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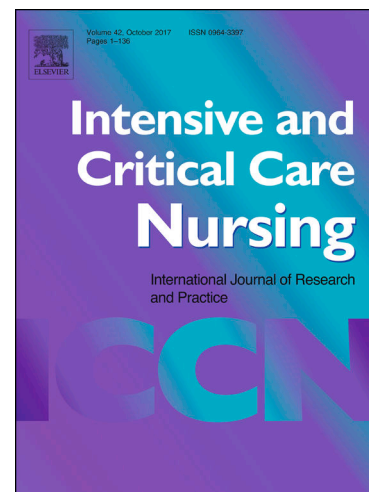
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Family member perspectives on ICU in-person visiting restrictions during the COVID-19 Pandemic: a qualitative study

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Conflict of Interest

No conflicts of interest have been identified.

Abstract

Background: Family member presence in the intensive care unit (ICU) is important for patient well-being and recovery. Limitations to ICU visits increase the risk of psychological distress in family members. During the COVID-19 pandemic, in-person visiting restrictions were introduced to prevent the spread of infection.

Purpose: To explore the experience of in-person visiting restrictions imposed during the pandemic on family members of patients with COVID-19 admitted to an ICU.

Method: Qualitative method with thematic analysis. Individual semi-structured telephone interviews were conducted.

Findings: We interviewed 21 family members. The results are presented in one overall theme with two main themes and five sub-themes. The theme ‘Striving for closeness even at a distance’ describes the experience of being kept at a physical distance when participants needed closeness the most. Even participants who were allowed in-person visits perceived a ‘distance’ due to personal protective equipment or because they could only view the patient from a window. Participants reported that contact with and information about the patient was of utmost importance. Visits were viewed as essential in providing for the patient’s wellbeing. Meaningful contact with the ICU team was vital for getting useful information. Phone calls became a lifeline, with digital aids such as video calls used occasionally to overcome the feeling of distance.

Conclusion: Visiting restrictions imposed during the COVID-19 pandemic made straightforward and comprehensible communication of information from the ICU team more essential to reduce family members’ perceptions of distance and exclusion from the ICU.

Keywords: Covid-19, Experiences, Family, Family-Centered Care, Intensive Care, Nursing, Qualitative, Relative, Visitor Restrictions

Implication for Clinical Practice

- Family members appreciate a designated contact person from ICU staff to provide daily updates. The use of a designated contact person facilitates a trusting relationship between family and ICU staff.
- As a supplement to in-person visiting, digital technology such as video calls can be used to reduce the sense of distance.

- In-person visits to the ICU are of utmost importance for a family to be able to provide support to the patient.

Introduction

In Sweden, intensive care unit (ICU) admissions during the first wave of the COVID-19 pandemic peaked between March to May 2020. The number of COVID-19 patients requiring ICU admission demanded a large increase in ICU capacity (Bergman et al., 2021). Across the world, in-person family visiting was strictly prohibited in most cases (Valley et al., 2020; Wallace et al., 2020; Weiner et al., 2021) to reduce the spread of infection. Before the pandemic struck, daily visits were the ordinary protocol in most intensive care units, one study states that during the first pandemic wave only 49 % of participants were allowed in-person visits. Of that 49%, only 4% were allowed daily visits, 5% 2-3 times a week and 40% only for major events. In addition to fewer in-person visits, only 28% of those who were allowed in-person visits were allowed physical contact with the patient (Langer et al., 2022). Having a patient as a relative in the ICU is stressful for family members (Alfheim et al., 2019), irrespective of the additional stress of being unable to visit. Many family members experienced anxiety and/or depression (Cattelan et al., 2021; Chen et al., 2021; Koukouli et al., 2018; Lee et al., 2019; Schmidt & Azoulay, 2012; Wetzig & Mitchell, 2017). Feelings such as sadness, grief, distress, frustration, anger, and fear are also common (Bjork et al., 2019; Koukouli et al., 2018). A COVID-19-diagnosis alone can lead to family members experiencing anxiety and depression (Cattelan et al., 2021; Chen et al., 2021) – given worry about the consequences of the disease (Hanna et al., 2021).

Research shows that family members play an important role in an ICU patient's wellbeing and motivation for recovery. Family members' bedside presence in the ICU makes patients feel

happy and creates a sense of inner calm, security and safety, giving patients the extra strength to get well (Engström & Söderberg, 2007; Mitchell & Aitken, 2017). As early as the late 1970s, Molter described the importance to families in the ICU of receiving necessary information (Molter, 1979). More recent studies validate these findings. Family members indicate a desire for straightforward and honest information that is easy to understand (Creutzfeldt et al., 2021; Frivold et al., 2015; Koukouli et al., 2018; Minton et al., 2019; Wetzig & Mitchell, 2017), and provided on numerous occasions (Davidson et al., 2007). Families also need time to comprehend the information given to them (Koukouli et al., 2018; Wetzig & Mitchell, 2017). To facilitate comprehension, family members find visiting the patient in the ICU important since this helps them understand and cope with the situation (Bjork et al., 2019; Creutzfeldt et al., 2021; Wetzig & Mitchell, 2017).

To provide person-centred care for ICU patients, care plans must be family-centred, since families should be seen as extensions of the patient (Mitchell et al., 2016). A strong argument for involving families in patient care is to reduce family members' symptoms of anxiety, stress, depression and post-traumatic stress disorder (PTSD) both during and after the time in the ICU. Support from the ICU nurse is important to family members, and information and communication are important tools to reduce the risk of psychological symptoms (Gerritsen et al., 2017). Family members often feel helpless but inviting them to participate in care can alleviate these feelings. It can also help establish a trusting relationship with the ICU team (Mitchell & Chaboyer, 2010).

Previous studies indicated that limitations to ICU visiting hours increased the risk of family member psychological distress (Eugênio et al., 2022). A growing evidence base has begun to elucidate the consequences of restricted visiting. At the time of the study, social distancing was recommended for all with much uncertainty affecting family members of patients in the ICU. Various new visiting policies and technologies were developed to help communication with

these families. Therefore, more studies are needed that increase our understanding of the impact of these visiting policies and technologies and what we can learn in terms of optimising family member outcomes.

Aim

To explore the experience of in-person visiting restrictions imposed during the pandemic on family members of patients with COVID-19 admitted to an ICU.

Method

Study Design

We conducted a descriptive qualitative study using semi-structured interviews.

Setting

The study was conducted in two general adult ICUs at one regional and one university hospital in Sweden. During the pandemic, the ICUs had a maximum capacity of 20 (university hospital) and 9 (regional hospital) beds for COVID-19 patients. In Swedish ICUs, the nurse-to-patient ratio is normally 1:2. Each ICU nurse has a nurse assistant to help with patient care. Due to the increased ICU capacity required to address the number of COVID-19 patients, nurse-to-patient ratios were as low as 1:6, requiring assistance from healthcare staff from anaesthesiology and operating departments, who had limited ICU experience. In-person visiting was restricted in April 2020 to safeguard staff and family members from COVID-19 infection. Policies for in-person visiting differed between hospitals. Exceptions were allowed when patients neared death. In some cases, family members were allowed at the bedside with appropriate personal protective equipment (PPE). In other cases, visitors were only allowed to view patients through

a window. The telephone was the primary mode of communication and in some cases videoconferencing.

Participants

Inclusion criterion were family members of adult patients admitted with COVID-19 during the first and second pandemic waves in Sweden (March to November 2020). The only exclusion criterion was the inability to speak or understand Swedish or English.

Data collection

Both ICUs were invited to participate in the study. A designated research nurse was asked to identify family members eligible for the interview. Family members were contacted by telephone by a member of the research team to provide study information and obtain informed consent. Family members who answered the phone within two attempts (they were called two times at different times within two days) were asked to participate in the study. Interviews were scheduled at a convenient time for the participants. Two ICU nurses trained in qualitative research and interview methods conducted the telephone interviews (December 2020 to March 2021), with semi-structured interview questions using an interview guide (Appendix 1). The interviews were held until we didn't get any new answers and we reached data maturity. The interviews were audio-recorded and transcribed by a professional transcript company.

Data analysis

We chose thematic analysis methods as described by Braun and Clarke (2006) to provide a detailed description of participant experience. For trustworthiness and rigour, we followed the process of six phases of thematic analysis. Two investigators (■■■■) read the transcript and listened to the material again examining patterns in the data. One author (■■) coded the data with the resulting long list being broken down into broad themes. Codes were sorted by content, and themes and sub-themes were identified using a mind map to help visualise the data. Two authors (■■■■) then discussed this to ensure arising themes were true to the meaning of the

data and to identify preliminary themes and subthemes. Themes were re-evaluated and discussed with another author (■■■■). We then examined whether themes reflected the entire dataset. Finally, data and themes were discussed with the whole research team, to reach agreement on the final result.

Ethics

Ethical approval was obtained from the Human Research Ethics Committee in Sweden (Approval no Ö 42-2020/3.1). Informed consent was obtained from the participants. Whenever needed, psychological support for a study participant was offered by those responsible for the study and the ICU.

Findings

We invited 27 family members, 6 declined and 21 were recruited, 11 from hospital A and 10 from hospital B. 15 (71%) were female; age range 27–74. The relationships to the patient in ICU included: parent (n=1), wife (n=6), husband (n=2), adult son or daughter (n=10), or sibling (n=2). Of these, 13 (62%) did not visit the ICU, 8 (38 %) were allowed in-person ICU visiting, of whom 7 (33%) visited wearing PPE, and the remaining participant visited via a window. Three of the participants experienced bereavement. **During admission to ICU, 10 participants were in contact with the patient via phone calls, 6 via video calls, 2 had the opportunity to use video calls but chose phone calls, and 3 participants had no contact with the patient at all.** The results are presented with one overall theme and two main themes one with three sub-themes, and the other with two (Figure 1). Quotations to illustrate each theme are shown in Table 1.

Figure 1. Overall theme with its main and subtheme

The overall theme identified from our dataset was ‘striving for closeness even at a distance. This theme encompasses participants’ experiences of being unable to be physically close to the patient when they needed it the most. Even participants allowed in-person visits perceived distance due to PPE or only allowed to visit via a window.

ICU team as a bridge between family members and patients

This main theme describes the information and support that participants received from the ICU team, family members’ involvement in care, and how participants perceived the care given to patients.

Phone calls are a lifeline to information for the family

Most participants felt that they received good, relevant, and comprehensible information about the patient’s condition. When information wasn’t understood, they felt comfortable asking for explanations to facilitate understanding. Daily updates via phone were mainly provided by ICU nurses, with contact from a physician to provide information about medical prognosis and progress. Most participants identified one family member who acted as a key contact person to avoid burdening staff. Participants appreciated the reassurance as a result of the staff telling them they could call anytime, but perceived a lack of a key ICU contact person. The lack of a key contact person led to participants talking to many different members of the ICU staff which was sometimes experienced as being difficult. Participants expressed that such a contact person could facilitate a trusting relationship with the ICU team and follow up on care plans. The university hospital provided such a contact person, which was greatly appreciated by

participants with a patient as a relative in this hospital. Waiting to receive a phone call from the ICU was described as difficult. The lack of information or difficulties in understanding made it harder for participants to comprehend the situation.

Digital aids to help communication between family and patient

Participants expressed that it was important to contact patients visually. They got in touch with the help of the ICU team, who relayed encouraging messages and greetings, put pictures up next to the patient, held the phone next to the patient's ear during phone calls, or helped connect the patient to video calls. Connections with patients were also established with recorded mp3 voice messages played by the ICU team. To stay in touch, participants suggested video calls, because it was important to see patients and remind them of their life and family outside the hospital. Participants appreciated seeing the patient, although they felt that patients who were sedated and intubated did not always profit from the video call. Participants sometimes experienced barriers to video calls particularly if the patient had hearing issues or was experiencing delirium. Seeing patients in poor health was challenging and led to feelings of worry and sadness. Participants suggested that a daily email from the ICU team summarising the patients' status could help satisfy their need for information.

Challenge of involvement in care

Participants who did not feel included in care identified that no one asked about the patient's personality or for their opinion in relation to care planning and decision-making. They felt a need to force information about the patient on the ICU team. When this information was ignored, it led to feelings of hopelessness. Disappointment and annoyance occurred when the participants' need for information was not met, or participants were misinformed or insufficiently informed. Frequent and comprehensible information made participants feel included in the care. Having their questions answered or answering questions about patients also contributed to feelings of involvement as did engagement and supporting the patient in

activities such as memory training and reorientation, by phone or, when allowed, in-person visiting. They also expressed gratitude for being allowed to leave personal belongings, such as photographs and food. This made them feel more connected to the patient, which they perceived would give them strength to recover.

Limited physical closeness

This main theme describes the participants' experiences of being unable to be close to the patients. It also describes their understanding of visiting restrictions and the special and unfortunate situation created by the pandemic.

Unable to provide important support and physical closeness at a distance

Participants wished for in-person visits to provide support and closeness to patients to give them the strength to recover. Participants indicated that telephone and video calls could not replace physical in-person visits which enable physical closeness in a way that no phone or video call can replicate. Participants also wished for an individualised assessment regarding the capacity to visit in person. Participants noted they were allowed to visit if the situation was acute such as when the ICU team considered the patient to be unstable, when participants were struggling to cope, e.g., during medical induced coma or when near death. During end-of-life situations, participants expressed that they wished they had been permitted to visit sooner. They felt stressed and worried that they would not make it in time.

Participants restricted from any in-person visiting identified that this led to feelings of uncertainty and psychological distress. The lack of information about the patient's condition made the whole situation seem unreal and made them feel lost, helpless, and powerless. Even if in a medically induced coma, participants thought the patient would have sensed and been encouraged by their presence.

When patients were awake and feeling better, participants felt an even greater desire to visit to encourage recovery and help them to cope with delirium-induced hallucinations, nightmares and the ICU environment. Those participants who were allowed in-person visits appreciated the opportunity to be close even though it was tough seeing the patient in a weakened condition. However, these visits still did not create feelings of closeness or nearness because of the required PPE. Participants felt forbidden to approach, touch, or hug the patients, which was perceived as challenging.

Understanding the situation also constitutes sacrifice

Participants not allowed to visit in person understood the reasons for the visiting restrictions (i.e., to protect themselves, the patients, and staff) and accepted them because of the pandemic. They worried that in-person visits could lead to COVID-19 infection, which would make life at home difficult.

The fear of losing the patient if their condition changed quickly, and not being there, constantly worried participants. Participants also felt a degree of gratitude for visiting restrictions, since they had learned that in-person visits were only permitted for severely ill patients nearing death.

Table 1

Themes and quotations

Main theme	Subthemes	Quotations
ICU* team as a bridge between family members and patients	Phone calls are a lifeline to information for the family	<i>“But this daily information that we received via phone calls from the family contact person, that information was, it has been incredibly good. I really, really appreciated it as a daughter [...] we call after [hours] and so did they. They were very flexible, and I appreciated that”</i>
	Digital aids to help communication between family and patient	<i>“They passed on greetings to him from me [...] he told me since he got home from the hospital, that they passed on greetings every time I called them”</i>

	Challenge of involvement in care	<p><i>“The ICU, they call relatives by Skype so that one can see. Even if they are sedated and on a ventilator, you can talk to them.. just to be able to talk, even if the doesn't answer me”</i></p> <p><i>“No, I haven't been involved at all. I kind of have no idea about what they do and don't do [...] It seems like no one accepts the information I give them, or at least doesn't put it in writing somewhere. I can't explain. And that makes one even more insecure. Why don't you accept the information?”</i></p> <p><i>“I remember they phoned me and asked about my mother's personality and such things”</i></p>
Limited physical closeness	Unable to provide important support and physical closeness at a distance	<p><i>“For us family members it is important to meet our loved ones [...] to see the process, to see the improvement [...] You don't really understand when they tell you, this parameter says this, that parameter says that. But when you see it with your own eyes”</i></p>
	Understanding the situation also constitutes sacrifice	<p><i>“Terribly hard, not being able to touch him and not being able to hug him, especially on the visits”</i></p> <p><i>“Mentally I understand how and why the situation is like it is, but emotionally it is incredibly hard”</i></p> <p><i>“I know that if he had been a little, little worse I would have been allowed to come in and say goodbye but by then it maybe would have been too late [...] So it has been terrible.”</i></p>

* Intensive Care Unit

Discussion

Our main findings show that family members need good and relevant information that is easy to understand. They wish for one key contact person to handle the information sharing about

the patient. That could make it easier to facilitate a trusting relationship and follow up on care plans. Participants in our study expressed the importance of contact with the patient, preferably through in-person visits but if that were not possible, with video calls. Participants in our study expressed that they wanted the ICU staff to ask questions about the patient, and information and communication with the care team were key to making them feel involved in the care. Most important for participants were in-person visits. Participants felt that physical closeness at the bedside was very important when having a relative as a patient in the ICU. Other studies conducted during the pandemic also show that it is important for family members to be present at the bedside to be able to advocate for and support recovery (Creutzfeldt et al., 2021). When in-person visiting restrictions were applied in ICU during the COVID-19 pandemic, our study shows that family members constantly strived to compensate for not being present bedside. Video calls, sending personal photos to the patient and a dedicated contact person in the ICU team albeit, over the phone, became highly important to our participants.

When information needs are met it increases family members' positive perception of the care provided (Ersek et al., 2021; Feder et al., 2021). We found that when a family member's need for information was not met, or when they were given the wrong information, they experienced feelings of disappointment, frustration, and irritation. When communication fails, family members lose confidence in the ICU team which can lead to anxiety and higher stress levels (Cody et al., 2018). When information channels are limited, such as during in-person visiting restrictions, feelings of not having information needs met increase. When in-person visits are allowed, information sharing occurs at the patient's bedside. Interacting with the ICU team and seeing the patient's condition might lead to a deeper understanding of the patient's condition.

Eugênio et al. (2022) also found that flexible in-person visiting in ICU allows more information sharing between ICU-staff and families, decreases families anxiety and stress, and increases family satisfaction with care.

We identified that those family members who interacted with a specific ICU contact person were more satisfied with information access than those who were not given a key contact. This appeared to create a sense of trust and safety. Participants without a specific key contact expressed difficulties talking to many different members of the ICU team, particularly following up on decisions and building a trusting relationship. Previous research validates the importance of a single point of contact for ICU family members (Creutzfeldt et al., 2021; Frivold et al., 2015).

Our participants repeatedly highlighted the importance of in-person visits to support the patients, provide physical closeness, and strengthen their fight for recovery. While video calls were not perceived as a replacement for in-person visits, they provided information and enabled the family members some perception of involvement in care. Previous research also shows that in-person visits cannot be replaced by video calls but it is better than not seeing the patient at all (Rose, Graham, et al., 2022). Previous research also shows that virtual visits can facilitate information-sharing but does not seem to replace family member needs to be there for the patients (Kennedy et al., 2021). Video calls could decrease family members' feelings of psychological distress (Rose, Cook, et al., 2022) and provide relief seeing the patient is alive (Rose, Graham, et al., 2022). Video calls can be used to improve patient-centred care, reorientate delirious patients and overcome barriers to communication or language difficulties (Rose et al., 2021) when in-person visits are not possible. Even though video calls can reduce psychological distress, many family members still experience severe distress despite video calls (Rose, Cook, et al., 2022). Video calls can provide support and bring happiness to families, but can also be emotionally challenging and can be problematic as a member of the ICU team is unable help family members cope after a video call in the same manner as if the visit was in person (Jeitziner et al., 2022). The restriction of in-person visits was experienced as psychologically distressing for participants and could make them feel lost, powerless and

hopeless. Studies both before and during the COVID-19 restrictions validate these findings (Bjork et al., 2019; Cody et al., 2018; Creutzfeldt et al., 2021; Klop et al., 2021). In-person visits are the most important for our participants, and other studies validate these findings (Bartoli et al., 2022; Rose, Cook, et al., 2022) even though it could be upsetting to see the patient in such a serious state, it also created an increased comprehension of the situation (Bartoli et al., 2022).

Although participants understood why visiting restrictions were in place, they also recognised the importance of their presence to provide patients comfort and support during a critical illness. Research shows that patients feel their family members' presence in ICU, even while asleep, increasing their sense of security and inner calm (Engström & Söderberg, 2007), **decreasing patients stress and anxiety** (Eugênio et al., 2022) and empowering them to fight harder for recovery (Engström & Söderberg, 2007; Mitchell & Aitken, 2017). Family member presence at the bedside also connects patients to the social context outside the ICU and can provide a reality check for the patients, dispelling hallucinations and delusions associated with delirium (Olsen et al., 2009; Ringdal et al., 2008).

Limitations

Despite efforts to ensure rigour and data trustworthiness, this study has limitations. First, there is a limitation because of the different routines in the two hospitals due to visiting restrictions and the changes in routines during the study. During the first wave of COVID-19, in the spring of 2020, little was known about the disease and safety equipment was lacking, which may have influenced in-person visiting restrictions. However, participants had different visiting experiences which provided us with a broader picture of their experiences. Second, we had no information about the conditions of the patients, which would have impacted the participants' points of view. Third, the data is obtained through phone calls and therefore we might have missed out on important information or our interpretation of the information through the

participants' facial expressions, posture and body language. Finally, this is a convenience sample, although we aspired to have the same number of participants from the two hospitals and reached maturity in the data as no new information emerged. As a narrative, this study will make an important contribution to the family situation in ICU during the extraordinary circumstances of the pandemic.

Conclusion

In this descriptive qualitative study of family members experiencing visiting restrictions in Swedish ICUs, we found the importance of straightforward and comprehensible information to family members from a dedicated contact person in the ICU even more important than when in-person visiting is allowed. Clinicians need to strive for optimising patient and family involvement, even in situations when a physical presence is hampered. Hence, healthcare providers should invest in digital solutions to take advantage of family member knowledge of the patients to maintain family-centred care in the ICU when in-person visits are restricted. Since phone calls seem to help keep family members informed and to gain knowledge of the patient, further digital investments may be a good idea for the contact between family members and patients.

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Abstract

Background: Family member presence in the intensive care unit (ICU) is important for patient well-being and recovery. Limitations to ICU visits increase the risk of psychological distress in family members. During the COVID-19 pandemic, in-person visiting restrictions were introduced to prevent the spread of infection.

Purpose: To explore the experience of in-person visiting restrictions imposed during the pandemic on family members of patients with COVID-19 admitted to an ICU.

Method: Qualitative method with thematic analysis. Individual semi-structured telephone interviews were conducted.

Findings: We interviewed 21 family members. The results are presented in one overall theme with two main themes and five sub-themes. The theme ‘Striving for closeness even at a distance’ describes the experience of being kept at a physical distance when participants needed closeness the most. Even participants who were allowed in-person visits perceived a ‘distance’ due to personal protective equipment or because they could only view the patient from a window. Participants reported that contact with and information about the patient was of utmost importance. Visits were viewed as essential in providing for the patient’s wellbeing. Meaningful contact with the ICU team was vital for getting useful information. Phone calls became a lifeline, with digital aids such as video calls used occasionally to overcome the feeling of distance.

Conclusion: Visiting restrictions imposed during the COVID-19 pandemic made straightforward and comprehensible communication of information from the ICU team more essential to reduce family members’ perceptions of distance and exclusion from the ICU.

Keywords: Covid-19, Experiences, Family, Family-Centered Care, Intensive Care, Nursing, Qualitative, Relative, Visitor Restrictions

Ethics

Ethical approval was obtained from the Human Research Ethics Committee in Sweden (Approval no Ö 42-2020/3.1). Informed consent was obtained from participants. Whenever needed, psychological support for a study participant was offered from those responsible for the study and the ICU.

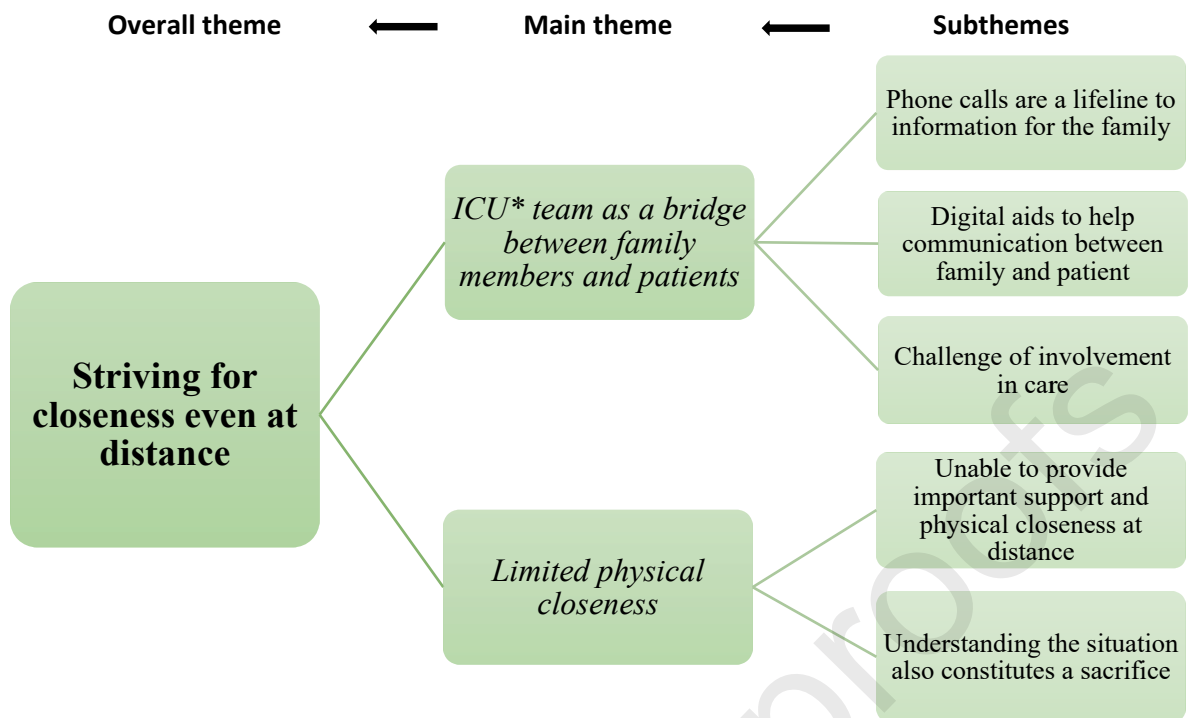


Figure 1. Overall theme with its main and subthemes

* Intensive Care Unit