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The lived experiences of family members who visit their relatives in Covid-19 intensive care unit for the first time: A phenomenological study



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ABSTRACT

Background: COVID-19 patient experiences in the intensive care unit (ICU) are marked by family separation. Families understand the importance of isolation and hospital visiting policies, but they consider it necessary to visit their loved ones and use personal protective equipment.

Objective: To describe the lived experiences of family members in their first contact with a relative in a COVID-ICU.

Methods: A phenomenological study was conducted using Cohen's method. The subjects were interviewed using an open-question format to allow them full freedom of expression. Twelve family members were recruited between February and March 2021.

Results: Analysis of the qualitative data resulted in five major themes: (1) fear of contagion related to donning/doffing procedures, (2) positive emotions related to first contact with the hospitalized relative, (3) concern for the emotional state of the hospitalized relative, (4) impact of the COVID-ICU and comparisons between imagination and reality regarding the severity of the disease, and (5) recognition of and gratitude toward healthcare professionals.

Conclusions: It has been confirmed that visits to the ICU reduce anxiety among family members. Our findings constitute an internationally relevant contribution to understanding of the needs of relatives who meet loved ones for the first time while wearing personal protective equipment.

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Introduction

Globally, as of April 6, 2021, there had been 131,309,792 confirmed cases of coronavirus disease 2019 (COVID-19), including 2854,276 deaths worldwide and 46,085,310 confirmed cases in Europe. 1 Approximately 18% of patients experience mild or no symptoms and are managed with self-isolation at home,² while 14% develop severe symptoms; 5% become seriously ill and are hospitalized or require medical attention hospitalization in the intensive care unit (ICU).3

Abbreviations: COVID-19. Coronavirus Disease 2019: COVID-ICU, COVID-19 Intensive Care Unit; EOL, End of Life; FS-ICU, Family Satisfaction in Intensive Care Unit; ICU, Intensive Care Unit; NIV, Non-invasive Ventilation; PICS-F, Post-intensive Care Syndrome Family; PPE, Personal Protective Equipment; vICU, Virtual ICU; WHO, World Health Organization

Lack of preparedness among relatives visiting the ICU leads to unsatisfactory communication and difficulty in understanding the information provided by healthcare workers, which are necessary elements of informed health decisions.⁴ Delayed negative prognostic communication at end of life (EOL)⁵ and immense emotional distress, ⁶ such as post-traumatic stress disorder, ⁷ are also important factors. These elements can lead to the development of adverse psychological outcomes, including symptoms of depression and complicated pain.8 In 2010, the Society for Critical Care Medicine examined these issues and coined the term "post-intensive care family syndrome (PICS-F)" to better describe these symptoms among the family members of ICU patients.9

The experiences of patients hospitalized in the COVID-ICU are characterized by separation from family members and loneliness associated with EOL assistance (provided by unknown caregivers) and environments. 10 A phenomenological study on the relatives of COVID patients hospitalized in the ICU described how the lack of

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contact and information between leaving home and hospitalization in the ICU generated fear among family members.¹¹

In a study by Akgun et al., fear and suffering among family members of COVID-19 patients, resulting from isolation regulations designed to manage infection rates, led to devastating realities and communication challenges for patients and their families, who were kept physically apart.¹² A study in Michigan, USA¹³ analyzing several hospital realities showed how family remoteness may lead to problems during the COVID-19 pandemic, such as cancelation of the decision-making role, increased sedation of patients, limited access to technology, and barriers due to new communication styles. Moreover, family separation near the end of a patient's life was considered tragic, especially for members of some cultures and religions.¹⁴ At this stage of the pandemic, the role of the nurse is fundamental in providing family-centered care by implementing interventions to reduce the effects of separation.¹⁵

Family-centered care during the COVID-19 pandemic has three objectives: respect for the role of family members as care partners, collaboration between family members and the health team, and maintenance of family integrity (all implemented in compliance with precautionary physical distancing). The pandemic necessitates efforts to meet these goals and to adapt to a rapidly changing clinical environment.¹⁶

Many studies have evaluated the experience of relatives entering the ICU,¹⁷⁻¹⁹ but few have investigated families' access to COVID-ICU patients. Recently, methods to maintain relationships between families, patients, and COVID-ICU staff have been studied.¹⁶ One study examined relatives' direct access to a virtual ICU (vICU) from home via an internet portal, which enabled them to communicate with the ICU and see what was happening.²⁰ Recent studies on the relatives of patients with COVID-19 in the ICU have shown that communication by telephone or video was considered insufficient compared to inperson interactions²¹ and that relatives needed to stay close to their loved ones during the EOL period.²² In addition, the authors, in a phenomenological study,²³ analyzed the lived experiences of family members of ventilated COVID-19 patients in the ICU and the findings suggested that the restrictions on visits should be more flexible.

For these reasons, the aim of this study was to investigate the lived experiences of family members during their first visit to relatives confined to the COVID- ICU, and to describe the families' needs that emerged.

Methods

Design

This study was based on Cohen's method.²⁴ This method combines descriptive (Husserlian) and interpretive (Gadamerian) phenomenology. Phenomenology is a form of inductive qualitative research rooted in twentieth-century tradition.²⁵ As suggested by Husserl, the founder of this methodology, phenomenology suspends all suppositions, but it is related to consciousness and is based on the meaning of the individual's experience. In descriptive phenomenology, daily experiences are described, while preconceived opinions are set aside and bracketed.²⁵ Interpretative qualitative research is, in contrast, a qualitative approach that aims to provide detailed examinations of personal lived experiences. It is a particularly useful methodology for examining topics that are complex, ambiguous, and emotionally laden.²⁴ This method, used in a prior study,²⁶ was chosen because of its suitability in terms of gaining a deeper understanding of both lived experiences and the meanings attributed to such experiences by families.

Study setting and participants

Convenience sampling was used, with participants recruited at Sant'Andrea University Hospital in the north of Rome, Italy, between

Table 1 Eligibility for study participants.

Inc	noisiil	Criteria			

Each participant be 18 years old or older (under 70 years old);

Speak Italian:

Be a relative of a patient admitted to COVID-ICU;

Patient who remains alive in the ICU during the study;

Have a smartphone that allowed video calls to be made after visiting the COVID-ICU;

Test negative for COVID-19 on a SARS-COV-2 molecular test;

Carry a certification document confirming the negative test result on the day of admission to the COVID-ICU (the test was to be carried out no later than 48 h before the day of the admission);

Have undergone specific training by nursing staff on the donning and doffing procedures;

Participants signed the informed consent form and had to be aware of the contraindications (psychological, cardiological and pulmonary diseases) to the donning and doffing procedures

February and March 2021. The sample was drawn from a larger study that evaluated the satisfaction of family members with the training they received prior to entering the COVID-ICU.

Seventy-six participants were selected from the survey study and asked to participate in the phenomenological study. Initially, 13 participants agreed to participate, but one participant lost a family member after signing the consent form for the interview and was excluded according to the eligibility criteria. Before signing the consent form, the family members were informed of the purpose and nature of the study. Complete confidentiality was ensured at all stages of the study, and the collected data did not contain identifying information. All participants were given the opportunity to withdraw from the study at any time. The eligibility criteria are presented in Table 1.

Data collection

The first step entailed *bracketing* by all of the researchers. This approach reduces the probability of researcher bias influencing the extrapolation of the themes that emerged from the interviews. The interviews should be performed in the participants' natural environments. Indeed, as suggested by the phenomenological method, conducting interviews in the participants' natural environments makes it easier for them to describe their experiences. Due to isolation and pandemic prevention and control requirements, the interviews in the present study were conducted by video calls through mobile phones.

This study made use of voice over internet protocol technology. The Zoom app was used to interview family members; the app has been identified as the most useful in qualitative research.²⁷ The video interviews were conducted at appointed timeslots, typically in the afternoon when participants were at home and preferred to be alone, no later than 24 h after entering the COVID-ICU, in order to collect relatives' initial impressions and to avoid the later processing of their thoughts and feelings. Indeed, previously, relatives had not had the opportunity to visit their patients. All had previously seen their loved ones only by videocall, and, in the majority of cases, they suffered watching their patients during non-invasive ventilation (NIV) therapy, with their face contracted, exhausted by labored breathing and not being able to speak through a telephone. The video interviews were conducted by the two authors, neither of whom knew the COVID-19 patients nor the patients' family members.

To collect the demographic data, which were used to better understand the composition of the sample, the demographic data section of the Family Satisfaction-ICU (FS-ICU) was used.²⁸ For a more detailed view of the sample, data on the ICU patients were collected, such as the length of ICU stay, patient's state of consciousness

Table 2 Socio-demographic characteristics of relatives (n = 12).

ID	Gender	Age	Relationship	ICU experience		How often do you see your relative?	Where do you live?	Educational status	Length of ICU stay (days)	Ventilation and state of consciousness	Age of patients
A00	F	44	Sister	No	No	More than once a week	In city	High school	13	ETT/S	51
A01	F	41	Daughter	No	No	Once a week	In city	Degree	39	NIV/A	69
A02	F	43	Daughter	No	No	Once a week	In city	Degree	18	ETT/S	74
A03	M	45	Son	No	No	More than once a week	In city	High school	18	ETT/S	75
A04	F	48	Daughter	Yes	No	More than once a week	In city	Degree	11	ETT/S	79
A05	F	63	Partner	No	Yes		In city	Middle school	49	T/A	66
A06	F	28	Daughter	No	No	More than once a week	In city	Master's degree	49	ETT/S	53
A07	F	37	Daughter	No	No	More than once a week	In city	Some courses after high school	32	T/A	63
A08	M	38	Son	No	No	Once a week	Out of town	High school	15	ETT/S	61
A09		61	Wife	No	Yes		In city	High school	62	T/A	65
A10	F	46	Sister	No	No	More than once a week	Out of town	High school	13	NIV/A	49
A11	F	36	Daughter	Yes	No	Once a week	Out of town	High school	15	ETT/S	70

Note: M = male; F = female; ETT/S = endotracheal tube/sedated; T/A = tracheostomy/awake; NIV/A = non-invasive ventilation/awake.

(vigilant or sedated), and ventilation mode, i.e., invasive ventilation through endotracheal tube or tracheostomy or NIV.

The interview began with an open question: ²⁴ "Tell me about your experience after seeing your family member through the PPE [personal protective equipment]. How did you feel when you saw your relative in the COVID-ICU?" The interviewers maintained a cordial attitude²⁶ during the interviews in order to better facilitate conversation. As suggested by the phenomenological methodology, during the interviews, the interviewers wrote notes on the environment, the context of the interview, the body language of the participants, and their own reflections.

The interviewers transcribed these field notes in an investigator's journal. Finally, when the participants stopped describing their experiences, the interviewers asked if they had more to say. The data collection process ended when data saturation had been achieved – specifically, a redundancy of themes – and the 12 transcribed interviews were stored.

Each interview was audio-recorded and was between 30 and 50 min in duration. The interviews, data analysis, and verification of the results were conducted in Italian. After having prepared the scientific report, translation processes and back translation were performed according to the World Health Organization (WHO) methodology for the validation of instruments in cultures and languages different from the source language.²⁹

Data analysis

The interviews were transcribed verbatim. The researchers (DB and FT) immersed themselves in the data, carefully reinterpreting the interviews and field notes. After this phase, the researchers reread the transcripts, line by line, and gave tentative names to various passages in the texts.

To ensure credibility, the final structuring of the themes and subsequent content justifications were agreed upon by all members of the research team. This process, called "member checking," is fundamental in Cohen's phenomenology.²⁴ Indeed, themes should be verified with participants to ensure that the themes appropriately capture the meaning that participants sought to convey. Disagreements in interpretation should send the researcher back to the field text for clarification. No discrepancies were detected during these procedures.

To ensure dependability, the tentative extracted themes were then confirmed or corrected by each participant during a second virtual meeting with the researchers. During this meeting, the interviewers explained the tentative theme labels to each participant in order to confirm that the themes accurately captured their experiences. With the participants asked to confirm the accuracy of the interview excerpts, the validity of the results was guaranteed. The Lincoln

and Guba criteria for qualitative research were met, thereby ensuring the scientific rigor of this study.³⁰

Ethical approval

For this study, the IRB of the university hospital granted medical ethical approval, and the local hospital research protocol was provided with the following research number: 5773 of April 22, 2020.

Results

The study sample (Table 2) consisted of 12 relatives, 83% of whom were women. The degree of kinship of the sample consisted of six daughters, two sisters, two sons, a wife, and a partner, whose average age was 43.5 years. Two of the participants had previous experience in a general ICU as family members, but not in a COVID-ICU. The average level of education of the participants was medium-high. On average, patients were confined to the COVID-ICU for 27.83 days (SD = 17.714 days) before being transferred to a COVID sub-intensive area. Ten ICU patients were mechanically ventilated, and seven were sedated. From the analysis of the interviews, five themes emerged (Fig. 1).

Fear of contagion related to donning and doffing procedures

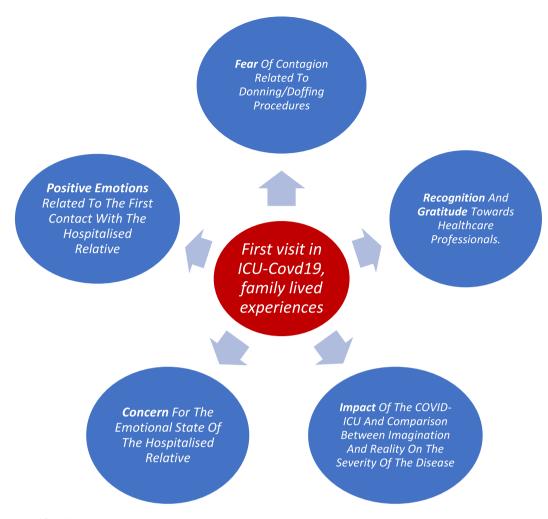
Many interviews were characterized by fear related to donning and doffing procedures using PPE. Some family members were afraid of feeling sick during their visit inside the COVID-ICU because the presence of PPE would not allow them to breathe properly; others were afraid of the contagion related to the doffing procedure once outside the COVID area.

A sister (A00) said, "[...] I have to be honest, I was very focused on my breath because I was afraid to faint. [...] The strangest feeling is that I felt like I was dressed up for two hours; instead, it was only 15 min! [...]"

A daughter (A01) expressed her fear of contagion during the doffing procedure: "[...] doffing procedure was more particular because I was afraid. While I was inside the COVID area I was not feeling afraid. In fact, I touched his [her father's] hand, I gave him a caress, but then outside I was not sure about the procedure, to have understood well, to remember it well. There was always a person who followed me [...] the fear of getting infected, even accidentally, to touch yourself when you don't have to. That gave me a little anxiety [...]."

Positive emotions related to first contact with the hospitalized relative

Many interviews were characterized by enthusiastic descriptions of the first meeting with loved ones, who turned out to be alert and contactable and to be subjected to non-invasive mechanical



 $\textbf{Fig. 1.} \ \ \textbf{Five themes emerged from the interviews.}$

Themes that emerged from family members in the first visit to COVID-ICU:

- 1. Fear Of Contagion
- 2. Positive Emotions
- 3. Gratitude Towards Healthcare Workers
- 4. The Impact Of Covid-ICU
- 5.Concern About What Your Hospitalized Relative May See.

ventilation. A sister (A10) expressed joy related to her memory of the first contact: "[...] It was really a beautiful thing, also because you do not imagine that it is possible. So, when they [healthcare personnel] told me about that the first time, I didn't think it was an experience that I could do, but I am grateful because you made me do it, it was nice [...]." A daughter (A07) reported: "[...] I think both Mom and I had a vital need for this contact. Mom told me that she was so happy that I was there, that she really needed this contact [...]." Another daughter (A06) described the experience as follows: "[...] I faced the situation with positivity, also because I was happy to see my father but even happier [...]." A daughter (A04) described the experience of seeing her father intubated for the first time: "[...] having seen him like this, asleep, gave me a bit of dull relief because I know that he is worse than before, but I wanted to imagine him with the eyes of love because surely he is exhausted by so much suffering [...]."

Concern for the emotional state of the hospitalized relative

It should be noted that in every interview, the concern of family members was related to the emotions of their loved ones—with what thoughts they might have while they are left alone in the ICU, in the absence of communication with their family, who are forced to quarantine at home. A sister (A010) said, "[...] I saw her [her sister] with

her eyes lost and scared [...], the destruction of that kind of place is that even if you feel better, as in ICU, maybe you turn around and there is another patient with the helmet [a kind of non-invasive ventilation]; you look the other way and there's the lady who passes away like it happened yesterday, right? My sister was very tested by the situations around her [...]." A daughter (A00) stated, "[...] I think that a patient who is in the same condition as my mom, even from the moral point of view, needs to feel supported, not to feel abandoned by their family, because they [patients] obviously do not know what we're doing [families] outside. They know that they are there [in the ICU], they no longer see a familiar face for days and days, so I think that even from a psychological point of view it is terrible [...]."Another daughter (A02) expressed, "[...] the ugliest thing about this horrible disease is that it isolates you completely from everyone, and he [her father] finds himself perhaps having to die here alone, among strangers. I don't want him to think that we abandoned him. I wrote him lots of messages, messages that he never read on his phone, obviously because he was already too sick [...]."

Impact of the COVID-ICU and comparison between imagination and reality on the severity of the disease

Entering the COVID-ICU shocked family members, who were facing the reality of the disease. On the one hand, this impact caused

emotions related to increased awareness of the seriousness of the situation; on the other hand, in some cases, seeing their family member in the COVID-ICU positively allayed concerns related to the state of the illness, after their relative had lost the possibility to communicate via telephone, because of the induced state of coma. A sister (A00) described her experience after entering the COVID-ICU for the first time: "I started to think about what might be a possible downside of the situation, because then clearly, until you see them [their loved ones] you say 'Yes, they will definitely be fine!' Then, the context did not impress me, but surely you realize effectively what it is, how many critical situations there may be, and how it could also become hers [her sister's], right? Clearly seeing the type of problem, [...] what may be the consequences. But this first impact [...] makes you reason more, makes you more aware [...]." A daughter (A04) described the experience of seeing her father in the COVID-ICU: "[...] He wore the helmet [device for non-invasive mechanical ventilation and therefore, the idea of having seen him, even in video calls, so trapped and suffering, and even after, when I could no longer see him [by phone, because of intubation], I imagined him. The imagination can be positive or negative; it can worsen or improve the reality of things [...], and having seen him, asleep, gave me some relief [...]."

Recognition of and gratitude toward healthcare professionals

In all the interviews, family members expressed appreciation for the role of healthcare personnel; in particular, they expressed gratitude for the possibility of entering the COVID-ICU and meeting their loved ones. A sister (A010) said, "[...] healthcare personnel were fantastic, following us step by step during the donning procedure. I keep them right in my heart [...]. I thought of them, working eight hours or more in those conditions [wearing PPE]. They deserve more than applause! [...] It has probably become the 'normality' for them, meaning that they live the situation in a more conscious and quieter way, but watching them from the outside is a beautiful sight, for sure [...]."A son (A08) stated, "[...] This initiative [entry of relatives into the COVID-ICU] is a must do! The hospital must allow it. I thank all the healthcare workers, everyone, who helps me during the donning and doffing procedures, who comforts me with a word [...]."

Discussion

The purpose of this study was to investigate the experience of the encounter between family members and patients in the COVID-ICU after a period of detachment because of the policy of restricting visits by family members to hospitals. The sample was mostly represented by women. These data reflect the literature, as it has emerged that 57% to 81% of all caregivers of elderly patients are women,³¹ and they are also more likely to share their experiences in critical situations.³²

The main results were fear-related, in both the donning procedure, because of its side effects, such as claustrophobia and syncope, and the doffing procedure, as it was associated with fear of contamination. To date, these effects have all been described, ^{33,34} but only for healthcare personnel. The current COVID-19 pandemic requires relatives to be trained in these procedures through *just-in-time* training, including the use of video training, which can be a mechanism to improve donning and doffing procedures, resulting in a secondary effect of reduced anxiety. ³⁵

With regard to positive emotions about the first contact with the hospitalized relative, this was a constant component of this study. The encounter was described by family members with emotions of relief, joy, and comfort concerning the patient, who lived in isolation during the course of the illness. On this theme, the concept of the necessity of contact was strong. This concept confirmed the notion expressed in the literature^{36,37} about the loneliness that has characterized the pandemic because physical contact generates high levels of affection and positive emotions that cannot be realized through

telephone contact alone. In some cases, seeing loved ones virtually on an ICU bed has generated feelings of suffering and upset relatives.²³ As observed in our findings, family members of intubated and sedated patients experienced positive emotions, as they had previously seen their loved ones suffer during NIV therapy, trapped inside the helmet during video calls, with their face contracted, exhausted by labored breathing and not being able to speak through a telephone—unlike the vision of their relative intubated and subjected to sedation, resulting in a state of rest in contrast to conscious suffering from the disease. This vision brought serenity to these family members. These new data contrast with findings in previous studies, specifically that family members are scared to see their loved ones intubated, sedated, and mechanically ventilated.³⁸

The emotional concern of family members toward their loved ones was generated by the fact that, inside the COVID-ICU with its open space structure, patients could see other people die if in a state of vigilance, or the fact of feeling alone to face the disease or die in solitude. The fear of dying alone is a universal feeling;³⁹ in the COVID-ICU, this feeling was amplified because patients could not be near relatives, taking an emotional toll on both family members and patients.⁴⁰ The study sample showed that although their loved ones may be awake or sedated, intubated, tracheotomized, or in NIV, the encounter generated positive emotions.

The theme of awareness of the severity of the disease acquired by entering the COVID-ICU was a concept common to all the interviews. The participants admitted that staying at home led them to search for information on the internet and to associate intubation and helmets with a violent and stifling event. On the contrary, entering the COVID-ICU with previous preparation made them aware of the criticality of their loved one as they connected all the information they had received from the doctor by telephone or had seen through means of telecommunication. All this has been confirmed in studies that have detected several stressful factors in an intensive care environment, such as fear of unknown consequences, disruption of routine, lack of familiarity with the environment, and emotional upheavals. 41,42 Visits by relatives in the ICU are fundamental because they generate satisfaction and awareness for the family members.

Finally, the participants described great appreciation for nurses, praising their ability to work with PPE for many hours, their empathy, and their capacity to train and reassure visitors during the donning and doffing procedures and throughout the whole course of the visit. This theme confirmed what was expressed by a recent study on the experiences of family members of COVID-19 patients: that family members enhance the ability of nurses to support the patient and the emotional load of relatives without detracting from the assistance being provided, despite all the difficulties related to PPE and the well-being of nurses. ^{23,44}

This study has several implications. Firstly, to our knowledge, this is one of the first articles that have analysed the experiences of family members who visit relatives in a covid-19 intensive care unit for the first time. The study's findings demonstrate how COVID-19 has not only had positive and negative psychological repercussions for those who firstly visited their parents in COVID-ICU, such as the fear of contagion related to donning and doffing procedures and happiness. Knowing that the feelings most described by the family members have been fear and happiness is fundamental to understanding how strong the psychological impact of COVID-19 has been. Hospital administrations and governments should understand how important it is to offer psychological support to family members, for example giving the opportunity to have open COVID-ICU for relatives and parents. It could be enlightening if future studies analyze both the physical and psychological long-term impact on open COVID-ICU in family members and patients. The results could be used as fundamental data for establishing a safer healthcare system that can protect both members (relatives and patients). It is necessary to specifically understand the problems and demands of family

members for establishing a safe healthcare system that can respond effectively to their needs. In addition, our findings constitute an internationally relevant contribution to the understanding of the needs of relatives who meet their loved ones for the first time while wearing PPE. In this way, an opportunity is presented to contact relatives even if patients are intubated, sedated, or at EOL because it was previously found that video calls generate conflicting feelings in family members. The novelty of this study is the possibility of using its findings to improve nurses' and physicians' preparation to face extreme situations, such as COVID-19, and to help those who lived through it to explain the meaning they gave to it through the narration of their experience. The intent of this paper is to highlight the positive aspects of nursing such as advocacy, elevated responsibility of the role, and humanity towards relatives and parents, giving them the opportunity to be close to their patients in the most difficult moment.

Limitations

This study was conducted only in an Italian region (Lazio) and in a single hospital. First, there may be slight cultural differences, both between Italian regions and between countries. In addition, the interviews, as they were conducted by video call, limited the recording of the field notes, in particular description of the environment. Furthermore, the interviews were conducted after a few hours or the day after family members had entered the COVID- ICU because it was not possible to interview relatives in the waiting room, as doing so would have involved a longer stay in the ICU waiting room. Additionally, having a sample with a female majority could also be a limitation, one that could reflect a more feminine – and thus less representative – vision of the phenomenon. Also, it was not possible to differentiate between interviews with family members of a patient who was intubated, extubated, undergoing tracheostomy, or wearing a helmet. Finally, it was not permitted for persons over 70 years of age who had psychological, cardiological, or pulmonary disease to meet with their family members due to risks related to donning and doffing procedures.

Conclusion

It has been confirmed that visits to the ICU reduce anxiety among family members. Our study strengthens this concept, as it demonstrates that such visits evoke positive emotions as well, specifically among family members in the context of the current COVID-19 pandemic. Restrictions on visits to hospitals can be guaranteed by maintaining an adequate influx, at a fixed time, for one or a maximum of two family members. None of the visitors tested positive for COVID-19 after visiting their relative. It is proposed that future research assess the satisfaction of visits to a COVID-ICU, differentiating between visits by family members with sedated patients from those to patients on mechanical ventilation, as well as those involving patients on NIV, always maintaining a balance between safety and family needs.

Declaration of Competing Interest

The author declares no conflicts of interest.

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