergoing Hemodialysis
- The Effect of Deep Breathing Relaxation on Changes of Blood Pressure on Hypertention Patients
- The Description of Alexithymia in Nursing Students at Padjadjaran University with Social Media Addiction
- Job Satisfaction Analysis Of Nurses Using Science And Cano Integration
- The Effect of Health Education in Postpartum Mothers on Colostrum on the Intensity of Early Breasfeeding in Newborn Babies
- The Use of Trauma Healing in Treating PTSD in Post-Disaster Victims: A Narrative Review
- Is Acupressure Effective To Treat Pruritus In Hemodialysis Patients? A Literatur Review
- Nurse's Competency Toward Covid-19: A Systematic Review
- Home-based Pediatric Palliative Care: A Narrative Review
- The Effect of Disaster Education of Increasing Earthquake Disaster Preparedness : A Narrative Review

JURNAL KEPERAWATAN KOMPREHENSIF	VOL. 8	NO. 4	Page 433 - 576	Bandung October 2022	ISSN 2354-8428 e-ISSN 2598-8727
------------------------------------	--------	-------	-------------------	----------------------------	--



Research Article

Response, Emotional Impact and Expectation of Family Caregiver in Caring For Family Member with Covid-19: A Qualitative Study

T. Widya Naralia^{1*}

Henny Permatasari²

¹Community Nursing – Nursing Diploma, Akademi Keperawatan PELNI Jakarta - Indonesia

²Community Nursing – Faculty of Nursing, Universitas Indonesia -Indonesia

*contact

widya.naralia@gmail.com

Received : 11/09/2022 Revised : 12/10/2022 Accepted : 23/10/2022 Online : 31/10/2022 Published : 31/10/2022

Abstract

Aims: The increasing number of COVID-19 cases has led to the collapse of health facilities so that treatment is not only carried out at the hospital, but also at home by involving the family. The rapid spread, rapid deterioration of health status and the uncertain treatment have caused fear for Covid-19 patients and also for those around them. Family caregivers are the closest people who responsible to provide care the Covid-19 patients at home. Various experiences of family caregivers provide an overview of the emotional response and impact as well as expectations while caring for family members with Covid-19. The purpose of this study was to obtain meaning and significance from family experiences in caring for family members who were confirmed to be COVID-19.

Methods: The method used is qualitative with a descriptive phenomenological approach with data collection through in-depth interviews. There are 14 participants who are families who take care of family members with COVID-19 at homes in the North Sumatra. Data analysis was performed using the Colaizzi technique.

Results: The results of this study discuss 2 main themes, namely the theme of response and emotional impact, and the expectations of family caregivers while providing care. Conclusion: family caregivers reveal negative emotional responses and emotional impacts, psychological and social changes from family caregivers. Family caregivers also expressed hope for assistance from the government and the community around their life.

Conclusion: The results of this study provide a real picture of how the feelings and expectations felt by the family caregivers of Covid-19 patients.

Keywords:

Family Caregiver Experience, Response dan Emotional impact, Expectation





INTRODUCTION

The Covid-19 disease entered Indonesia in March 2020 and to date has infected millions of people up to hundreds of thousands of people have died in Indonesia due to pandemic Covid-19 (1). The deterioration condition of Covid-19 patients occurs so quickly if the treatment not in right away, from the initial symptoms that are only fever and cough, to finally cyanosis & respiratory failure in just a matter of hours (2). This condition has an impact of fear for patients and their families as caregivers. Moreover, the treatment of Covid-19 cases is not only carried out in hospitals but also at home and the family caregiver should be responsible to care (laporcovid19.org, 2021).

Family caregivers are the closest people who have the most role in providing care to sick family members. (3) stated that the more severe the condition of the sick family member, the heavier the responsibility of the family caregiver will be. A survey on the experience of family caregivers caring for Covid-19 patients stated that caregivers feel very afraid if their family will be rejected in health services, feel very worried about the condition of sick family members getting worse, to the point of feeling afraid that other family members will be infected (4). Various family responses in responding to the health conditions of family members infected with Covid-19 indicate a heavy emotional impact on the family caregiver. The condition of psychological stress due to Covid-19 occurs in moderate to severe psychological pressure, including on family caregivers, especially in the female gender (5,6).

Family caregivers express feelings of crisis in social relationships and a decrease in financial condition while providing care to sick family members (7). Research on the experience of families caring for Covid-19 patients by Rahimi (8) shows that family caregivers expect support from people and the government. around them Therefore, it is important to know the emotional impact and expectations of family caregivers so that appropriate support and treatment can be immediately provided. This research was conducted in North Sumatra Province in 2021 with the aim of obtaining in-depth data about the response. emotional impact and expectations of the family caregiver phenomenon when providing care to family members with Covid-19.

METHODS

This study uses a qualitative research design with a descriptive phenomenological approach. The participants involved are family caregivers who have cared for their family members with COVID-19. The selection of participants was carried out using a snowbal sampling technique or participants selecting from the recommendations of previous participants, with inclusion criteria (1) the family has provided care to a family member confirmed to have COVID-19 at home (2) willing to become a participant indicated by signing a consent form (3) family members living with clients with confirmed COVID-19 (4) able to tell their experiences in caring for family members confirmed COVID-19 (5) able to speak Indonesian in conveying information. This research has passed the ethical review (SK-118/UN2.F12.D1.2.1/ ETIK 2021) for research in North Sumatra Province, Indonesia. Data was collected by means of in-depth interviews. There were 14 participants, 11 participants were interviewed by telephone (voice and video call), while 3 others were interviewed faceto-face. Data is collected through voice recorder. The data analysis of this study used the thematic analysis data with seven steps of Colaizzi method (1978 in Morrow (9)) by involving participants in the process of validating research results.





RESULTS

Table 1 Show the characteristics of family caregiver and length of care the patient at home. The 14 participants in the survey came from a wide range backgrounds and came from various regions in the province of North Sumatra.

No.	Age (years)	Gen der	Etnic	Educati onal Level	Employe Status	Relationship to Patient	People at home	Length of care*
P1	24	F	Javanese	Bachelor	Housewife	Husband	5	3
P2	70	F	Bataknese	Master	Retired	Child	3	2
P3	30	F	Javanese	Diploma	Housewife	Husband	3	2
P4	26	М	Bataknese	Bachelor	Enterpreneur	Brother	4	2
P5	37	F	Javanese	Diploma	Housewife	Husband	2	2
P6	42	М	Bataknese	Diploma	Enterpreneur	Wife	5	4
P7	26	F	Acehnese	Bachelor	Enterpreneur	Sister	2	2
P8	39	М	Javanese	Bachelor	Employee	Wife	5	2
P9	57	F	Bataknese	Bachelor	Civil Servant	Child	4	2
P10	27	F	Bataknese	Bachelor	Enterpreneur	Mother	3	2
P111	54	F	Bataknese	Diploma	Housewife	Child & Husband	3	2
P12	57	F	Bataknese	Master	Lecturer	Cild	3	2
P13	28	F	Javanes	Bachelor	Nurse	Husband	2	2
P14	31	М	Malay	Bachelor	Civil servant	Parents	3	2

Table 01.Characteristics of family caregiver

Length of care*: in weeks

A total of 14 participants spread across various regions of North Sumatra Province, were interviewed in-depth interview by telephone and met in person. The average age of the participants was 39 years with 10 women and 4 men. As many as 50% of the participants are Batak ethnic and all participants have a university education background. All sick family members are part of the nuclear family, namely wife, children, husband, siblings and parents, with an average of 3-4 other family members living together during the treatment period. The average length of treatment is 2-3 weeks.

The response and emotional impact of family caregivers in providing care to confirmed members of Covid-19 is part of the results of a qualitative analysis of the experience of families caring for family members confirmed by Covid-19 in North Sumatra Province. There are 5 responses emotional impact from and family caregivers when caring for their family members with confirmed Covid-19, namely (1) Action response: Contact the health care service, (2) First emotional response of family caregiver (3) Response and emotional impact during care. (4)Caregiver's physiological response, (5) Caregiver's social response. In addition to the emotional response and impact, family caregivers also expressed their hopes while providing care to family members with Covid-19. There are 3 main things that become the expectations of the family caregiver, namely (1) Improving the condition of the sick family member, (2) Assistance from the government, (3) Attention from the surrounding community. The process of analyzing sub-themes and themes can be seen in the table 02.





Table 02.				
Subthemes and Themes from Family Caregiver Experience During Care				
the Member Family with Covid-19				

Themes	Subthemes	Categories		
Respons and	Action response: Contact the	Clinic and Primary Health Care		
emotional impact	health care service	Hospital		
		Laboratory Clinic		
	First emotional response of	Sad and Crying		
	family caregiver	Shock and unbelievable		
		Panic and abiguity		
		Affraid and felt guilty		
	Response and emotional impact	Gloomy and moody		
	during care	Deeply afraid		
		Mental rediness		
		Anxiety		
		Surrender		
	Caregiver's physiological response	Exhaustion		
	Caregiver's social response	Absent from work		
		Absent from event		
Expectations of family	Improving the condition of the	Recover soon and no spread of		
caregiver	sick family member	disease		
	Assistance from the	Telecounseling		
	government,	Material and food assistance		
		Isolation room in community		
	Attention from the surrounding	Don't stigmatize		
	community.	Help from neighbors		

Response and Emotional Impact of Family Caregiver

Action response: contact the health care service

Participants told that they feel suspicions with family members who began to get sick with signs of COVID-19 symptoms. The symptoms were fever, cough, muscle and bone pain and loss of sense of smell. The participant then invited their sick family to have an examination at a health facility. All participants responded to their suspicions by taking sick family members to health facilities, namely clinics, hospitals, health centers and laboratories. This is illustrated by the following statements:

> "Well, as soon as we know (we have lost our sense of

smell) we go to the clinic for treatment, there is a rapid antibody test check service, the antigen doesn't exist yet" (P04)

"Because his condition isn't good, we'll have it checked... check it out at the hospital" (P05)

"..I took my husband and children to check there (puskesmas), and swab test in there ..." (P11)

When revealing the initial condition of the suspicion, the majority of participants expressed panic and fear when they were going to have an examination at a health facility.

┙ https://doi.org/<u>10.33755/jkk</u>





First emotional response of family caregiver

As many as 13 participants of family caregivers show a response of shocked, shocked and sadness when they find out that the family has been confirmed to have COVID-19, this can be seen from the following statement:

> "...I wonder how he got the virus, where did this come from, even though the procedure for wearing masks, washing hands, keeping a distance is really done, we rarely go out if it's not important" (P03)

> "The first one was really panic.. I really panicked. Moreover, I also have quite a lot of interaction with my brother.... This panic is also due to the influence of the media...there are many people who died due to Covid" (P04)

One of the participants, namely participant 6 (P06) revealed that the initial response when he found out his wife had COVID-19 was to try to be ready to take care of his wife who had confirmed COVID-19. This participant 6 revealed that it had become a risk if a nurse was at risk of being infected with COVID-19 so he tried to be ready to take care of his wife as a nurse. With a low tone of voice indicating sadness, participant 6 expressed the following statements:

"When I first found out it was positive Covid-19, I tried to feel that I had to be ready to take care of her until she recovered... I feel like this is my responsibility.. because my wife is a the nurse, so it's a risk as a nurse" (P06)

Participant 14 stated that at first he felt complaints such as fever, cough and flu, but he considered the fever he felt was just an ordinary fever and did not realize that it was a symptom of COVID-19 disease so that Participant 14 was still in close contact with his parents which eventually resulted in both parents contracted COVID-19. Both parents of participant 14 then experienced symptoms of COVID-19 until finally the participant's mother had shortness of breath and had to be hospitalized, while her father was advised to self-isolate at home. This can be seen from the expression of the participant 14 (P14):

> "...I feel depressed and stressed... (participant's face looks sad) I don't know what the symptoms of Covid were before, because I still think of this disease as common disease. Fever, cough, runny nose... if we look at using ordinary medicines, it can also be cured.... I feel very depressed, I also feel guilty I just realized that I was the one who spread the covid-19 virus to my parents" (P14)

Response and emotional impact during care

The emotional response and impact of family caregivers while caring for sick family members. The negative emotional responses expressed by participants during take care for a family member with COVID-19 were sad, afraid, trying to strengthen mentally, sincere and give up, feeling a heavy burden, stressed and anxious. This emotional response can be seen in the following expressions:

> "Yeah, really keep your distance. I didn't dare to go too far into his room, so I put a table at the door of the room. Come out, he's sunbathing behind it, so we're far away" (P02)

"...I just feel sincere..., I think it's okay to do it, if not I'll be the one to help who else will it be, sis, especially since







we're just the two of us here" (P07)

"It's really hard.. it's hard (participants were silent and the volume of the voice weakened).. because I have to take care of children, take care of sick people... Yes, I do all the work myself.... all I provide, food, vitamins, medicine... taken care of, not only my wife, but also there are 3 children, that's why I'm really overwhelmed but no matter what, I have to take care of it" (P08)

Caregiver's physiological response

This physiological response is the fourth sub-theme that is formed from the participants' expressions which state their physical complaints when caring for their family members. This can be seen from the following expression:

> "I feel very tired, huh... I thought and felt that I was tired... But yeah, I can't give up either, right, no one wants a situation or condition like this" (P12)

"I feel tired, I'm sure... Tired because... it's not just taking care of my husband at home, тv child is still in kindergarten, he needs attention. Even тv husband's illness is contagious, so we're afraid that we'll be infected later..."(P03)

Caregiver's social response

Family caregivers stated that they were forced to change their daily routine, from being able to usually go to work and interact with other people, to being isolated at home and not doing outdoor activities and having to take care of sick families. The expression was then formed into the fifth sub-theme, namely social response while caring for the family. This can be seen from the following participant statements:

> "My routine is work, so I have to try to stay at home first, that's a problem for me too... various jobs I have to leave and postpone" (P04)

> "I was forced to stay at home and not go to work, my job was replaced by my employees" (P06)

> "I was supposed to be a speaker in a seminar when my child was infected Covid-19 and that would actually add to my finances, but in the end I turned it down because I also thought it would be unethical because I live with my child who has Covid (risk of transmitting)." (P12)

Expectations of Family Caregiver

Improving condition of the sick family member

Participants expressed the expectation that their family members would get well soon and that there would be no transmission from sick family members. This can be seen from the following statement:

> "Yes, I hope to my family recovery soon, and after that, we have to be more careful, right. Even more, especially if we have been infected before, it will be easy to get infected again So you have to follow the health protocol, right?" (P05)

> "Hopefully she will recover soon, be negative soon and don't let anyone get infected from my mother. Even then, I really hope that she will recover, lest there are other persistent symptoms" (P10)

https://doi.org/<u>10.33755/jkk</u>



Assistance from the government

The second sub-theme, namely the existence of government assistance, was formed from the category of providing online consultation media. material assistance and the availability of posthospitalized isolation rooms. Participants expressed their hopes that the government would facilitate some of these needs, this can be seen from the following participant statements:

> "At least it is the media that can be a place for us to consult, Sis. It takes time, it feels like there is a trusted media that we can consult with professionals like that, to doctors or nurses who really understand about selfisolation. So if we just have to look and search on the internet, we will be confused" (P07)

> "Hopefully there will also be assistance from the government. What we really need is... If we people don't have enough money, while we need suplement and vitamin but we don't have it, surely our immunity being worse even more. Moreover, if the infected with covid is the husband who earns his daily living, so the finances are really collapsing" (P03)

> "...Hopefully, this is the government's program, after dav the 7th of being hospitalized and the symptoms have started to decrease and are stable, the patient will be sent home, so that's what it means when the patient is still positive and the condition must be sent home, it means that it will put at home at make a risk for other family member. There

Jurnal Keperawatan Komprehensif Vol. 8 No. 4 October 2022



should be one more tiered room provided" (P12)

Attention from the surrounding community

The third sub-theme is the attention of the surrounding community, namely the community does not isolate and provide energy assistance to sick families. This is illustrated by the following statements by the participants.

> "Hopefully this community will understand what they want. Then don't be swayed by hoax information. If there are people who get Covid, don't want this neighbor to continue to isolate them, it's a pity for people who have Covid, I feel that times are really difficult there" (P14)

"If what I need is someone else's help. Because on the one hand I have to take care of my child, on the other hand I have to take care of my wife who is sick too." (P08)

DISCUSSION

Response and Emotional Impact

All participants had the right response in making the decision to take care a sick family member to go health facility to find out the diagnosis of a family member's illness. There are differences in the level of use of health facilities in this study and these results are not due to differences in socioeconomic factors and social factors of each family. This is due to the homogeneity of the data, namely all participants who have college education and 90% of participants who are in the productive age, namely 15-64 years old.

Access to health facilities is a factor that causes differences in the level of use of health care facilities in this study. One of the participants even revealed that to confirm the diagnosis of their sick family, the participant was willing to repeat the results of the examination, from the rapid antibody



https://doi.org/10.33755/jkk



examination to the PCR swab. The participant also revealed that he and his sick family went to Medan City which is 287 Km from their place of residence in Labuhan Batu with the aim of confirming the family's diagnosis and getting a PCR swab examination because the facility was not vet available in the area.

Educational background is an important factor in assessing the ability of families to find and determine the health facilities used. Research on factors influencing health seeking behavior in Yemen found that family caregivers with secondary school education were six times more likely to seek medical care than caregivers with no education. This implies that the higher a person's education level, the better their health seeking behavior (10). In line with research on health information seeking behavior, it was found that caregivers with low education tend to be less confident in seeking health information and using health facilities (11)

The next sub-theme is the negative emotional response to knowing that a family member has been confirmed to have COVID-19. Family caregivers express feelings of sadness, worry, anxiety, fear, anger and the like are referred to as negative emotional responses (12). Mirzaei et al stated that this psychological response will affect changes in a person's vital signs such as an increase in cardiovascular flow, blood pressure and heart rate. And these psychological response describe the family caregiver burden during care the patient. This is in line with the statements of several participants who said that they felt so shocked that they were shocked and cried when they heard the news that their family members had confirmed COVID-19. Research on the impact of determining the status of the COVID-19 epidemic on the psychological condition of people in China shows that the majority of people give negative emotional responses such as anxiety, depression, worry, anger and irritation after it was announced that an epidemic had occurred in China (13).

Jurnal Keperawatan Komprehensif Vol. 8 No. 4 October 2022



448

In addition to the emotional response of sadness and fear, the majority of participants expressed an emotional response of disbelief or rejection of the fact that their family members had contracted COVID-19. The rejection expressed by participants also occurred in the early phase of the spread of the Corona Virus from Wuhan, which was threatening life in the Western world. Denial is defined as a form of denial of reality that can be caused by external and internal factors of the individual (14). Participants revealed that they had rejected the fact that their family members had been confirmed for COVID-19 because they felt they had implemented health protocols in their daily lives. However, some participants directly confirmed that the health protocols can only be applied when their family members are at home, the participants themselves are not able to ensure that their family members will continue to apply the health protocols when interacting outside the home such as at the office or outside the home.

As many as 12 of the 14 participants stated that the most likely their family was infected with COVID-19 due to close contact with their family members' co-workers at the office. The office, as an individual workplace with a closed room without ventilation, can have the impact of increasing the transmission of the Corona Virus through the air that is getting easier. This is evidenced from a case report of massive transmission occurring in a room when 25 people suspected of having been infected with the Corona Virus interacted directly for 2.5 hours. This interaction then resulted in 53 out of 61 people contracting COVID-19 on the same day (15).

Another sub-theme expressed by the participants was the emotional response during care for their sick family. Participants expressed various responses when caring for their families, namely emotional responses such as sadness, fear, trying to be sincere and preparing mentally; then the physiological response is feeling





tired; and a change in behavior. The majority of participants expressed a negative emotional response that was almost the same as the initial response to knowing the family had confirmed COVID-19, namely feeling sad and afraid.

One of the participants expressed feelings of sadness caused by feeling that they had to fend for themselves while caring for their husband and child who were confirmed to have COVID-19. This 54-vear-old participant has to take care of her husband and children without any direct help from her family and is shunned by her neighbors. A study on the family as a caregiver shows that families who feel a burden that must be borne alone and feel lonely are at risk of experiencing depression (16). In fact, as many as 60% of the 1349 respondents as family caregivers who were confirmed to have COVID-19 have shown symptoms of depression in the caregiver. Unfortunately, caregivers who have shown symptoms of depression do not have access to any support either online or face-to-face to deal with depression symptoms that have been experienced by the caregiver. Furthermore, (16) state that it is important to facilitate the prevention and treatment of depression in families as caregivers during a pandemic.

Many participants also expressed their fear of having to take care of their family members who were confirmed to have COVID-19. The majority of participants expressed their fear of contracting the Corona Virus from family members who were sick both to themselves and to other family members who were at home. The fear of infection felt by families as caregivers was also justified in a study of the fear felt by individuals and families during COVID-19 in Italy. Cori (17) stated that > 60% of the 207,341 respondents reported a sense of fear of transmitting COVID-19 to their family members. One of these fears is influenced by gender factors. Women are considered more worried and afraid of the transmission of COVID-19 disease than men (18). Other studies have

also revealed that women have higher levels of stress, anxiety and insomnia than men (19)). This is in line with one of the statements of the female participant who stated that she was really afraid of getting infected so she really kept her distance, while one of the male participants revealed that he was in very close contact, touching to provide massage assistance to his wife who was confirmed to be COVID-19

The sub-theme of the physiological response felt by the participants was the feeling of fatigue while providing care to sick families. Participants revealed the reason for feeling tired because they had to make various efforts to restore the condition of their sick family and continue to carry out health protocols at home. Not only that, some participants also revealed that they felt stressed when their family members experienced worsening conditions during self-isolation. Fatigue caused by physical and psychological fatigue will trigger the occurrence of excessive fatigue or compassion fatigue. Compassion fatigue is a condition in which a person feels very tired due to the demands of physical activity and psychological pressure because he feels very deep empathy for the conditions of other people that can happen to health workers. Lynch and Lobo (20) explained in their research that compassion fatigue does not only occur in health workers, but also occurs in families as caregivers.

Compassion fatigue occurs in families as caregivers who provide daily care for sick family members and simultaneously the caregiver is exposed to the patient's pain to produce deep psychological responses such as stress and physical fatigue (20). Another qualitative study explains that caregivers in the family express a feeling of wanting to always be present, supervise the care provided, ensure the care needs of their sick family to feel empathy for their family's condition (21). This condition of compassion fatigue can also affect changes in the behavior of a caregiver. This is in line



with the feelings of the participants in this study who stated that they were very worried about the care given to their sick husband. The worry he experienced made him become more silent until he felt depressed. Physical fatigue conditions coupled with psychological stress can trigger compassion fatigue which can lead to a loss of desire for activities, loss of enthusiasm and pleasure (20,22)

Family caregivers not only express their emotional and physiological responses, but also social responses. The family caregiver stated that she was forced to take time off work and refused a job that had been previously planned because she had to take care of her sick family. A person who plays a role as a caregiver also has an impact on a person's work and economic conditions. Keating (23) stated that the economic effect on family caregivers can affect the individual, family, and social relationships. The economic impact can be in the form of job loss, decreased income, reduced social interaction for family caregivers, and increased family expenses (23,24). This impact usually occurs in the condition of family caregivers who have to take care of their family members with chronic diseases and need treatment for a long time. In this study, there were no participants who revealed that they lost their jobs due to taking care of their family members, only that they had to postpone and refuse participatory jobs.

Expectations of Family Caregiver

The theme of caregiver expectations is formed based on participants' answers about the expectations they feel while caring for their sick family. The expectations expressed are grouped into 3 sub-themes, namely expectations for sick families, for the government, and for the surrounding community. A person who is in a state of pressure and stress will hope to immediately end the discomfort that is felt due to the stress. Likewise, the expectations expressed by caregivers for their families so that they can recover quickly and end the

Jurnal Keperawatan Komprehensif Vol. 8 No. 4 October 2022



450

isolation period. Isolation conditions will have an impact on feelings of worry, fear, and even psychological disturbances for COVID-19 patients and families who are in close contact with COVID-19 patients (25). The discomfort that is formed will encourage the hope to immediately end the stressful situation that is felt. Hope for healing in sick families is included in the hope that can be achieved by caregivers.

In addition to the hope of healing for sick families, caregivers also hope for health services via telephone or tele-health and the like. A study with a randomized controlled trial design was proven to provide benefits and convenience for families to reach health information and assistance through long distance health services such as telehomecare. The study used nurses as patient health monitors through tele-homecare which was carried out on 200 patients in Taiwan after hospitalization. A total of 100 people were grouped as a sample scheduled for home visits after hospitalization and another 100 people as a control group. The result is a decrease in the number of visits to the emergency department in patients who follow the tele-homecare program compared to the control group, and an increase in the quality of life of patients who use tele-homecare (26).

Nurses become leaders who monitor patients for 24 hours giving a good influence on patient activities and improving their quality of life, through this study it can be seen that the independent role and function of nurses can strengthen the care of patients with chronic diseases.

Not only to sick families and the government, participants also expressed hope for the surrounding community to be able to understand the condition of the family confirmed by COVID-19 and not to stigmatize the family. Another case of stigma is found in the citv of Padangsidimpuan. National media reported that residents burned the corpse of COVID-19 patients in May 2021 at the Imam Bonjol TPU, Padangsidimpuan (Siagian, 2021).





Residents do not accept if there are corpse of COVID-19 patients buried in public cemetery areas not far from local residents' settlements. As a result, people living around the area were angry and took action to burn the tomb. The news of the incident has then been spread in various media and is known by many people of North Sumatra. One of them is in a family who lives in the Tapanuli Tengah area. Researchers received information that since the tomb burning incident, many families are afraid of being diagnosed with COVID-19 and are afraid to get treatment at the hospital. Based on the report of a nurse (15 June 2021) who lives in South Tapanuli Regency that many people cover up the condition of their sick family members and try to take care of their sick family at home for fear of being ostracized and discriminated against by their neighbors. Even the nurse also stated that there were many incidents of residents who died suddenly with symptoms similar typhoid fever without to а swab examination but there was a significant decrease in saturation when treated by their families at home. This happens due to the fear felt by the family if using health facilities such as hospitals and health centers it will be discriminated against by local residents. As a result, many families try to care for their own family members without using health facilities for fear of being discriminated against and stigmatized by society. This statement of hope was expressed by participants who were stigmatized by their environment and hoped that this would not happen again. One of the causes of the high stigma of COVID-19 in the community is the high level of transmission so that people discriminate sufferers against and even their surrounding families (27).

CONCLUSION

Through this qualitative study, we can see the emotional picture and expectations of family caregivers while providing Covid-19 care at home. The years 2020-2021 will be a quite scary pandemic period due to the high Jurnal Keperawatan Komprehensif Vol. 8 No. 4 October 2022



number of Covid-19 cases in Indonesia, the large number of fatalities and the uneven vaccination process. This is what causes the family caregiver to express an emotional response that tends to be negative as well as the emotional impact on the family while providing care. caregiver The condition of the health facility, which at that time was collapsing, caused the family caregiver to do a major role in caring for Covid-19 patients at home, the family caregiver being the closest person and the person most at risk of being infected. There were 2 out of 14 participants who became infected while providing care to their family members. The family caregiver also expressed a deep sense of exhaustion because the pressure was not only physical fatigue, but also psychological pressure when seeing the health condition of the sick family decline.

With these various conditions, family caregivers express their hopes while providing care. Family caregivers really hope for government support in the form of medical and financial assistance because of the increased need during the isolation period and delayed sources of income due to being unable to work temporarily. Another hope is the attention of the local community and the absence of stigma around it. In 2020-2021, the Covid-19 stigma in the community is still quite high, causing family caregivers to often cover up the actual situation for fear of being stigmatized by the community.

The Covid-19 pandemic not only has a negative impact, but there are also positive things, one of which is the development of technology and communication in the health sector. The high number of Covid-19 cases has finally prompted the government to create a mass telehealth system that can be accessed by the entire community to get help from health workers. This study can be used as a basis for nurse decisions to pay attention to the condition of family caregivers, especially caregivers on infectious diseases.

🔮 ł





452

REFERENCES

- 1. Coronavirus WHO. Dashboard | WHO coronavirus (COVID-19) dashboard with vaccination data. 2021.
- 2. Prevention C for DC and. Symptoms of coronavirus. 2020.
- 3. Tang WK, Yip WC, Lum CM, Xiang YT, Lee E, Ungvari GS. Caregiving burden and quality of life of pneumoconiosis caregivers in Hong Kong. Heart & Lung. 2011;40(5):412–9.
- 4. of Pittsburgh U. EFFECTS OF COVID-19 ON FAMILY CAREGIVERS. 2020.
- 5. Ruiz-Frutos C, Ortega-Moreno M, Allande-Cussó R, Domínguez-Salas S, Dias A, Gómez-Salgado J. Healthrelated factors of psychological distress during the COVID-19 pandemic among non-health workers in Spain. Saf Sci. 2021;133:104996.
- 6. Wang C, Pan R, Wan X, Tan Y, Xu L, Ho CS, et al. Immediate psychological responses and associated factors during the initial stage of the 2019 coronavirus disease (COVID-19) epidemic among the general population in China. Int J Environ Res Public Health. 2020;17(5):1729.
- Bassi MA, Lopez MA, Confalone L, Gaudio RM, Lombardo L, Lauritano D. Enhanced Reader. Nature. 2020;388:539–47.
- 8. Rahimi T, Dastyar N, Rafati F. Experiences of family caregivers of patients with COVID-19. BMC Fam Pract. 2021;22(1):1–10.
- 9. Morrow R, Rodriguez A, King N. Colaizzi's descriptive phenomenological method. Psychologist. 2015;28(8):643–4.
- Webair HH, Bin-Gouth A. Factors affecting health seeking behavior for common childhood illnesses in Yemen. Patient Prefer Adherence. 2013; 7: 1129.
- 11. Bangerter LR, Griffin J, Harden K, Rutten LJ. Health information– seeking behaviors of family

caregivers: analysis of the health information national trends survey. JMIR Aging. 2019;2(1):e11237.

- 12. Mirzaei A, Raesi R, Saghari S, Raei M. Evaluation of family caregiver burden among COVID-19 patients. Open Public Health J. 2020;13(1).
- Li S, Wang Y, Xue J, Zhao N, Zhu T. The impact of COVID-19 epidemic declaration on psychological consequences: a study on active Weibo users. Int J Environ Res Public Health. 2020;17(6):2032.
- Walker G, McCabe T. Psychological defence mechanisms during the COVID-19 pandemic: A case series. Eur J Psychiatry. 2021;35(1):41–5.
- 15. Bazant MZ, Bush JWM. A guideline to limit indoor airborne transmission of COVID-19. Proceedings of the National Academv of Sciences [Internet]. 2021 Apr 27;118(17):e2018995118. Available from: https://doi.org/10.1073/pnas.20189 95118
- 16. Gallagher S, Wetherell MA. Risk of depression in family caregivers: unintended consequence of COVID-19. BJPsych Open. 2020;6(6).
- 17. Cori L, Curzio O, Adorni F, Prinelli F, Noale M, Trevisan C, et al. Fear of COVID-19 for individuals and family members: Indications from the national cross-sectional study of the epicovid19 web-based survey. Int J Environ Res Public Health. 2021;18(6):3248.
- Broche-Pérez Y, Fernández-Fleites Z, Jiménez-Puig E, Fernández-Castillo E, Rodríguez-Martin BC. Gender and fear of COVID-19 in a Cuban population sample. Int J Ment Health Addict. 2020;1–9.
- Jacques-Aviñó C, López-Jiménez T, Medina-Perucha L, de Bont J, Gonçalves AQ, Duarte-Salles T, et al. Gender-based approach on the social impact and mental health in Spain

┙ https://doi.org/<u>10.33755/jkk</u>



during COVID-19 lockdown: a crosssectional study. BMJ Open. 2020;10(11):e044617.

- 20. Lynch SH, Lobo ML. Compassion fatigue in family caregivers: a Wilsonian concept analysis. J Adv Nurs. 2012;68(9):2125–34.
- Beth Perry RN, Margaret Edwards RN. A Qualitative Study of Compassion Fatigue among Famly Caregivers in Long-Term Care Homes. Perspectives (Montclair). 2015;38(3):14.
- 22. Marie Blair RN BN, Beth Perry RN. Family caregiving and compassion fatigue: A literature review. Perspectives (Montclair). 2017;39(2):14.
- 23. Keating NC, Fast JE, Lero DS, Lucas SJ, Eales J. A taxonomy of the economic costs of family care to adults. The



453

Journal of the Economics of Ageing. 2014;3:11–20.

- 24. Feinberg L, Choula R. Understanding the impact of family caregiving on work. AARP Public Policy Institute; 2012.
- 25. Szkody E, Stearns M, Stanhope L, McKinney C. Stress-buffering role of social support during COVID-19. Fam Process. 2021;60(3):1002–15.
- Liang HY, Hann Lin L, Yu Chang C, Mei 26. Wu F, Yu S. Effectiveness of a nursetele-homecare program led for patients with multiple chronic illnesses and a high risk for readmission: randomized а controlled trial. Journal of Nursing Scholarship. 2021;53(2):161-70.
- Abdelhafiz AS, Alorabi M. Social stigma: the hidden threat of COVID-19. Front Public Health. 2020;8:429.



