

RESEARCH ARTICLE

Close relatives' perspective of critical illness due to COVID-19: Keeping in touch at a distance

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Abstract

Aim: To elucidate the meaning of being a close relative of a critically ill person cared for in intensive care during the initial phase of the COVID-19 pandemic.

Design: A narrative inquiry design following the COREQ guidelines.

Methods: Individual interviews with fifteen close relatives of patients critically ill with COVID-19 were analysed using phenomenological hermeneutics.

Results: The surreal existence of not being allowed to be near was emotionally difficult. While distancing due to restrictions was challenging, physicians' phone calls served as a connection to their relatives and brought a sense of security. Keeping notes helped them remember what happened and brought order to a chaotic situation.

Conclusion: Close relatives feel secure when they receive regular information about their critically ill relative, not just when their condition worsens. They wish to be physically near to their critically ill person; when this is impossible, digital technology can provide support, but further accessibility developments are needed.

KEYWORDS

COVID-19, critical care, nursing, person-centred care, relatives

1 | INTRODUCTION

In several countries, relatives are allowed to visit intensive care units (ICUs) and remain at the bedside of their critically ill family member. During the COVID-19 pandemic, healthcare organizations around the world were encouraged to introduce different actions such as imposing visiting restrictions on relatives and significant others to prevent the spread of the virus (World Health Organization, 2020); social distancing was encouraged in Sweden (OECD/European Observatory on Health Systems and Policies, 2021).

Close relatives play a supportive role for critically ill patients who rely on them as their proxies to make decisions and communicate their needs to healthcare staff (Creutzfeldt et al., 2021; Engström, 2008;

Engström et al., 2014; Löf et al., 2010). Close relatives are also highly valuable to ICU staff wishing to learn more about the patient and their family (Andersson et al., 2022). Restrictive visitation policies to protect public health negatively affected patients and their families, because they were unable to meet and comfort each other (Boulton et al., 2021; Creutzfeldt et al., 2021; Engström et al., 2022).

2 | BACKGROUND

People have their own needs and worries when their close family member is critically ill (Davidson et al., 2010; Obringer et al., 2012; Plakas et al., 2013; Verhaeghe et al., 2005); they can experience

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physiological, emotional and psychological changes such as insecurity, pain, suffering, sadness, fear and anguish (Chang et al., 2018; Rückholdt et al., 2019). A strategy to manage these emotions may include watching monitors and evaluating the contents of drainage bags to make their own daily assessment of the patient's condition and understand different care decisions (Chen et al., 2021; Rückholdt et al., 2019); due to visitation restrictions, however, this was not possible during the COVID-19 pandemic (Creutzfeldt et al., 2021).

Visitation restrictions affected patients within ICUs and during their recovery process, following severe COVID-19 infection (Rose et al., 2020). These restrictions may have also worsened the depersonalization of ICU patients, brought about a sense of isolation and contributed to their disorientation and lack of awareness (Kotfis et al., 2020). Knowing a patient's life story and focusing on their needs and preferences are important pillars in person-centred care (McCormack & McCance, 2017); it is imperative that patients are never be reduced to their diseases (Leplege et al., 2007). Previous studies by Boulton et al. (2021) and Maaskant et al. (2021) found that critical care nurses (CCNs) missed the presence of patients' close relatives during this time, as this made it difficult to relate to the patient as a person.

COVID-19 manifestation varies, with some infected people remaining asymptomatic and others only exhibiting mild flu-like symptoms; for some, however, the infection can cause serious illness and require admission to the ICU and ventilator support for acute respiratory failure (Smith et al., 2020). During the COVID-19 pandemic, several key determinants of person-centred care were and continue to be under threat due to health-service responses, infection-control measures, visiting restrictions, social distancing and isolation (Edvardsson et al., 2020).

Even though visits were restricted during the pandemic to ensure close relatives did not infect other family members, patients or healthcare professionals, the conditions for person-centred care were challenged when relatives were prohibited from entering the ICU and were therefore unable to inform the CCNs of their family member's medical background, needs and preferences, and this situation may have been harmful to relatives, patients and for ICU staff. There is currently a lack of studies focusing on the close relatives of critically ill people with COVID-19 in ICUs with visitation prohibits.

3 | THE STUDY

3.1 | Aim

The aim of this study is to elucidate the meaning of being a close relative of a critically ill person cared for in intensive care during the initial phase of the COVID-19 pandemic.

3.2 | Design

This study utilized a phenomenological study design. Data collection was conducted as individual interviews with a narrative approach,

and data were analysed with a phenomenological hermeneutic interpretation in accordance with Ricoeur (1976).

3.3 | Setting

This study was conducted in northern Sweden; hospitals in this region responded to the pandemic by reorganizing their facilities, implementing a restricted visitation policy and establishing special COVID-19 ICUs to provide intensive care for severely ill patients. All critically ill patients were transferred from other hospitals in the region, and upon admission to the COVID-19 ICU, they were intubated and invasively mechanically ventilated, if this had not already been done. The distance between the COVID-19 ICU and relatives at home was an average of 167 km, with a range of 55–389 km.

3.4 | Ethical considerations

The ethical committee in Sweden approved the study (nr 2020-02805). All participants verified their participation by completing and returning a written consent form. Prior to the interviews, all participants were presented with verbal and written information about the nature of the study, told their participation was voluntary and reassured they could withdraw from the study at any time without providing an explanation; as each interview began, the researcher (ÅE) confirmed the participant understood the aim of the study. All the participants were guaranteed confidentiality and an anonymous presentation of the findings.

3.5 | Participants

By means of purposive sampling, 20 close relatives of patients who were critically ill with COVID-19 during the spring of 2020 and admitted to a COVID-19 ICU in northern Sweden were informed about the study by mail and asked to participate. In this study, a 'close relative' is defined as a person with a close relationship with someone who was critically ill; it could have been their partner, child and/or a close friend. A total of 15 close relatives 25–77 years of age agreed to participate by returning a written informed consent; six were males and nine were females.

3.6 | Data collection

The interviews took place between July 2020 and January 2021. Data were collected by one of the researchers (ÅE) using individual telephone interviews ($n = 13$) and face-to-face interviews ($n = 2$). The participants were asked to narrate their experience of being a close relative to someone who was critically ill with COVID-19, from when they initially fell critically ill until they were discharged from the ICU.

Follow-up questions were asked, such as, 'What happened then?'; 'How did you feel?' and 'Can you give an example?' The interviews lasted between 26–66 min ($md=39$ min) and were audiotaped, then transcribed verbatim.

3.7 | Data analysis

The interview transcripts were analysed and interpreted according to Ricœur's (1976) dialectical process, which prioritizes understanding and explanation; according to Ricœur, the relationship between phenomenology and hermeneutic philosophy can be assessed to discover the meaning of lived experiences. Inspired by Ricœur's work, Lindseth and Norberg developed a phenomenological hermeneutical method to research lived experiences involving three stepwise phases: the formation of a naïve understanding, structural analysis and the formation of a comprehensive understanding (Lindseth & Norberg, 2004).

The transcripts were first read and reread several times to grasp the overall meaning of the experiences related and form a naïve understanding of those experiences. During structural analysis, the transcripts were decontextualized, which involved dividing the transcribed text into units of meaning, then organizing these into subthemes, themes and a primary theme, and these were then deliberated to validate or invalidate the naïve understanding, under the assumption that the trustworthiness of a structural analysis is dependent upon the coherence of the parts and the whole (Lindseth & Norberg, 2004); throughout this analysis, the perspective continually alternated focus between the individual transcripts, the transcripts as a whole and the interpretation thereof. Finally, the naïve understanding and structural analysis results were integrated to gain an in-depth interpretation and form a comprehensive understanding; the comprehensive understanding of the related experiences as a whole took shape with reference to the authors' preconceptions, the study aims and extant literature on the topic.

3.8 | Rigour

While knowledge of methodological rigour proposes that results may be applicable to other relatives of critically ill people, the whole truth about a phenomenon can never be revealed (Lindseth & Norberg, 2004). In accordance with Ricœur (1976), our aim was not to find the one and only truth, but the most probable one. The researchers were therefore careful during the interviews to allow the participants to describe their experiences without pushing them forward. Furthermore, the data were thoroughly analysed, and we withheld our pre-understanding during the analysis. As specialist nurses in intensive care nursing and nursing researchers with clinical experience before and during COVID-19, our understanding may have prevented certain follow-up questions from being asked, since we already knew the context; our pre-understanding

could, however, be seen as a strength when conducting the analysis process, and the findings from this study are therefore considered transferable to other contexts.

4 | FINDINGS

4.1 | Naïve understanding: Keeping in touch at a distance

The participants could not believe COVID-19 would affect their families and did not understand the severity of the illness until their close relative's symptoms became severe; upon contact with health care, seriously ill individuals were largely neglected, which often extended patients' stays and led to a deterioration of their general condition. When their close relative was admitted to the hospital, they felt despair, because visiting restrictions prevented them from being near each other. Daily conversations with physicians served as the sole connection to their close relatives, which led to feelings of security and hope. Even as the recurrent conversations provided a structure, anxiety arose if they were delayed and feelings of passivity between phone calls characterized their day. The responsibility of disseminating information required both time and energy and gave rise to emotions stemming from being the one who brought the concerns of others in the family. Participants tried to overcome the distance by catching glimpses of their close relatives through, for example, windows. Everyday chores and socializing with family and friends were difficult due to social restrictions, creating a sense of isolation and unreality. Participants tried to shift unpleasant thoughts by engaging in activities and making new plans for the future. Keeping notes helped them to remember what had happened and brought some order to a chaotic situation.

4.2 | Structural analysis

The structural analysis resulted in one primary theme with three themes and nine subthemes, as shown in Table 1.

The structural analysis for the theme 'An approaching crisis' is delineated in Table 2.

4.2.1 | An approaching crisis

Does not apply to us

Many participants were in denial, recounting how they did not believe COVID-19 could affect them or their relatives. Initially, everyday life was more about limitations than worries about becoming critically ill, and even when they or their relative showed symptoms, their first thought was not that they were infected. Participants said that it was initially incomprehensible that their relative had been transformed from being an active person in good health to being critically ill: 'I guess I thought [...] yes it sounded awful, but it does not affect [people] like us' (3).

Keeping in touch at a distance		
An approaching crisis	A lifeline and an impediment	A surreal existence
This does not apply to us	Remote communication	A wish to be near
Pieces coming together	Disseminating information	Creating a new pattern
Handing over	Structuring the day	Connecting memories and events

TABLE 1 Overview of findings presented as primary theme with themes (n = 3) and subthemes (n = 9).

TABLE 2 Example from the structural analysis.

Meaning unit	Condensation	Sub-theme	Theme
'At first I thought it was just the flu, it was so new.'	Did not understand the seriousness	Does not apply to us	An approaching crisis
'We were asked to not search unnecessarily, call 1177 or an ambulance or seek the emergency room.'	Urged to not seek care unnecessarily	Pieces coming together	
'We had to sit in the ER garage—out there in the car—and wait, and then she started getting worse and worse. I had to go to the emergency room [because] it was urgent: 'You have to do something now; she cannot sit in the car, she's becoming ill!'	Sat waiting in the ER	Handing over	

Pieces coming together

Some participants described their relative's symptoms as different than a regular cold, with high fever and body aches, but no respiratory effects until some days later when they began to cough. Slowly they understood that this was something else other than a common cold:

We thought she was doing pretty well. It went up and down a little and I thought [...] in the beginning, she had no problems with her breathing the first week. But then this breathing problem began to appear and I was like, 'No.' Then it started to get uncomfortable. (9)

Participants also reacted to variations in intensity. One day their relatives felt better, yet the condition worsened the next day. Participants hesitated about what level of health care would be appropriate when they realized they needed to seek for help since health care information clearly declared not to burden them with unnecessary phone calls. In addition, a societal opinion to not attend health care due to the risk of spreading the disease was described; this was reinforced by contacts with healthcare providers actively telling them to stay at home and wait, despite their relatives experiencing breathing difficulties and high fevers:

We did not call because of the very clear request that we were asked not to apply; do not burden health-care unnecessarily. We were urged not to seek care unnecessarily; do not call 1177 or the ambulance or seek emergency care. (15)

Handing over

When symptoms became severe, healthcare contacts were necessary. Admittance to the hospital was mostly acute due to the condition of their relatives. Confusion, weakness, shortness of breath, hypoxia and

high fever meant that transport to the hospital in many cases took place by ambulance or helicopter: 'But then we saw the helicopter. [...] I just had to look and watch when it went. It felt awful. Then I thought [...] it was [his wife]. I wondered if she would come back' (12).

The struggle with family and work and having a critically ill relative left the participants in despair and with the feeling of being in a vacuum. Participants related feeling a sense of security when handing their relative over to professional healthcare workers. At the same time, they pulled themselves together while everything was critical, and afterwards, they collapsed: 'It is not possible to describe the feeling. I think I just rambled around. I did not know where to go, what to do, how to behave. I knew nothing' (10).

4.2.2 | A lifeline and an impediment

Remote communication

Participants initially tried to gain control of the situation by making several telephone calls to the ICU. When physicians called twice a day to inform them of the situation and answer their questions, participants described receiving detailed information and stated they felt the staff cared about their relatives, which provided support and gave them hope. Participants described the interaction as being relaxed and reliable because the physicians were able to anticipate their frustration and anxiety. The participants expressed gratitude and described the telephone calls from the physicians as providing security and being a link to their relatives; the calls were perceived as lifelines in a chaotic situation:

The telephone calls were my link to my husband. So, when they called, he was there in some way, because that was what the conversation was about. If they had not called as they did, I do not think I would have survived. (14)

Participants described staying connected with their relatives via telephone, text message and FaceTime. After a while, however, the participants could tell from their relatives' voices that their health was deteriorating. The participants described the day when they received the message relatives were intubated as being tough and scary: 'I didn't have the strength to talk.' These feelings were changed to happiness and gratitude at the first conversation after their relatives had awoken after sedation; while it was nice to hear the voice of their relative again, it was also a dizzying conversation. The participants were unprepared for the conversation, and several participants described how they became completely silent and did not know what to say:

I was so shocked when they [the nurses] suddenly said, 'Do you want to talk? I can put the phone to his ear.' I just fell silent. I was not prepared. I was thinking, 'What should I say?' It was not a long first conversation. (1)

They experienced this as mostly a one-way communication and admitted it was sometimes difficult to hear what relatives said because their voice was weak and slurred. One participant likened the voice of a loved one to a mechanical voice. Even if the conversation was short, it provided security, and they were able to briefly discuss everyday things. When their relatives had special wishes, such as wanting a particular beverage or an item in their home, it felt good to be able to fulfil that wish. The conversations were very emotional, and they understood their relatives were cognitively intact and strong enough to come home from the ICU. The calls also aroused painful thoughts about how their relative would cope after they were discharged from the ICU:

[I] heard him sort of mumbling and [the nurse told me] he said he longs to go home to the sauna, and then I just felt like, 'Yes! He keeps up. Ha!' [...] It was such a relief he said such a thing! It felt as if, 'Yes, he wants to go home; he is already aiming for it.' But then there was the fear: Would he be himself again?

(7)

Disseminating information

Participants described how disseminating information about their critically ill relative to family and friends was a weighty, time-consuming and stressful matter when their friends and family sat at home waiting for them to call. Participants described how they became the person who worried others, and the task was described as being both a mechanical deliverance of information and a healing activity, which did not feel burdensome because they could discuss the situation. Participants described how they adapted information based on the people they talked to:

I became the person who had to worry about everyone else because I was the one who delivered the information to the siblings. Somehow, I had to take on

the role of 'informant'. I had to rein in my feelings a little in connection with my contact with them.

(8)

There were times when participants had to hold back their emotions to maintain the hope of those whom they were informing. Participants answered questions, but perhaps not directly, and sifted through the conversations when it became too burdensome. Other participants described how they could sense that the rest of the family did not actually believe they were providing accurate information. There were times when physicians needed to call people in the circle around the critically ill patient to inform them of the patient's condition. Participants with friends who increased their anxiety cancelled these contacts and let others handle them, and when people behaved badly or were too curious, they dismissed them and stopped answering certain questions:

I'm actually pretty good at speaking up so when [an acquaintance] started, 'Oh, what if...'; I just said, 'You know, I don't want to hear that negative crap, and I'm not going to call you anymore. I'll send [a text message] instead'.

(5)

Structuring the day

The conversations with physicians created routines around which the participants structured their days. In an otherwise chaotic existence, the participants had a sense of security and regularity knowing the calls would come at specific times twice a day and that they were not responsible to make the calls themselves. At the same time, however, this regularity created anxiety if the phone calls were delayed, followed by a sense of being shackled or living in a vacuum between phone calls:

I had routines. I watched [the television program] *Exercise with Sofia*, and I took walks. The doctors called. Then I talked to the kids in the morning and afternoon reporting. In the evening, I talked to my sister-in-law and my sister. I watched *Midsomer Murders* and took a shot of Jägermeister every night.

(6)

4.2.3 | A surreal existence

A wish to be near

The participants were informed that due to the restrictions, visits were only allowed if there was a risk that their relatives were not going to survive. They told us they wished to be near their loved ones in the ICU, but they understood why they could not be and accepted the restrictions, even though it was very emotional. It was difficult to get an opinion about their relative's condition when they were not allowed to be at their bedside. Standing outside their relatives' rooms on the ground floor of the hospital in the hopes of getting a glimpse of their relative through the window was a testament to their wishes to be nearby:

I felt really safe when he was to be transferred to another hospital. The only problem was in the other ICU he had a room with a window on the ground floor, so I could see him through the window while on a respirator, and it was great for me to get an idea of how he was doing and everything; I photographed him through the window, and it has been very valuable for him in retrospect as well. So, it was both good and bad when he moved, because I knew I would not see him anymore when he left.

(4)

Participants explained that even though it was difficult to explain to their young children, they still wanted to involve their children; they did this by waving together at the helicopter when their relative was transferred to another hospital or visiting when the restrictions were eased. Pictures of the critically ill person were also important for the children to understand what happened, and while some health care staffs provided photos, others denied the close relatives' request because permission could not be granted by the critically ill person due to being sedated. Participants described feelings of powerlessness when family members and friends who offered their support were not allowed to be near because of the risk of spreading the virus: 'Those weeks, I was almost completely destroyed, you know. I was alone at home all the time. Then [I] became [...] isolated [myself]. I was not even out there among people' (12).

Creating a new pattern

Participants described thoughts that dissipated through activity. Grinding thoughts or feelings of catastrophe led to anxiety and weight loss. A way to dispel those thoughts was to not allow themselves to consider that their relatives would not survive and to instead make plans for when their relatives came home; walking long distances to the point of exhaustion, planting in their garden for the first time, setting the table with a book or newspaper at their relative's seat or baking bread were other forms of activity to dispel negative thoughts. Some employers adapted their work tasks so they felt safe at the workplace, which was an important part of coping with the surreal world in which they were living:

My days went fast as hell, I can say, and [I] worked a little sometimes, but [I] made sure [I] went there without meeting people. I am also lucky that I can go to work when everyone else has already gone home because I could not bear to meet so many people and I did not want to expose anyone [to the virus].

(2)

It was difficult to dispel thoughts at night, which affected their sleep in different ways. One participant stated that even when they were tired, it was difficult to fall asleep or to stay asleep: '[I] slept for short periods of time, but was really tired, so [I] didn't sleep. Sitting watching TV in the middle of the night, I had never done that before' (11). Another

participant admitted that if they were awoken by the phone, it was difficult to fall asleep again: 'I woke up one night and had terrible anxiety. I do yoga, so I lay there and did breathing exercises, and I understood that maybe it's completely natural for me to have anxiety attacks like this' (6).

Connecting memories and events

The participants wrote notes after the phone calls with the physicians, and it was common to use the note function on their tablets or mobile phones. While the participants missed some developments because hospital staff could not keep a diary due to resources, some of their relatives also used these notes as a way to understand what had happened, and writing daily notes gave participants a task to fulfil:

It felt important. [...] If [I] otherwise feel powerless, like [I] couldn't do anything for him. [...] [crying] [I] couldn't hold his hand. [...] Well, then it was like [...] focusing on this—this is what I can do for him.

(4)

Participants who kept a diary or notes for their critically ill close relatives to read after recovery noticed it was also an important memory aid for themselves. Some admitted, however, that they could not read the diary notes because all of the despair they experienced during the care period would come back and remind them of everything that had happened.

I notice myself that every time I try to re-write the text properly, I just throw the diary into the corner, I can't bear to read it again actually, [...] I sent him [a text message] every day [...] But I can't bear to read those [messages], because then I remember how desperate I was in between.

(5)

5 | DISCUSSION

Participants had difficulty understanding that their relatives became critically ill from this previously unknown virus; Morse (2000) stated that a person falling critically ill is a situation which is hard to understand; and according to Ricoeur (1976), we need explanations to be able to understand, and with the help of explanations we can understand, because understanding and explanation overlap and intertwine. The initial reaction when something terrible happens, such as when a person becomes critically ill, is to go into a period of shock when everything that is happening feels unreal (Morse, 2000); by focusing on the present, however, participants were able to keep going on. According to Morse (2000), when enduring, people block out the past and the future is non-existent; there are strategies to hold on to the present, such as forming routines and counting something. One way to endure a stressful period, such as the experience of having a relative admitted into the ICU, is to write down one's reflections in a

diary, which many of the participants in this study described as being a valuable way to understand what happened during their close relative's illness (Johansson et al., 2015; Lepore & Smyth, 2002). Another way to endure is to find balance and structure (Millward et al., 2021); we found that the participants submerged themselves in daily routines to them get through their situations and provide both structure in their daily lives and a sense of balance.

When the participants were not allowed to be near their critically ill loved ones in the ICU, telephone conversations with their physicians became a connection to them. Engström (2008) concluded that relatives of the critically ill wish to be near their loved ones and participate in what is happening in the ICU. Furthermore, communication between ICU staff and patients' relatives is of great importance (Marra et al., 2020; Millward et al., 2021); Marra et al. (2020) highlighted the special skills that are needed to communicate when people are unable to see one another and nonverbal tools such as the tone, the voice, pauses and inflection become extra important. Knowing what happened to their critically ill relatives in the ICU and having access to information reduced the anxiety in families of patients in the ICU and helped them to manage their fears (Millward et al., 2021).

The participants in this study show described being stunned to hear the voices of their close relatives and anxious to know whether they were cognitively intact when the first conversation contained inaccuracies. While delirium often occurs with COVID-19, this life-threatening condition can be reduced by allowing critically ill individuals to hear the voices of their relatives (Marengoni et al., 2020; Munro et al., 2017; Tilouche et al., 2018); both ICU patients and their families can benefit when CCNs are able to find new ways for patients and relatives to communicate using digital services such as video calls. Rose et al. (2021) asserted that improving access and developing a more lasting approach to close relatives 'virtual visits might improve the quality of care in ICUs, both during and after a pandemic.

Participants described how they wished to be near their loved ones, but were not allowed to do so because of visitation restrictions; one of the World Health Organization (2020) recommendations to reduce the impact of COVID-19 disease was to restrict the number of visitors and the visiting periods. While the actual effects of visitor restriction as an intervention to reduce the spread of infection in general is not fully known and the existing evidence remains unclear (Jefferson et al., 2010); visits from close relatives and friends have been found to have several positive effects on the health and well-being of patients (Gillick, 2013). Hugelius et al. (2021) indicated that visiting restrictions imposed during the COVID-19 pandemic led to several negative consequences for both patients and family members, despite efforts to use technical solutions as substitutes for physical visits.

The participants stated that not being allowed to be present in the ICU created feelings of uncertainty about their loved one's condition. Close relatives' involvement in care benefits both themselves and the patient (Boehm et al., 2021; Creutzfeldt et al., 2021; Engström, 2008; Engström et al., 2014; Löf et al., 2010); engagement helped them to make sense of the situation and to feel they are an active part in the patients' recovery, providing comfort to them at the same time that the patient received support based on familiarity (Boehm et al., 2021).

Not being allowed to be at the bedside of the ICU patient may create concerns and engender feelings of failing to support and protect their loved ones (Creutzfeldt et al., 2021). The findings in the present study indicate similar feelings among the participants, all of whom reported how much they appreciated receiving photos, phone calls, text messages and FaceTime calls that at least created a semblance of control of the situation. Hugelius et al. (2021) found that despite such substitute methods, visiting restrictions reduced the how much family members understood their loved one's condition, the patient's overall situation and the care that was provided.

Technical workarounds are not a substitute for the actual presence of a person, and according to Creutzfeldt et al. (2021), such solutions should be used as a last resort to enable social contact. Bartoli et al. (2022) reported that close relatives who were allowed to visit ICU patients with COVID-19 were touched by meeting with their loved ones and were better able to realize the seriousness of the illness and to observe the care and treatment they were receiving. An integrative review by Hugelius et al. (2021) demonstrated the manner in which the visiting restrictions undermined the patients', the close relatives' and the ICU staffs' well-being and health; and Robert et al. (2020) concluded that the ICU staff had no choice but to adopt less-than-perfect solutions. At present, the level of evidence regarding the long-term consequences of visitation restrictions for close relatives of someone in the ICU during the COVID-19 pandemic is minimal, and further studies are needed.

5.1 | Limitations

This study was conducted during the first phase of the pandemic and therefore only reflects the experiences of relatives when COVID-19 was novel to Swedish health care and society. Furthermore, the aim of this study was to better understand the experiences of close relatives of those who became critically ill with COVID-19 and were admitted into an ICU; while no young or small children were interviewed, their perspectives would have enriched our understanding.

All interviews were informative and contained data with depth and richness, which is seen as a strength. According to Sandelowski (1995), a sample size should be large enough to provide variations in the narrated experiences, but small enough to permit a deep analysis of the data. One researcher conducted all interviews, which can also be seen as a strength. Related to the pandemic, 13 of the narrative interviews were conducted by telephone and two were face-to-face; even though face-to-face interviews are seen as the gold standard, Novick (2008) stated that in qualitative research, telephone interviews allow participants to relax and more easily disclose sensitive information; we considered this to be the safest method to use during the pandemic.

The choice of analysis method was determined due to the method's ability to do justice to the real-life world. The naïve understanding guided the structural analysis, which in turn validated or invalidated the naïve understanding (Lindseth & Norberg, 2004). In the comprehensive understanding, the whole text was read again,

with the naïve understanding, the findings of the structural analysis, the authors' pre-understanding and the extant literature in mind, to broaden and deepen our understanding and attain a new interpreted whole (Lindseth & Norberg, 2004). According to Ricoeur (1976), interpretation must not only be probable, but more probable than any other interpretation; as such, the findings in this study are based on the most probable interpretation we could reach.

5.2 | Implications and recommendations for practice

While close relatives of ICU patients are left alone with their worries when barred from visiting the ICU, their anxiety is reduced with a continuous flow of information. Compensating for the distance between relatives and patients is a challenge, but this is possible with the help of staff who take an overall perspective. Close relatives of critically ill individuals carry a tremendous burden in terms of information and serve as a buffer between healthcare professionals and other family members and friends; by providing family and friends with information, these close relatives feel this burden easing. Communication between ICU staff and the patient's relatives is therefore a prerequisite for them to be able to handle their situation.

6 | CONCLUSION

Close relatives strive to stay connected with their critically ill loved ones from a distance. Communication with healthcare staff provides a link between close relatives and their loved ones, and digital devices are commonly used. Close relatives feel comfortable and secure when they regularly receive information about their loved one, not just when their condition worsens. These family members have a deep wish to be near the critically ill person, and when it is impossible to be physically near, digital technology and services must be further developed. This is less a matter of guidelines for implementing high-tech digital solutions and more about such values as human rights, dignity and involving relatives in the continual care of critically ill persons, especially when close relatives are forced to keep their distance.

AUTHOR CONTRIBUTIONS

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CONFLICT OF INTEREST STATEMENT

We declare we have no conflict of interest.

DATA AVAILABILITY STATEMENT

Authors select to not share data.

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REFERENCES

- Andersson, M., Nordin, A., & Engström, Å. (2022). Critical care nurses' experiences of working during the first phase of the COVID-19 pandemic – Applying the person-centred practice framework. *Intensive and Critical Care Nursing*, 69, 103179. <https://doi.org/10.1016/j.iccn.2021.103179>
- Bartoli, D., Trotta, F., Pucciarelli, G., Simeone, S., Miccolis, R., Cappitella, C., Rotoli, D., & Rocco, M. (2022). The lived experiences of family members who visit their relatives in COVID-19 intensive care unit for the first time: A phenomenological study. *Heart & Lung*, 54, 49–55. <https://doi.org/10.1016/j.hrtlng.2022.03.012>
- Boehm, L. M., Jones, A. C., Selim, A. A., Virdun, C., Garrard, C. F., Walden, R. L., Ely, E. W., & Hosie, A. (2021). Delirium-related distress in the ICU: A qualitative meta-synthesis of patient and family perspectives and experiences. *International Journal of Nursing Studies*, 122, 104030. <https://doi.org/10.1016/j.ijnurstu.2021.104030>
- Boulton, A. J., Jordan, H., Adams, C. E., Polgarova, P., Morris, A. C., & Arora, N. (2021). Intensive care unit visiting and family communication during the COVID-19 pandemic: A UK survey. *Journal of the Intensive Care Society*, 23(3), 293–296. <https://doi.org/10.1177/17511437211007779>
- Chang, P.-Y., Wang, H.-P., Chang, T.-H., Yu, J.-M., & Lee, S.-Y. (2018). Stress, stress-related symptoms and social support among Taiwanese primary family caregivers in intensive care units. *Intensive and Critical Care Nursing*, 49, 37–43. <https://doi.org/10.1016/j.iccn.2018.05.002>
- Chen, C., Wittenberg, E., Sullivan, S. S., Lorenz, R. A., & Chang, Y.-P. (2021). The experiences of family members of ventilated COVID-19 patients in the intensive care unit: A qualitative study. *American Journal of Hospice and Palliative Medicine*, 38(7), 869–876. <https://doi.org/10.1177/10499091211006914>
- Creutzfeldt, C. J., Schutz, R. E. C., Zahuranec, D. B., Lutz, B. J., Curtis, J. R., & Engelberg, R. A. (2021). Family presence for patients with severe acute brain injury and the influence of the COVID-19 pandemic. *Journal of Palliative Medicine*, 24(5), 743–746. <https://doi.org/10.1089/jpm.2020.0520>
- Davidson, J. E., Daly, B. J., Agan, D., Brady, N. R., & Higgins, P. A. (2010). Facilitated sensemaking: A feasibility study for the provision of a family support program in the intensive care unit. *Critical Care Nursing Quarterly*, 33(2), 177–189. <https://doi.org/10.1097/cnq.0b013e3181d91369>
- Engström, Å. (2008). *A wish to be near: Experiences of close relatives within intensive care from the perspective of close relatives, formerly critically ill people and critical care nurses*. (Doctoral Thesis) Lulea University of Technology.
- Engström, Å., Dicksson, E., & Contreras, P. (2014). The desire of parents to be involved and present. *Nursing in Critical Care*, 20(6), 322–330. <https://doi.org/10.1111/nicc.12103>

- Gillick, M. R. (2013). The critical role of caregivers in achieving patient-centered care. *Jama*, 310(6), 575–576. <https://doi.org/10.1001/jama.2013.7310>
- Hugelius, K., Harada, N., & Marutani, M. (2021). Consequences of visiting restrictions during the COVID-19 pandemic: An integrative review. *International Journal of Nursing Studies*, 121, 104000. <https://doi.org/10.1016/j.ijnurstu.2021.104000>
- Jefferson, T., Del Mar, C., Dooley, L., Ferroni, E., Al-Ansary, L. A., Bawazeer, G. A., van Driel, M. L., Nair, S., Foxlee, R., & Rivetti, A. (2010). Physical interventions to interrupt or reduce the spread of respiratory viruses. *Cochrane Database of Systematic Reviews*, 1, CD006207. <https://doi.org/10.1002/14651858.cd006207.pub3>
- Johansson, M., Hanson, E., Runeson, I., & Wåhlin, I. (2015). Family members' experiences of keeping a diary during a sick relative's stay in the intensive care unit: A hermeneutic interview study. *Intensive and Critical Care Nursing*, 31(4), 241–249. <https://doi.org/10.1016/j.iccn.2014.11.002>
- Kotfis, K., Williams Roberson, S., Wilson, J. E., Dabrowski, W., Pun, B. T., & Ely, E. W. (2020). COVID-19: ICU delirium management during SARS-CoV-2 pandemic. *Critical Care*, 24(1), 176. <https://doi.org/10.1186/s13054-020-02882-x>
- Leplege, A., Gzil, F., Cammelli, M., Lefevre, C., Pachoud, B., & Ville, I. (2007). Person-centredness: Conceptual and historical perspectives. *Disability and Rehabilitation*, 29(20–21), 1555–1565. <https://doi.org/10.1080/09638280701618661>
- Lepore, S. J., & Smyth, J. M. (2002). The writing cure: An overview. In S. J. Lepore & J. M. Smyth (Eds.), *Writing cure: How expressive writing promotes health and emotional well-being* (1st ed., pp. 3–14). American Psychological Association.
- Lindseth, A., & Norberg, A. (2004). A phenomenological hermeneutical method for researching lived experience. *Scandinavian Journal of Caring Sciences*, 18(2), 145–153. <https://doi.org/10.1111/j.1471-6712.2004.00258.x>
- Löf, S., Sandström, A., & Engström, Å. (2010). Patients treated with therapeutic hypothermia after cardiac arrest: Relatives' experiences. *Journal of Advanced Nursing*, 66(8), 1760–1768. <https://doi.org/10.1111/j.1365-2648.2010.05352.x>
- Maaskant, J. M., Jongerden, I. P., Bik, J., Joosten, M., Musters, S., Storm-Versloot, M. N., Wielenga, J., Eskes, A. M., & FAM-Corona Group. (2021). Strict isolation requires a different approach to the family of hospitalised patients with COVID-19: A rapid qualitative study. *International Journal of Nursing Studies*, 117, 103858. <https://doi.org/10.1016/j.ijnurstu.2020.103858>
- Marengoni, A., Zucchelli, A., Grande, G., Fratiglioni, L., & Rizzuto, D. (2020). The impact of delirium on outcomes for older adults hospitalised with COVID-19. *Age and Ageing*, 49(6), 923–926. <https://doi.org/10.1093/ageing/afaa189>
- Marra, A., Buonanno, P., Vargas, M., Iacovazzo, C., Ely, E. W., & Servillo, G. (2020). How COVID-19 pandemic changed our communication with families: Losing nonverbal cues. *Critical Care*, 24, 297. <https://doi.org/10.1186/s13054-020-03035-w>
- McCormack, B., & McCance, T. (Eds.). (2017). *Person-Centred practice in nursing and health care: Theory and practice* (2nd ed.). John Wiley & Sons Ltd.
- Millward, K., McGraw, C., & Aitken, L. M. (2021). The expressed support needs of families of adults who have survived critical illness: A thematic synthesis. *International Journal of Nursing Studies*, 122, 104048. <https://doi.org/10.1016/j.ijnurstu.2021.104048>
- Morse, J. M. (2000). Responding to the cues of suffering. *Health Care for Women International*, 21, 1–9. <https://doi.org/10.1080/073993300245366>
- Munro, C. L., Cairns, P., Ji, M., Calero, K., Anderson, W. M. D., & Liang, Z. (2017). Delirium prevention in critically ill adults through an automated reorientation intervention – A pilot randomized controlled trial. *Heart & Lung*, 46(4), 234–238. <https://doi.org/10.1016/j.hrtlng.2017.05.002>
- Novick, G. (2008). Is there a bias against telephone interviews in qualitative research? *Research in Nursing & Health*, 31(4), 391–398. <https://doi.org/10.1002/nur.20259>
- Obringer, K., Hilgenberg, C., & Booker, K. (2012). Needs of adult family members of intensive care unit patients. *Journal of Clinical Nursing*, 21(11–12), 1651–1658. <https://doi.org/10.1111/j.1365-2702.2011.03989.x>
- OECD/European Observatory on Health Systems and Policies. (2021). *Sweden: Country health profile 2021, State of Health in the EU*. OECD Publishing. <https://doi.org/10.1787/b9027e42-en>
- Plakas, S., Taket, A., Cant, B., Fouka, G., & Vardaki, Z. (2013). The meaning and importance of vigilant attendance for the relatives of intensive care unit patients. *Nursing in Critical Care*, 19(5), 243–254. <https://doi.org/10.1111/nicc.12054>
- Ricœur, P. (1976). *Interpretation theory: Discourse and the surplus of meaning*. Texas Christian University Press.
- Robert, R., Kentish-Barnes, N., Boyer, A., Laurent, A., Azoulay, E., & Reignier, J. (2020). Ethical dilemmas due to the COVID-19 pandemic. *Annals of Intensive Care*, 10, 84. <https://doi.org/10.1186/s13613-020-00702-7>
- Rose, L., Cook, A., Casey, J., & Meyer, J. (2020). Restricted family visiting in intensive care during COVID-19. *Intensive and Critical Care Nursing*, 60, 102896. <https://doi.org/10.1016/j.iccn.2020.102896>
- Rose, L., Yu, L., Casey, J., Cook, A., Metaxa, V., Pattison, N., Rafferty, A. M., Ramsay, P., Saha, S., Xyrichis, A., & Meyer, J. (2021). Communication and virtual visiting for families of patients in intensive care during the COVID-19 pandemic: A UK national survey. *Annals of the American Thoracic Society*, 18(10), 1685–1692. <https://doi.org/10.1513/annalsats.202012-1500oc>
- Rückholdt, M., Tofler, G. H., Randall, S., & Buckley, T. (2019). Coping by family members of critically ill hospitalised patients: An integrative review. *International Journal of Nursing Studies*, 97, 40–54. <https://doi.org/10.1016/j.ijnurstu.2019.04.016>
- Sandelowski, M. (1995). Sample size in qualitative research. *Research in Nursing & Health*, 18(2), 179–183. <https://doi.org/10.1002/nur.4770180211>
- Smith, V., Devane, D., Nichol, A., & Roche, D. (2020). Care bundles for improving outcomes in patients with COVID-19 or related conditions in intensive care – A rapid scoping review. *Cochrane Database of Systematic Reviews*, 12, CD013819. <https://doi.org/10.1002/14651858.cd013819>
- Tilouche, N., Hassen, M. F., Ali, H. B., Jaoued, O., Gharbi, R., & El Atrous, S. S. (2018). Delirium in the intensive care unit: Incidence, risk factors, and impact on outcome. *Indian Journal of Critical Care Medicine*, 22(3), 144–149. https://doi.org/10.4103/ijccm.ijccm_244_17
- Verhaeghe, S., Defloor, T., Van Zuuren, F., Duijnste, M., & Grypdonck, M. (2005). The needs and experiences of family members of adult patients in an intensive care unit: A review of the literature. *Journal of Clinical Nursing*, 14(4), 501–509. <https://doi.org/10.1111/j.1365-2702.2004.01081.x>
- World Health Organization. (2020). *Maintaining essential health services: Operational guidance for the COVID-19 context: Interim guidance*, 1 June 2020. World Health Organization. <https://apps.who.int/iris/handle/10665/332240>

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