

# The Experiences of The Patients' Relatives During COVID-19 Intensive Care Process: A Qualitative Study

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## Abstract

This study is a qualitative study carried out to determine the experiences and opinions of the relatives of patients treated in intensive care with the diagnosis of COVID-19 during the pandemic process. A qualitative study using inductive content analysis. The relatives of 14 patients testing COVID-19 positive and treated in the intensive care unit were included in the study. The data were collected through online interviews with patient relatives. After the interviews, the data were recorded and analyzed using Colaizzi's phenomenological method. After completing the interviews with the relatives, 4 main themes and sub-themes were determined. Relatives of the patients expressed the importance of the patient in the intensive care unit in their lives as "congenital companion", "family elders", and "My mom!".

In our study, it was determined that the relatives of the patients experienced fear, uncertainty, and personal, pandemic-related anxiety due to the process since their patients were in the intensive care unit. In the study, the doctors of the patients who were treated with the diagnosis of COVID-19 in the general intensive care unit were interviewed and their phone numbers were obtained in order to talk to the relatives of the patients.

## Keywords

COVID-19, intensive care units, nursing, patients, relatives

## INTRODUCTION

After the World Health Organization (WHO) defined COVID-19 as a pandemic, most of the world's countries have begun to take drastic measures for the first time in more than a century to protect their population and health systems [1], [2], [3]. Since it is a serious public health concern, the decision to implement quarantine measures has been made, which has brought about economic challenges as well. The increasing occupancy and morbidity/mortality rates in all units of hospitals have led to a global health crisis ([4], [5], [6]).

Due to the increase in the number of patients treated in Intensive Care Units (ICUs) with the diagnosis of COVID-19, elective surgeries have been postponed and most of the normal clinics have started to provide ICU [18],[15]. Normal procedures in hospitals were suspended, relatives of patients were not allowed to see their patients due to isolation measures, and the main focus was set entirely on the fight against the pandemic ([7], [8]).

During the COVID-19 pandemic, these relatives were deprived of the chance to visit their patients in ICUs because of mandatory isolation rules, and the necessary information was, therefore, provided through technological tools [9]. Due to this chaos created by the unprecedented COVID-19 pandemic, it is of big importance to listen and understand how the relatives of the patients feel, what they are experiencing

and what kind of thoughts they bear in order to evaluate and spend the process in a healthier way. Protecting the biopsychosocial holistic health of not only patients but the relatives during the health and disease process is also of big significance in terms of providing quality health care [5], [10], [11]. It is necessary to contact the relatives of patients regularly to inform them about their patients, especially when making important care decisions so that the processes can run and go forward smoothly [10], [11]. The aim of this study is to understand the subjective experiences of the relatives of patients treated in the ICU with the diagnosis of COVID-19 during the pandemic process, and to determine their feelings and thoughts about the process, using semi-structured interviews.

## MATERIALS AND METHODS

**Design:** A qualitative study using inductive content analysis.

**Participants and Setting:** The study was conducted in the adult ICU of a private hospital in İzmir. The adult intensive care unit has a capacity of 6 beds. Relatives of patients (n: 14) who tested positive for COVID-19 in April-May 2021 and were therefore treated in the intensive care unit were included. Relatives of patients with COVID-19 negative who were treated in the intensive care unit were excluded.

**Data collection:** Due to isolation and control measures, interviews were conducted online. Prior to the interview, the

patient's relatives were contacted by phone and informed about the study, and the interviews were held online by making an appointment with the patient's relatives after their consent was taken. An interview lasted between 15-20 minutes on average. To increase reliability and consistency, interviews were conducted by a researcher.

**Interview outline:** Literature and expert opinions were used in the formation of interview questions. Basic interview questions were as follows: (1) "Can you tell us about your feelings and thoughts after your relative was hospitalized?" (2) "What would you like to say about the place and importance of your relative hospitalized due to COVID-19 in your life?" (3) "Could you tell what your thoughts and feelings are about your relative's current state of health?" (4) "How can you communicate with your relatives while he/she is in ICU?" (5) "How has your relative's hospitalization in the ICU made a difference in your thoughts about the COVID-19 infection?"

**Data analysis:** The data were transcribed after the interview and analyzed using phenomenological method. Phenomenological method focuses on participants' experiences and emotions which seeks common patterns rather than individual characteristics in research topics [12]. The two researchers independently coded, summarized and developed the interview materials to create themes. The inconsistencies were discussed by the research team and resolved by consensus [13].

**Ethical considerations:** Redacted

## RESULTS

### Study population

Most of the relatives of the patients interviewed are made up of males (male: 6, female: 8), university graduates, with a mean age of 43.71 (min: 26-max: 72).

### Themes

Following the interviews with the relatives of the patients, 4 themes were determined which are (1) the feelings experienced while the relative was in the ICU, (2) the feelings and thoughts about the health status of the relative, (3) the protection measures taken during the COVID-19 process and the personal ones while the relative was in the ICU, (4) the opinions about COVID-19 infection after their patient started to receive treatment in the ICU (Table 1).

**Table 1.** Themes Identified in Interviews with COVID-19 Relatives of Patients

Themes	Sub- Themes
<b>1. Feelings experienced when a relative is in intensive care</b>	1.1. Fear/anxiety 1.2. Anger/anger 1.3. Helplessness/ uncertainty
<b>2. Feelings and thoughts about the health status of the relative</b>	2.1. Fear/anxiety 2.1. Helplessness/ uncertainty 2.3. Sadness/ despair

<b>3. Protection measures are taken during the COVID-19 process and while their patient is in intensive care</b>	3.1. Mask/ distance/ visor 3.2. Not seeing friends/relatives/not going out 3.3. Use of disinfectant/frequent change of clothes 3.4. Not using public transport / not being in crowded environments
<b>4. Their opinions on COVID-19 infection after his relative started receiving treatment in the intensive care unit</b>	4.1. Taking the disease more seriously/considering it important 4.2. Resentment/anger at people who do not follow the measures 4.3. Paying more attention to preventive measures

### 1. Main Theme: The feelings experienced when a relative is in intensive care

#### Sub-theme

1.1. Fear/Anxiety: Most of the patients' relatives stated that they experienced fear and anxiety. R2: "At first, there was fear and that fear persists inside me. I feel fear and anxiety and intense sorrow. I have the fear of losing my patient, and the course of the disease is very severe. I'm worried about him". R5: "Our father was very scared, after all, he and my mother have been sharing the same bed for years".

1.2. Resentment/Anger: Some of the relatives of the patients feel anger and resentment against people who do not care about precautions because they have contracted the disease despite taking their own precautions. R3: "People especially the old people go out tactlessly, I don't know why they don't want to understand, they do understand only when they have someone infected with the disease in their family". R7: "When I look out the window, people my age are all wandering outside! Corona somehow does not find them; I don't understand why this has just found us".

1.3. Helplessness/Uncertainty: Relatives of the patients stated that they experienced a sense of uncertainty because they did not know how this process would end and what would happen, and they experienced a sense of helplessness as they could not do anything for their relatives. R5: "I don't know what to do. The children are all devastated, they want to see their grandmother, but we can't show her to them". R7: "I just want to see her recover! Not being able to get any news about her, not being able to go to the hospital are so difficult that... they already don't let me out, either".

### 2. Main Theme: Feelings and thoughts about the health status of the relative

The feelings and thoughts of the relatives of the patients during the treatment in the ICU and their feelings and thoughts about the health status of the relative were similar. In this respect, it was determined that they went through a period in which fear and anxiety prevailed, while feelings of

uncertainty and hopelessness were also experienced.

#### *Sub-theme*

2.1. Fear/ Concern: R1: "I am so afraid and very sad, we are faced with a disease that has turned the world upside down, and the fear of whether something will happen to us makes me very worried". R2: "What lies on the basis of anxiety and fear is these feelings", "I perceive the disease better as my relative is in this condition now, which has very destructive effects and this is what makes me feel afraid". R9: "Of course we are afraid, our fears are greater because of our advanced age, especially we are all very afraid of bringing this disease home with us".

2.2. Helplessness/ Uncertainty: R3: "We feel all devastated as the children go to the hospital and talk about it. It feels like time is not running out". R5: "We are waiting in great unease. We are praying, that's all we can do now. We are waiting in front of the hospital door". R14: "I don't have hope, but of course, it is never clear what will happen in the end, we are just waiting, there is nothing we can do, frankly, we can't even go to visit our patient".

2.3. Sadness/ Despair: R7: "I feel very sad, I don't know if the world is coming to an end, nor do I know what's going on". R14: "I am not very hopeful, he has been dealing with very serious health problems aside from COVID-19 for a long time, he has a previous history of cancer, he is a cancer survivor, we would not want this to happen to him, but we have to look after his well-being as he suffers so much".

### **3. Main Theme: Protection measures are taken during the COVID-19 process and while their patient is in intensive care**

Relatives of the patients stated that they the mask and social distancing rules as protection measures during the COVID-19 process and that they did not speak to their loved ones in person except for phone calls. Besides, they also reported that they did not accept anyone in their home as visitors, but they kept going to work because they had to work, stating that they used public transportation because they had too again.

#### *Sub-theme*

3.1. Mask/ Distance/ Visor: Almost all the patients' relatives stated that they paid attention to mask and social distancing rules. There are also relatives of patients who stated that they rarely used visors or glasses. R1: "I pay attention to mask use and hygiene. I pay more attention to social distancing rules. I didn't care about the mask before, but now I never take it off". R8: "We go to work, we put on our gloves, we wear double masks, and we try to wear protective glasses as well".

3.2. Not meeting with friends/relatives/not going out: All the relatives of the patients stated that they did not visit their relatives and friends during the pandemic, also they did not accept anyone into their homes, and they did not go out unless they had to. R9: "We do not see anyone, we do not pay any visits to people's homes, we stay away from people, we have

entirely postponed any of our visits to friends and family. I only talk on the phone, on Facebook and Twitter, we don't have any of the meetings and home visits as we used to have".

3.3. Use of disinfectant / Changing clothes frequently: Many relatives of patients were seen to be using disinfectants. Some relatives also stated that they changed their clothes immediately when they came home from outside. R2: "I take off my clothes and wash my hands soon after I come from outside". R3: "The amount of bleach we buy has increased, the children now say that our mother's hands are worn out, and we also buy softening cream. The amount of cologne we buy has increased, as well".

3.4. Not using public transportation/not being in crowded environments: R8: "We never join the crowd in such environments, we only try to go to secluded places". R9: "I do not use public transport". R11: "I try not to use public transport. I prefer to walk instead".

### **4. Main Theme: Their opinions on COVID-19 infection after his relative started receiving treatment in the ICU**

Relatives of the patients stated that their relative situation changed their perspective towards the pandemic process, thus making them pay more attention to protection measures. Just watching the ongoing events from the outside and going through them in person was so different for them, and they now have started to feel more panic.

#### *Sub-theme*

4.1. Caring about the disease/ taking it more seriously: Almost all of the relatives stated that they were not taking the disease very seriously until their relatives came down with it and were taken to the ICU, but they realized how serious the disease was after it happened to their own family, and they started to pay more attention to it. R3: "Those ignoring the disease, pulling the mask low on the nose outside, putting the mask just on the ear, or just wearing it on the wrist may even tend to scold us when you attempt to warn them about all these as they sit next to you on the bus. One must have a bit of conscience!".

4.2. Anger/rage at people who do not comply with the protection measures: The relatives stated that the pandemic has increased to this great extent just because of people not taking the disease seriously and that they feel pissed and anger towards those who do not take protective measures. R2: "It is a disease that pushes people away from each other more as they insist on not maintaining the distancing measures". R3: "I saw people ignoring, pulling the mask low on the nose even outside, just putting the mask on the ear, wearing it on the wrist, and what's more, they tend to scold me when I mention the risks as they sit next to me on the bus. One must have a bit of conscience".

4.3. Paying more attention to protection measures: R5: "We take our precautions, wash our hands, wear masks, all our children have masks, we do whatever is necessary, we have nothing else to do but comply. We go everywhere by car; we do not take taxis or public buses". R6: "Since this

pandemic broke out, we have isolated ourselves more as I am a healthcare professional, we are twice as careful because we already knew the hospital processes long before all bans were declared on media, so we can isolate ourselves voluntarily without feeling upset. We did not go out at all for 2 months, we paid attention to the distancing measures, we did not go to public places, we paid attention to hand washing, and we never went out”.

## DISCUSSION

In our study, we aimed to evaluate the feelings and thoughts of the relatives of the patients treated in the ICU due to COVID-19 as well as their views and thoughts about the pandemic process, the individual measures taken by them, and the process management, by using the phenomenological method.

In our study, the relatives of the patients stated that they experienced fear, anxiety, uncertainty, hopelessness, anxiety, and anxiety due to the pandemic process and the health status of their patients in the ICU. They also stated that they felt sorry and guilty and could not accept the situation because of not being able to go to the hospital to visit their patients in the quarantine process the most frequently reported emotion expressed by patients and their relatives during the pandemic process was uncertainty-related anxiety. 73.3% of the relatives expressed their concerns about their family members treated in the hospital, while 25% of them stated that they were worried about their patient's mental health as well as their physical well-being [14]. Since family ties are very tight in Turkish culture, it has been determined that the relatives experience intense fear of losing their relatives and anxiety because of not being able to see their patients. The relatives who must work during the pandemic process due to economic concerns, especially those with an elderly chronically ill family member at home, stated that they were afraid of transmitting the disease to their family relatives. It has been stated that the support to be provided by family and relatives is quite important for patients with infectious diseases, which significantly affects the compliance of patients and their relatives to the process [15]. When we look at the family structure of our society, there are many people living in the extended family aside from the nuclear family. In addition, in our society, the elderly generally lives with their children and grandchildren. Living together with family members enables strong family and kinship ties, that's why the hospitalization of one of the family members or relatives in the ICU during the pandemic affects the proximities more emotionally. The relatives also stated that they experienced the fear of losing their beloved ones more intensely. It is seen in the literature that the fear of losing the patient comes first. The pandemic-related high mortality rates and the gradual increase in the number of people afflicted with the virus in each new variant have caused an increased fear of death and anxiety in terms of both the patient and their relatives, which is thought to be related to the course of the disease. It is also supported by other studies that the most eminent and outstanding emotion

felt by those individuals is fear regardless of the age group or the reason for the intensive care hospitalization[16].

Other coping factors such as religion, a positive approach to life, a creative approach (eg listening to music, reading), and social media use have also been reported by patients and relatives (Dorman-Ilan et al., 2020). In our study, the relatives of the patients stated that they were constantly praying for the end of the pandemic and for their patients to recover as soon as possible. In our culture, one of the coping methods mostly resorted to in case of illness is constantly praying and reading the Qur'an.

Since the beginning of the pandemic, a number of recommendations have been made by health institutions, which address the measures such as keeping social distance, mask and visor use as well as hand hygiene. Washing hands with soap or alcohol-based disinfectants as a preventative measure has been strongly recommended since the beginning of the pandemic process [17]. In our country, the measures to be taken to prevent the spread of COVID-19 have been constantly explained by the administrators, and it has been observed that the majority of people still do not pay enough attention to these measures, not complying with the quarantine process despite the sanctions imposed, and continue to keep in touch with their relatives and friends despite the campaigns to the contrary.

Amid the turmoil of an unprecedented pandemic, patients and their families are constantly seeking reliable information and guidance. The reason for this is that the internet and media often convey inconsistent messages, and there is rapidly changing information. For this reason, patients and their families need information from reliable sources and from healthcare professionals who take the health status of their relatives and individual risk factors into account. Particularly when making important care decisions, it is important to communicate regularly with relatives to inform them of progress and to ensure their active involvement in the caregiving process [18].

## Study Limitations

Only relatives of the patients hospitalized in adult intensive care units of a private hospital due to COVID-19 were included in the study. By its very nature, qualitative research does not produce clear and generalizable results that are performed as phenomenological design, whereas it produces examples, explanations, and life experiences that help to better describe and understand a case. Therefore, the limitation of this study is that it cannot be generalized.

## CONCLUSION

In our study, it was determined that the relatives of the patients experienced intense feelings of anxiety, unease, anxiety, uncertainty, and hopelessness, and particularly, they experienced sadness and fear of losing their relatives as they could not see them during the pandemic.

**Relevance to clinical practice;** Since the relatives of the patients cannot see their patients during the pandemic

process, they get the necessary information about the most recent conditions of their patients treated in the hospital from health professionals, and they feel the need for their support. During the pandemic processes, the increasing number of cases makes it difficult to manage the process, and the psychology of the society may be adversely affected as the process gets longer and the protection measures are intensified. As a result, we recommend that approaches are taken to meet the psychological needs of the patient's relatives, especially in this process, to ensure that they meet with the patient in line with isolation measures, and to reduce their anxiety and fear levels.

**Patient or Public Contribution:** In the study, the doctors of the patients who were treated with the diagnosis of COVID-19 in the general intensive care unit were interviewed and their phone numbers were obtained in order to talk to the relatives of the patients. A phone call was made with the relatives of the patients and they were informed about the study, and an appointment was made for the interview from the relatives of the patients who agreed to participate in the study.

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