




RESEARCH ARTICLE

Piloting and watch over in the end-of-life care of intensive care unit patients with COVID-19—A qualitative study

Charlotte Pettersson RN, CCN, MSN¹ | Johanna Forsén RN, CCN, MSN¹ |
 Eva Joelsson-Alm RN, CCN^{1,2} | Isabell Fridh RN, CCN³  |
 Gunilla Björling RN, CCN^{4,5,6}  | Janet Mattsson RN, CCN^{5,7,8} 

¹Department of Anaesthesiology and Intensive Care, Stockholm South General Hospital, Stockholm, Sweden

²Department of Clinical Science and Education, Karolinska Institutet, Stockholm, Sweden

³Faculty of Caring Science, Work Life and Social Welfare, University of Borås, Borås, Sweden

⁴School of Health and Welfare, Jönköping University, Jönköping, Sweden

⁵Department of Neurobiology, Care Sciences, and Society, Karolinska Institutet, Stockholm, Sweden

⁶Faculty of Nursing, Kilimanjaro Christian Medical University College, Moshi, Tanzania

⁷Faculty of Nursing and Health Sciences, University of South-Eastern Norway, Notodden, Norway

⁸Department of Health Science, Kristianstad University, Kristianstad, Sweden

Correspondence

Janet Mattsson, Department of Neurobiology, Care Sciences, and Society, Karolinska Institutet, SE-177 76 Stockholm, Sweden.
 Email: janet.mattsson@usn.no

Abstract

Background: During the COVID-19 pandemic, intensive care units (ICUs) were under heavy pressure, with a significantly increased number of severely ill patients. Hospitals introduced restrictions, and families could not visit their ill and dying family members. Patients were cared for without privacy, and several died in shared patient rooms, leaving the intensive care nurse to protect the patient's need for loving care in a vulnerable situation at the end of life.

Aims: This study aimed to investigate how piloting and watch over were revealed in end-of-life care for patients with COVID-19 in intensive care COVID-19.

Study Design: A qualitative study was conducted with an abductive approach was conducted. Data were collected via semi-structured interviews to cover the research area while allowing the informant to talk freely about the topic; 11 informants were interviewed.

Results: The findings are presented based on four categories: *The road to the decision*, *End-of-life care*, *Farewell of close family members* and *Closure*. Each category and sub-category reveal how piloting and watch over were addressed in the end-of-life care of patients with COVID-19 in the ICU during the pandemic. Overall findings indicated that workload and organization of care directly affect the quality of care given, the acceptance of privacy and the possibility of dignified end-of-life care.

Conclusions: Workload directly affects the quality of care, risking dehumanization of the patient. Visiting restrictions hindered supporting family members through the various piloting phases. Visiting restrictions also forced the ICU nurses to take on the role of the relative in watching over the patient.

Relevance to Clinical Practice: Collaboration with family members is essential for the intensive care nurse to be able to provide a person-centred and dignified end-of-life care.

KEYWORDS

COVID-19, end-of-life care, ICU, nursing care

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial-NoDerivs](https://creativecommons.org/licenses/by-nc-nd/4.0/) License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2024 The Author(s). *Nursing in Critical Care* published by John Wiley & Sons Ltd on behalf of British Association of Critical Care Nurses.

1 | INTRODUCTION

During the COVID-19 pandemic, intensive care units (ICUs) were under heavy pressure, with a significantly increased number of severely ill patients. The mortality rate for COVID-19 patients in intensive care was initially high, and knowledge of infection routes and treatment was lacking. Hospitals introduced restrictions, and families could not visit their ill and dying family members. Patients were cared for without privacy, and several died in shared patient rooms, leaving the intensive care nurse to protect the patient's need for loving care in a vulnerable situation at the end of life. For good end-of-life care, it is essential that the nurse supports the family and facilitates them to watch over the dying patient.

2 | BACKGROUND

During the first wave of the COVID-19 pandemic in Sweden, the number of ICU patients more than doubled, and the total ICU mortality increased from 7.4% to 9.4%.¹ Operating theatres, recovery wards and similar premises were converted into ICUs to enable more patients to be cared for.^{1,2} The care team was reinforced with other health care professionals because of a shortage of ICU nurses.³ The ICU nurse in charge often had responsibility for more patients than usual, which led to primary nursing care being deprioritized.¹

In the ICU, the transition from therapeutic to palliative care is a challenge, and the decision to withdraw life-sustaining treatment has long been an ethical dilemma and one of the most challenging tasks.⁴ Both staff and family members may feel that 'nothing' is being done when treatment ends, and they might also think that continuing the medical treatment exposes the patient to prolonged suffering.^{5,6} The COVID-19 pandemic led to difficult ethical decisions and lack of space required prioritization of intensive care beds in favour of patients with the best prognosis and decisions to accelerate the withdrawal of life-sustaining treatment taken.⁷ Older adults with a history of previous illness were in some cases, only offered palliative sedation.⁸ Visitation restrictions prevented family members from meeting their dying family members.⁷ Dying patients without the presence of family members are particularly vulnerable, and the intensive care nurse must, therefore, safeguard the patient's need for care.^{9,10} Information and support for the patient's family is a pivotal part of the nurse's duties.^{9,10} Continuous, clear and truthful information about the patient's condition is vital for family members and can improve the outcome of end-of-life care.¹¹ Health professionals also find that family members present at the end of a patient's life find it easier to understand and accept death.¹² Family members may feel that being with their critically ill loved one is the most important thing. However, seeing the person being seriously ill might be frightening and seem unreal.¹³ It can be experienced as a theft of their shared time if they must sit and wait in another room.¹⁴ The most challenging part is waiting for information and not knowing whether their family member will survive.¹³ The possibility of privacy is a wish held by family

What is known about the topic

- Family members experience proximity to the sick person, flexible visiting hours, good communication with the staff and the opportunity for privacy are essential parts of end-of-life care.
- For good end-of-life care, the nurse must facilitate the close relatives watching over the dying patient and pilot family members through the final period.
- During the Covid-19 pandemic, family members have not been allowed to visit their seriously ill family member or have had the opportunity to say goodbye in connection with death.

What this paper adds

- Overall findings indicate that workload and organization of care directly affect the quality of care given, the acceptance of privacy, and the possibility of dignified end-of-life care.
- Visiting restrictions led to ICU nurses having to take on the role of the relative in watching over the patient.
- Family members are an essential resource for the intensive care nurse to be able to provide person-centered care, and the absence of family members increases the risk of dehumanization of the patient.

members.¹¹ However, the environment of an ICU and the lack of single rooms obstruct giving patients a dignified end.^{10,15}

2.1 | Piloting and watching over

Piloting and watch over are two essential concepts for nursing care at the end of life in the ICU. Piloting is a structured caring act, which implies intimate knowledge of dying, and of all its difficulties and dangers, to be followed by family members. It is an act performed by nurses/carers to benefit patients and family members. When the family members are absent, they will miss this support, and the nurses/caregivers take over the vigil without the emotional involvement that the term implies for family members.¹⁶

From a caring science perspective, watch over means being present by someone's side to protect, assist and support in connection with serious illness and dying. This is done continuously by health care professionals or family members and involves an emotional commitment where one's own needs are set aside to care for the dying patient.¹⁷ During the pandemic, dying patients were cared for without privacy in multi-bedrooms, and family members could not visit their loved ones or, in case of death, say goodbye. There is limited research on how this has affected nursing care in the ICU.

3 | AIM

This study aimed to investigate how piloting and watch over were revealed in end-of-life care for patients with COVID-19 in intensive care during the pandemic.

4 | METHOD

4.1 | Design

A qualitative study with an abductive approach,¹⁸ which meant that an iterative process between theoretical concepts and tentative explanations was conducted. The study was reported according to the Standards for Reporting Qualitative Research—a synthesis of recommendation (SRQR) checklist.¹⁹

4.2 | Setting

Intensive care nurses at four ICUs at three different hospitals, level one and two, in Sweden were asked to participate in the study. The wards where the informants worked during the pandemic had increased patient beds and had to open and equip makeshift wards, such as operating theatres and postoperative wards. Staff from operating and anaesthetic wards were reassigned to work in these wards. Hospitals also called in undergraduate nurses from wards, teams from private clinics and other staff were also called upon. ICU nurses reported being responsible for two to four patients during their shifts.

4.3 | Sampling

Strategic sampling was used to generate rich material and obtain data variations. Each head of the ICU was contacted by email and sent an information letter. They, in turn, sent an interest request via email to all intensive care nurses on the ward with the attached study information. The informants voluntarily registered their interest to the head of the ICU or the authors directly. A consent form was signed in connection with the interview.

4.4 | Inclusion criteria and participants

The inclusion criteria were that the ICU nurses should have cared for COVID-19 patients at the end of life. Eleven nurses working in ICU for 1.5–23 years were included in the study.

4.5 | Data collection

Data were collected via semi-structured interviews to cover the research area while allowing the informants, 11 ICU nurses, to talk

freely about the topic. One pilot interview took place before the interviews started. No questions were altered, and the analysis included the pilot interview. The interviews were conducted consecutively after the informants agreed to participate in the study between February and March 2022. The interviews ranged from 19 to 30 min, with a median time of 25 min. To ensure confidentiality, names and workplaces were omitted from the transcribed material, and the transcribed text was stored securely where no unauthorized persons had access.

4.6 | Data analysis

Data were analysed using a deductive, or a priori, analysis which means applying theory¹⁷ to the data after the inductive phase. The analysis followed Graneheim and Lundman's²⁰ methodological description, aiming to identify patterns in the text and describe similarities and differences in the data based on these patterns. The material was analysed in the first stage using a deductive approach, meaning that the analysis is based on the four critical phases of piloting: presence, protection, preparation, termination, and the concept of watch over,¹⁷ which were used as predetermined domains in the study. The recorded interviews were listened through and then transcribed verbatim, including laughter and pauses. The texts were checked against the audio recordings to understand the whole. The texts were then reread with the five domains in mind and carefully reviewed repeatedly by the authors.

Meaning-bearing units relevant to the domains were identified. These were highlighted in the text and then copied into a new document. In the next step, meaning units were condensed to make the text more manageable without losing central content. The condensed sentence units were then coded using an analysis matrix based on the five domains. Each domain was sorted, and codes with similar content were divided into subcategories. Some sentence units were then found to belong to a different domain and moved to another subcategory. The analysis resulted in eight subcategories, which were scrutinized using an inductive approach, which means that an unbiased analysis was made, looking for patterns and differences in the material.¹⁸

4.7 | Ethical aspects

The World Medical Association Declaration of Helsinki²¹ has guided ethical considerations throughout the study. The heads of the ICUs approved the study before it started. Participants were given written and verbal information about the study before the interviews. Participation was voluntary, and they could withdraw without explanation and any effects on their work situation. Informants gave written consent to participate.

5 | FINDINGS

The findings are presented based on four categories: *The road to the decision*, *End-of-life care*, *Farewell of close family members* and *Closure*

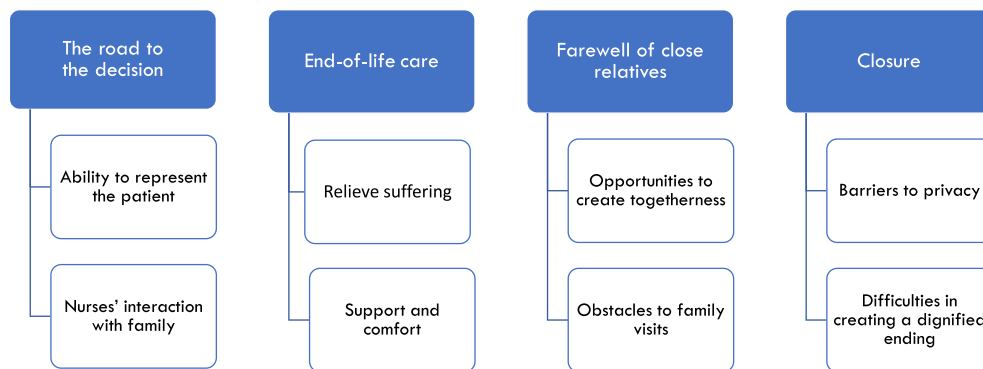


FIGURE 1 Overview of categories and subcategories.

(Figure 1). Each category and subcategory reveal how piloting and watch over were addressed in the end-of-life care of patients with COVID-19 in the ICU during the pandemic. Overall findings indicated that workload and organization of care directly affect the quality of care given, the acceptance of privacy and the possibility of dignified end-of-life care.

5.1 | The road to the decision

This category and its subcategories highlight the process of deciding the patient's clinical pathway during end-of-life care. It highlights how difficult it has been for ICU nurses to support family members through the various piloting phases and uncovers ethical dilemmas for ICU nurses.

5.1.1 | Ability to represent the patient

During the COVID-19 pandemic, it was less common for patients and their family members to be involved in decisions to discontinue life-sustaining treatment. It was difficult to inform patients of the decision because of their severe condition, and knowledge was limited about the course of the disease and treatment. If the patient expressed the desire to continue to fight or interrupt care, the staff tried to respect this wish. The team discussed with the patient the pros and cons of the treatment. In cases where the patient was too ill to decide or affected by their condition, the staff had to determine whether the continued care would benefit the patient. If family members had a different wish, the staff represented the patient and spoke on their behalf. This excerpt highlights this:

they've kind of been with this NIV mask and they've been fighting for air and still kind of been done with, I don't want this. And then they had this conversation and after the conversation, it became so peaceful in a way.

(informant 7)

Often, when working in teams, doctors and nurses discussed and jointly decided to discontinue life-sustaining treatment. If the nurse

was at the bedside with the patient and could not participate in the discussion, they did not feel involved in the decision. Sometimes, the arguments for the decision were perceived as vague or forced through because of lack of space. When treatment restrictions were introduced, such as forgoing cardiopulmonary resuscitation, it was perceived that staff began to give up, and the care process lost momentum. The considerable number of severely ill patients where life-sustaining treatment was withdrawn was debilitating and led to patient de-identification. Staff referred to them as bed numbers, and it was difficult to establish any relationship with the patient when family members were not allowed to visit.

5.1.2 | Nurses' interaction with family

Family members were updated daily by telephone, with the physician as the primary contact. Therefore, nurses had fewer opportunities to obtain information about their patients' daily lives before falling ill.

A patient's condition could change rapidly from stable to life-threatening, making it difficult to inform and prepare family members. Sometimes, the family was informed by telephone about the decision to transition to end-of-life care. At that time, the nurse had no opportunity to participate. Even if the conversation took place in the ICU, it was difficult for the nurses to participate because of the heavy workload. If the family objected to the decision or the patient wanted to fight longer, their wishes were respected. The excerpt below highlights this:

It also felt like many times we were running for a very long time before decisions were made. Just because family members wanted it differently. Many times, we wanted to give up earlier.

(informant 1)

Because family members could not visit and had not gained an insight into their relative's disease, conflict could arise when they opposed the decision to discontinue life-sustaining treatment. The fact that nurses had not met them before the decision to withdraw the life-sustaining treatment was made, was perceived as creating additional distance to the family members. The nurse had to explain

the environment in the ICU and, at the same time, try to comfort and support family members.

5.2 | End-of-life care

This category and its subcategories highlight the process of watching over the patients in the clinical setting during end-of-life care. It emphasizes how the watch over was related to suffering for the patient and the ICU nurses in diverse ways.

5.2.1 | Relieve suffering

The informants described the time spent caring for patients as one long struggle. The sedated patients were turned to the prone position to improve oxygenation, and when they were turned back on their backs, they deteriorated. Patients who were not sedated felt anxious and stressed because of breathing difficulties, and this suffering was hard for nurses to alleviate. The patients often struggled for a long time until they expressed that they could not take it anymore. The nurses then tried to relieve their suffering. However, once the decision to withdraw life-sustaining treatment was made, there was a sense of calm. The excerpt below highlights this:

When you have been fighting for the patient to survive but at the same time there comes a point when you can't, it's not possible to save the life and then you just want the patient not to suffer.

(informant 10)

When collaborating with a physician temporarily working in the ICU during the pandemic, informants saw decision-making pathways becoming unnecessarily long, thus prolonging the suffering of patients.

5.2.2 | Support and comfort

During the COVID-19 pandemic, ICU nurses had to take on the role of the relative in watching over the patient. They were constantly present with the patients throughout the disease. When it was time for the patient to die, someone from the staff sat next to the patient, held hands and tried to comfort the patient. However, sometimes, the workload was overwhelming, and the patient died without closeness. The excerpt below highlights this:

When you see that it is close, you sit down there when the opportunity arises and hold hands if family members are not present. That is the way it was because most of them actually died alone.

(informant 9)

It was perceived as highly challenging to care for awake patients when life-sustaining treatment was withdrawn. It was difficult to cope with being present, facing the patient's anxiety, looking them in the eye and seeing their struggle while breathing. Patients were often without a loved one when told they would not survive, and that life-sustaining treatment would be withdrawn. The patients were awake and could have a dialogue with the ICU nurse:

She was reading a book because she was so, she hardly looked sick, except that she had a hard time breathing. And I had just finished that book, so we sat and discussed what it was about. Yeah, she was so full of life as well, she was watching TV on her app, and she was talking to her family members. You could not believe that, just two, three days later she, well she passed away.

(informant 8)

For nurses, memories of individual patients were few and the relation with the patient became secondary to making them survive. The lack of contact with family members meant that the nurses were not as emotionally affected as they used to be. The protective equipment also led to a feeling of distance and numbness; one could not be close and see, feel and hear as before the pandemic.

5.3 | Farewell of close family members

This category and its subcategories highlight how watching over ICU patients' end-of-life care altered from being conducted by the family to being the nurses' responsibility, jeopardizing privacy and closure for the patient and family and giving the ICU nurse an unwanted part of an intimate encounter.

5.3.1 | Opportunities to create togetherness

Despite visitation restrictions, the family was sometimes contacted and offered visits when staff saw deterioration in the patient and survival was uncertain. The staff ensured that family members and patients could meet safely from an infection control perspective. The excerpt below shows this:

We always let family members visit when it was near the end. I thought it was important to keep that because it is horrible to have to die alone, even though several patients had to do it anyway.

(informant 6)

A visit to the ward enabled the family to understand the decision to end the life-sustaining treatment. However, a visit from the family to say goodbye could feel as if the staff had made a mistake as the family only visited when the patient was dying.

Families were offered alternative ways as telephone calls, Face-Time and Zoom meetings to have contact and say goodbye to the dying patient. It was perceived as positive. On the other hand, privacy and good closure were compromised when family members said goodbye over the phone and ICU nurses held the phone to the patient's ear, hearing every word.

5.3.2 | Obstacles to family visits

Informants experienced frustration with the restrictions on visits by families of dying patients. Especially at the beginning of the pandemic, there was neither space nor time for family. Patients who were dying benefited from having a family member by their side, the excerpt below highlights this:

It is a double sorrow that you are losing your loved one but also that you have not been able to support and be there and help in some way with what you can as a relative.

(informant 2)

Sometimes, families were reluctant to visit the hospital because they feared being infected or because of a troubled relationship with the patient. Even though the health care staff went to fetch the family, some still did not dare to come. In retrospect, the family has given a voice to a feeling of as if they are living in a nightmare and as if the deceased is still alive. The nurses described that the part of their job that involves supporting the patient and the family members was felt to be lost.

5.4 | Closure

This category and its subcategories highlight the process of piloting and watching over patients during the last moments of life. It highlights how the closure was related to breached privacy and dignity for the patient, fellow patients and the ICU nurses in diverse ways.

5.4.1 | Barriers to privacy

It was impossible to provide single rooms for patients as care was given to 6–9 patients per module. Single wards were redesigned to accommodate two patients. Operating theatres were transformed into wards, where three patients could be cared for:

No, of course, you wished you didn't finish two next to each other with only a folding wall in between, but we had nowhere else to go and this was necessary. We could not postpone it because there was no time.

(informant 1)

On occasions when life-sustaining treatment had to be withdrawn, a screen around the patient shielded the patient in a crowded room. Also, the patient was moved to the far end of the room for privacy. However, situations arose where life support was withdrawn from one patient as other patients were cared for, neither sedated nor conscious, in the same room.

5.4.2 | Difficulties in creating a dignified ending

Environmental constraints and workload made it challenging to provide dignified end-of-life care. During the first wave, patients died in chaotic conditions with other patients in the same room, where life-sustaining treatment had to be completed on several patients simultaneously. Nurses could work several hours without noticing that fellow nurses' patients had died. In these situations, there was no time to do anything extra for families at the end. In the second wave, it was more common for patients to be aware and communicate with their loved ones when the curative treatment was completed and 'turned off'.

It was just awful really. When we were going to shut down there. He was awake and they were communicating the last thing and then we turned it off and they were standing there crying and screaming like: 'We love you! It felt like we were at an execution. Intensive care is something completely different for me.

(informant 4)

The lack of privacy felt unethical, and the protective equipment was perceived as challenging to comfort family and patients when shouting to make oneself heard through the shields. It built a barrier to creating a dignified environment. Also, handling the dead felt unethical and immoral as the conditions of the pandemic changed routines rapidly. At the beginning of the pandemic, the dead were placed directly in burial bags and transported away immediately, which meant that family members were not allowed to say goodbye:

You're used to the fact that when a patient passes away, you make it into something that's still a bit natural and beautiful in some way. Now it was just keeping all the entrances, and down in this, it is not called a body bag but.... Pull up some thick zipper and put a knot around it.

(informant 3)

Every effort was made to ensure that the moment of death was dignified for both family and patient. It was considered necessary that closure was calm when family members were present. Patients deemed gasping for air were sedated so family members would feel that the patient had a dignified death. Special requests at the end of life were met, when possible, like playing the patient's favourite music. When family members were absent, staff stood or sat down with the patient, waiting for death.

6 | DISCUSSION

The results showed that piloting as a care process was not fully transferable to the conditions through the pandemic. Piloting as a care process aims to support the dying patient and their family members in end-of-life care. The intensive care nurse is present with the dying patient, represents the patient, protects the patient from scrutiny and alleviates symptoms. By facilitating family and patient interaction, acting as an interpreter for the family and coordinating the withdrawal of supportive care, the ICU nurse prepares the patient and family for the end of life. In the final piloting phase, the ICU nurse, in Sweden, tries to create a dignified death.⁹ Visiting restrictions meant that family members could not be present to the same extent as before the pandemic, and ICU staff had to assume the role of family members in this process. Families are, in Sweden, a significant resource for the ICU nurse to provide person-centred nursing care.^{22,23} The considerable number of patients, high workload and working environment increased the risk of dehumanization and contributed to difficulties in creating a dignified ending. Also, the environment and rapidly changing routines jeopardized the privacy and dignity of the patients and their families, putting the nurses in an ethically demanding position. Fridh and Åkerman¹⁵ considered the environment in an ICU, in Sweden, to be an obstacle to giving patients a dignified ending. When the life-support treatment was withdrawn, the nurses felt it was challenging to be present with awake patients. Other studies in the United Kingdom,^{10,24} also reflect this finding. In line with Wendlandt et al.¹² from the United States, the informants stated that the care period could be prolonged, and sometimes, the decision to withdraw life-sustaining treatment was delayed, which led to suffering for the patients. The decision delay could be the result of insufficient knowledge and experience about the disease, lack of intensive care expertise of the responsible physician or family members opposing the decision. Several studies from France, the United States and Sweden also described similar findings.²⁵⁻²⁸

Dehumanization involves a loss of control, respect and integrity for the patient and can make the patient feel like an object.^{28,29} Nurses described the considerable number of patients where life-sustaining treatment was withdrawn as debilitating and depressing, contributing to an increased dehumanization of patients. The number of patients also meant that patients were referred to by room number, not name. This lack of involvement made it a challenge to be present and care for awake patients. Other studies also reflect these findings.¹⁶⁻²⁸ In line with Wendlandt et al.¹² the nurses stated that the care period could be prolonged, and sometimes, the decision to withdraw life-sustaining treatment was delayed, leading to suffering for the patients and ethical challenges for the nurses. This means that nurses can detach their emotions from the patient, increasing the risk of dehumanization.^{28,30} Another example of dehumanization from the organizational perspective was how the handling of the deceased was considered immoral and unethical by the informants. The dead were placed in funeral bags sealed with cable ties, sanitized and transported away without the family members having the opportunity to say goodbye, which Montgomery et al. also described in their study.²⁴ In

this scenario, no time was given or support for a dignified and comforting ritual, something that can help process the grief of losing a patient.³¹ This may have affected staff negatively, physically and psychologically.

7 | LIMITATIONS

Informants were from the same region in Sweden, which is a weakness as parts of the organization were similar. It could have increased the transferability of the study if informants from other areas in Sweden were included. Most interviews were conducted digitally as it was easier to find a suitable time. A disadvantage of digital interviews is that there is no closeness and nuances in the participant's language can be missed. Facial expressions and gestures may also be missed.

8 | IMPLICATIONS FOR PRACTICE

The results can be used to develop a framework to provide person-centred care, together with family members during the process of end-of-life care. It is pivotal for both family and patients to say goodbye without restrictions, regardless of the circumstances. When deciding to withdraw life-sustaining treatment, everyone in the team around the patient must be involved. Ethical rounds can be an aid to these decisions and facilitate a closure. During the pandemic, the use of digital tools evolved. These can be a complement for contact between family members and patients but cannot replace a physical visit.

9 | CONCLUSION

Family members are a crucial resource for the intensive care nurse to provide person-centred care, and the absence of family members increases the risk of dehumanization of the patient.

Visiting restrictions hindered supporting family members through the various piloting phases. Visiting restrictions meant that the ICU nurses had to take on the role of the relative in watching over the patient.

ETHICS STATEMENT

The study was approved by the University Ethical Committee and follows the Swedish ethical regulations and the Declaration of Helsinki (World Medical Association, 2018). Permission to conduct the study was also obtained from the heads of the intensive care units before the study started.

PATIENT CONSENT STATEMENT

The participants were given written and verbal information about the study before the interviews. Participation was voluntary, and the participants could withdraw without explanation without any effects on their work situation. All informants gave their written consent to participate.

DATA AVAILABILITY STATEMENT

Data can be seen on request. It is anonymised due to its nature.

ORCID

Isabell Fridh  <https://orcid.org/0000-0002-9828-961X>

Gunilla Björling  <https://orcid.org/0000-0003-1445-900X>

Janet Mattsson  <https://orcid.org/0000-0002-4091-3432>

REFERENCES

- Bergman L, Falk AC, Wolf A, Larsson IM. Registered nurses' experiences of working in the intensive care unit during the COVID-19 pandemic. *Nurs Crit Care*. 2021;26:467-475. doi:10.1111/nicc.12649
- Stattin K, Frithiof R, Hultstrom M, Lipcsey M, Kawati R. Strain on the ICU resources and patient outcomes in the COVID-19 pandemic: a Swedish national registry cohort study. *Eur J Anaesthesiol*. 2023;40:13-20. doi:10.1097/EJA.0000000000001760
- Jensen HI, Akerman E, Lind R, et al. Conditions and strategies to meet the challenges imposed by the COVID-19-related visiting restrictions in the intensive care unit: a Scandinavian cross-sectional study. *Intensive Crit Care Nurs*. 2022;68:103116. doi:10.1016/j.iccn.2021.103116
- Coombs MA, Addington-Hall J, Long-Suthehall T. Challenges in transition from intervention to end of life care in intensive care: a qualitative study. *Int J Nurs Stud*. 2012;49:519-527. doi:10.1016/j.ijnurstu.2011.10.019
- Truog RD, Campbell ML, Curtis JR, et al. Recommendations for end-of-life care in the intensive care unit: a consensus statement by the American college [corrected] of critical care medicine. *Crit Care Med*. 2008;36:953-963. doi:10.1097/CCM.0B013E3181659096
- Gonzalez-Rincon M, Diaz de Herrera-Marchal P, Martinez-Martin ML. The role of the nurse at the end of the life of a critically ill patient. *Enferm Intensiva (Engl Ed)*. 2019;30:78-91. doi:10.1016/j.enfi.2018.02.001
- Reignier J, Kentish-Barnes N, Boyer A, Laurent A, Azoulay E, Reignier J. Ethical dilemmas due to the Covid-19 pandemic. *Ann Intensive Care*. 2020;10:84. doi:10.1186/s13613-020-00702-7
- Palacios-Cena D, Velarde-Garcia JF, Espejo MM, et al. Ethical challenges during the COVID-19 pandemic: perspectives of nursing students. *Nurs Ethics*. 2022;29:264-279. doi:10.1177/09697330211030676
- Fridh I, Forsberg A, Bergbom I. Doing one's utmost: nurses' descriptions of caring for dying patients in an intensive care environment. *Intensive Crit Care Nurs*. 2009;25:233-241. doi:10.1016/j.iccn.2009.06.007
- Efstathiou N, Walker W. Intensive care nurses' experiences of providing end-of-life care after treatment withdrawal: a qualitative study. *J Clin Nurs*. 2014;23:3188-3196. doi:10.1111/jocn.12565
- Fridh I. Caring for the dying patient in the ICU - the past, the present and the future. *Intensive Crit Care Nurs*. 2014;30:306-311. doi:10.1016/j.iccn.2014.07.004
- Wendlandt B, Kime M, Carson S. The impact of family visitor restrictions on healthcare workers in the ICU during the COVID-19 pandemic. *Intensive Crit Care Nurs*. 2022;68:103123.
- Engstrom A, Soderberg S. The experiences of partners of critically ill persons in an intensive care unit. *Intensive Crit Care Nurs*. 2004;20:299-308; quiz 09-10. doi:10.1016/j.iccn.2004.05.009
- Fridh I, Forsberg A, Bergbom I. Close family members' experiences of caring and of the physical environment when a loved one dies in an ICU. *Intensive Crit Care Nurs*. 2009;25:111-119. doi:10.1016/j.iccn.2008.11.002
- Fridh I, Akerman E. Family-centred end-of-life care and bereavement services in Swedish intensive care units: a cross-sectional study. *Nurs Crit Care*. 2020;25:291-298. doi:10.1111/nicc.12480
- Fridh I. To watch (Vaka och vakandet). In: Wiklund Gustin L, Asp M, eds. *Concepts in Caring Science, Theory and Practice (Vårdvetenskapliga Begrepp i Teori Och Praktik)*. 3rd ed. Studentlitteratur; 2023.
- Fridh I, Bergbom I. To watch - a concept analysis (Att vaka - en begreppsanalytisk studie). *Vård i Norden*. 2006;26:4-8. doi:10.1177/010740830602600102
- Graneheim UH, Lindgren BM, Lundman B. Methodological challenges in qualitative content analysis: a discussion paper. *Nurs Educ Today*. 2017;56:29-34. doi:10.1016/j.nedt.2017.06.002
- O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med*. 2014;89:1245-1251. doi:10.1097/ACM.0000000000000388
- Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurs Educ Today*. 2004;24:105-112. doi:10.1016/j.nedt.2003.10.001
- (VMA) TWMA. WMA declaration of Helsinki - ethical principles for medical research involving human subjects. [www document]. 2018. <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>
- Engstrom A, Soderberg S. Close family members in intensive care from the perspective of critical care nurses. *J Clin Nurs*. 2007;16:1651-1659. doi:10.1111/j.1478-5153.2009.00347.x
- Engstrom A, Fredholm A, Nordin A, Andersson M. Institutional constraints as an obstacle for prioritizing nursing interventions during the COVID-19 pandemic-critical care Nurses' experiences. *SAGE Open Nurs*. 2022;8:103449. doi:10.1177/23779608221133656
- Montgomery CM, Humphreys S, McCulloch C, Docherty AB, Sturdy S, Pattison N. Critical care work during COVID-19: a qualitative study of staff experiences in the UK. *BMJ Open*. 2021;11:e048124.
- Kentish-Barnes N, Cohen-Solal Z, Morin L, Souppart V, Pochard F, Azoulay E. Lived experiences of family members of patients with severe COVID-19 who died in intensive care units in France. *JAMA Netw Open*. 2021;4:4. doi:10.1001/jamanetworkopen.2021.13355
- Ersek M, Smith D, Griffin H, et al. End-of-life care in the time of COVID-19: communication matters more than ever. *J Pain Symptom Manag*. 2021;62:213-222. doi:10.1016/j.jpainsymman.2020.12.024
- Stenman L, Hogberg L, Engstrom A. Critical care Nurses' experiences caring for patients when family members were not allowed in the ICUs due to COVID-19 pandemic. *Sage Open Nurs*. 2022;8:8. doi:10.1177/23779608221103627
- Basile MJ, Rubin E, Wilson ME, et al. Humanizing the ICU patient: a qualitative exploration of behaviors experienced by patients, caregivers, and ICU staff. *Crit Care Explor*. 2021;3:e0463. doi:10.1097/CCE.0000000000000463
- Wilson ME, Beesley S, Grow A, et al. Humanizing the intensive care unit. *Crit Care*. 2019;23:32. doi:10.1186/s13054-019-2327-7
- Andersson M, Nordin A, Engstrom A. Critical care nurses' experiences of working during the first phase of the COVID-19 pandemic-applying the person-centred practice framework. *Intens Crit Care Nurs*. 2022;69:69. doi:10.1016/j.iccn.2021.103179
- Gerow L, Conejo P, Alonzo A, Davis N, Rodgers S, Domian EW. Creating a curtain of protection: Nurses' experiences of grief following patient death. *J Nurs Scholarship*. 2010;42:122-129. doi:10.1111/j.1547-5069.2010.01343.x

How to cite this article: Pettersson C, Forsén J, Joelsson-Alm E, Fridh I, Björling G, Mattsson J. Piloting and watch over in the end-of-life care of intensive care unit patients with COVID-19—A qualitative study. *Nurs Crit Care*. 2024;1-8. doi:10.1111/nicc.13126