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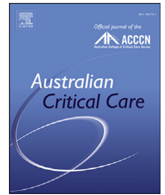

Research paper

Finding the right words: A focus group investigation of nurses' experiences of writing diaries for intensive care patients with a poor prognosis

Lisa Maria Högvall, RN, MPhil [a, b, *], Ingrid Egerod, RN, PhD [c, d], Suzanne Forsyth Herling, RN, PhD [d, e], Tone Rustøen, RN, PhD [a, b], Helene Berntzen, RN, PhD [f]

[a] *Department of Research and Development, Division of Emergencies and Critical Care, Oslo University Hospital, Norway;* [b] *Department of Public Health Science, Institute of Health and Society, Faculty of Medicine, University of Oslo, Norway;* [c] *Department of Intensive Care, Copenhagen University Hospital, Rigshospitalet, Denmark;* [d] *Faculty of Health C Medical Sciences, University of Copenhagen, Denmark;* [e] *The Neuroscience Centre, Copenhagen University Hospital, Rigshospitalet, Copenhagen, Denmark;* [f] *Department of Postoperative and Intensive Care Nursing, Division of Emergencies and Critical Care, Oslo University Hospital, Norway*

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ABSTRACT

Background: The overall purpose of diaries written during an intensive care stay is to help patients fill in memory gaps from the illness trajectory, which might promote long-term psychological recovery. Diaries have also been shown to benefit nurses in maintaining a view of the patient as a person in the highly technical environment and to promote reflection. There is a lack of research on how nurses might be affected by writing a diary for critically ill patients with a poor prognosis.
Objectives: The aim of this study was to investigate nurses' experience of writing diaries for intensive care patients with a poor prognosis.
Methods: This study has a qualitative descriptive design and was inspired by the methodology of interpretive description. Twenty-three nurses from three Norwegian hospitals with a well-established practice of writing diaries participated in four focus groups. Reflexive thematic analysis was used. The study was reported according to the Consolidated Criteria for Reporting Qualitative Research checklist.
Findings: The overarching theme resulting from our analysis was “Finding the right words”. This theme represents the challenge of writing in view of the uncertainty of the patient's survival and of who would read the diary. It was important to strike the right tone with these uncertainties in mind. When the patient's life could not be saved, the purpose of the diary expanded to comforting the family. To put an extra effort into making the diary something special when the patient was dying was also a meaningful activity for the nurses.
Conclusions: Diaries may serve other purposes than helping patients to understand their critical illness trajectory. In cases of a poor prognosis, nurses adapted their writing to comfort the family rather than informing the patient. Diary writing was meaningful for the nurses in managing care of the dying patient.
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1. Background

A diary written during a stay in the intensive care unit (ICU) is an intervention intended to help patients understand their critical illness trajectory after returning home. The diary consists of daily entries describing events and patient responses during the ICU stay. Photographs of the patient and the ICU environment are often included. The overall purpose of a diary is to help the patient fill in memory gaps to provide a coherent illness narrative and to promote long-term psychological recovery.[1,2] Internationally, nurses, other professionals, and family members contribute to the diary.[3,4] Keeping an ICU diary is a complex nursing intervention, requiring personal commitment.[4,5] It has been described as a way of meeting the patient's individual needs[5] as the diary potentially reinforces the relationship between nurses, patients, and their families.[4,6,7]

Diaries benefit nurses by helping them to maintain their view of the patient as a person in the highly technical ICU environment,[6]

* Corresponding author at: Division of Emergencies and Critical Care, Oslo University Hospital, Norway.
E-mail address: lisa.hogvall@ous-hf.no (L.M. Högvall).

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and diaries are a powerful tool for nurses to learn about and reflect on the context of caring.[8] According to Johansson et al.,[8] nurses “strive to do good in words and actions” through the diary, and patients have described receiving a diary as a service beyond their expectations.[9] The experience of doing good and providing extra care is an important driving force for ICU staff, whereas those unable to do this may become frustrated.[10]

Writing diaries for ICU patients started in the Scandinavian countries in the early 1990s. In Norway, one of the pioneer countries, it evolved from an idealistic bottom-up initiative to the development of top-down national recommendations.[11–13] The Norwegian recommendations state that ICU diaries should be written by healthcare personnel, mainly nurses, thus making the diary a part of the medical record.[12,14] Consequently, family members can neither write in the diary nor read it without the patient's consent. Yet according to the recommendations, the diary may be handed over to the family if a patient dies.[12,13] In previous studies, diaries handed over to relatives after the death of a patient has shown to offer bereavement support.[15,16] Patients admitted to an ICU often have an uncertain prognosis, and the diary is usually started in this uncertainty. When a patient deteriorates and the prognosis becomes poor, the recommendations do not specify any change in the diary writing.[12,13] Poor prognosis, when it comes to diary writing, may refer to uncertainty about survival or future cognitive ability to read and utilise the diary.

Research on how nurses might be affected by writing a diary for critically ill patients with a poor prognosis is sparse, and available research on ICU diaries has a general perspective on nurses' overall experience of writing.[5,6,8] However, Ednell et al.[5] described the importance of maintaining hope through diary writing, even when the prognosis of the patient was uncertain. Perier et al.[6] found that healthcare personnel were concerned about delivering bad news in the diary and this could provoke a feeling of having failed the patient. Initiating a diary when the survival of the patient is uncertain has been described as challenging, yet nurses have expressed feelings of failure and guilt if they had not started a diary for a patient who survived.[8]

We assume that nurses' motivation for writing a diary might change if they learn that the patient might not survive. The aim of this study was to investigate nurses' experience of writing ICU diaries for patients with a poor prognosis.

2. Methods

2.1. Design

The study had a qualitative design, using the methodology of interpretive description (ID) and reflexive thematic analysis.[17,18] ID offers a flexible, yet sufficiently rigorous approach to qualitative research with the aim of bringing new knowledge back to the clinic by exploring the experiences of a certain population.[19] The present study was reported according to the Consolidated Criteria for Reporting Qualitative Research checklist.[20]

2.2. Setting and sample

Twenty-three nurses from six ICUs in three Norwegian hospitals participated. Five of these ICUs were in university hospitals, and one was in a regional hospital. All the ICUs treated patients with future risk of impaired cognitive function and had been using patient diaries for from 5 to over 20 years, adhering to the national recommendations. According to these, patients with an expected stay of several days in the ICU and in a state indicating mental disorientation and/or on ventilation support should be offered a diary.[12,13] As quality insurance, all units had resource teams of nurses who read every diary before it was handed over to the patient or the bereaved.

Purposive sampling was chosen for this study.[21] Nurses with diary-writing experience were invited, and to capture different views on ICU diaries, we welcomed participants with varying experience and viewpoints. Recruitment was aided by local coordinators, who provided lists of eligible participants. The participants were contacted by e-mail by LMH, with information about the study and an invitation to participate.

2.3. Data collection

Focus groups were chosen for data collection as they can generate rich data through discussions and interactions in a group sharing experiences on a common topic.[22,23] We conducted focus groups from June 2021 to March 2022. An interview guide based on previous knowledge, supporting the study aim, was developed by LMH and HB. We used a semistructured questioning route with an opening question to bring all participants into the conversation,[23] followed by questions covering the key subjects (Table 1). The focus group interviews were held in hospital conference rooms and were digitally recorded. LMH was the moderator, while HB was the assistant moderator who took field notes. Both investigators had personal experience in diary writing and part-time positions as ICU nurses at one of the participating hospitals; LMH was a former colleague with four of the 23 participants. This was addressed during the introduction of the focus group, emphasising her independent role as a researcher and interest in all nuances regarding their diary experience. Both investigators were authorised in group counselling of nurses, and HB was an experienced interviewer. During the focus groups, it was important to actively encourage expressions of negative experiences and bring these to the surface since nurses with a positive attitude towards diaries might be more likely to participate in a diary study. We piloted a focus group with participants matching the inclusion criteria to evaluate the procedure and performance of the interview guide and decided to include this group in the study as rich data were obtained. Recordings from the focus groups were transcribed verbatim by LMH.

2.4. Analysis

The ID methodology does not specify an analytical method. However, it states that the analysis should be rigorous and engage the processes of inductive reasoning to encourage the interpretation of early descriptive findings into the abstraction of new meaningful findings that illuminate the phenomenon under investigation.[24] We used reflexive thematic analysis as described by Braun and Clarke to find patterns and interpret the data. Reflexive thematic analysis is a recursive process that includes six phases, with a continuous movement back and forth between the phases over time.[18] The analysis commenced following each interview to allow for adaptations and adjustments to the interview guide as recommended in the ID.[19] After familiarisation with the data, inductive coding was performed by LMH. The NVivo software (QSR International, Burlington, MA, USA) was used in the early phases to organise the data, and the codes were structured into subthemes and themes. Throughout the analysis, we held regular reflection meetings where the coding and development of subthemes and themes were discussed. According to ID, qualitative studies search for a deeper understanding of the perspectives of the participants as the desired outcome, but saturation is not an attainable goal as new aspects may be continuously uncovered.[17] The data collection and the parallel analysis allowed early findings to be pursued, and we considered the collected data sufficient to answer the aim of the study after completing four focus groups.

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Table 1
Interview guide.

Subjects	Questions
Experience of writing a diary	What are your experiences of writing diaries? What is important to write in the diary? The purpose of the diary is often described as “filling memory gaps”. What other purposes can the diary have? Can you give examples of patients or patient groups that are more challenging when you write a diary?
Motivation for writing a diary	When is it particularly important to keep a diary? What motivates you to keep a patient diary?
Impact on the relationship with patients and relatives	How might diary writing affect your relationship with the patient? How might diary writing affect your relationship with the patient's family?
Impaired cognitive function	Are you ever concerned that the diary will not be read by the patient?
Uncertain prognosis	Might an uncertain prognosis affect the content of the diary? And if so, how? Might an uncertain prognosis affect the language in the diary? And if so, how? Do you continue to write if the patient is deteriorating and will probably never read the diary? Do you in some cases discontinue the diary?

2.5. *Trustworthiness*

Lincoln and Guba's criteria were used to ensure trustworthiness.[25,26] To enhance *credibility*, well-established research methods were used, and the research team regularly evaluated the research process and the generation of findings. To increase *transferability* and *dependability*, the context in which the diaries were written and the research process was carried out was described in detail. *Confirmability* was sought by researcher triangulation in the analysis and by presenting the findings with quotations from the focus groups. Preconceived expectations and opinions regarding diaries were discussed before and during data collection and analysis to increase awareness of how these might influence the research process.[19]

2.6. *Ethics*

The study was approved by the internal review board (20/23763) of Oslo University Hospital and by the data protection officer of all participating hospitals. The Regional Committee for Medical and Health Research Ethics waived to process the application (154315). All participants were informed about the right to withdraw at any time and gave written consent, and they were also asked to maintain confidentiality within the focus group. The participants were all experienced nurses and were not considered a vulnerable group. However, as authorised group counsellors, we felt prepared to handle any possible emotional distress related to or the topic of engaging in patients with poor prognoses.

3. Findings

3.1. *Focus group demographics*

We conducted four focus group interviews with a total of 23 participants (21 females and two males) (Table 2). Two of the focus groups were at one hospital, with participants from four different ICUs. At the other two hospitals, the participants were from the same ICU from that hospital.

3.2. *Qualitative findings*

The overarching theme in our analysis was “Finding the right words”. This theme expresses the challenge of writing a diary in view of the uncertainty of the patient's survival and of who would actually read the diary. It was important to strike the right tone with these uncertainties in mind. The main themes and subthemes are presented in Table 3. Quotations are labelled with focus group number/participant number.

Presentation of themes and subthemes

1.0 Forging a relationship with the patient

The first theme demonstrates the nurses' wish to establish a personal relationship with the patient and leave a lasting impression. They were challenged by uncertainty about who would actually read the diary.

1.1 *Creating a channel of communication*

In order to get to know the patient, nurses asked the family to bring photographs from home. The family's presentation of the patient as a person helped the nurses establish a relationship with the unresponsive patient. The diary became a channel of communication that strengthened the relationship. Although the communication was an informal one-way conversation at this time, it gave the nurses a sense of reciprocity because the text would be read later.

> “*It's somehow a way to talk to your patients. They're asleep, and when they wake up, maybe we won't be able to communicate with them (…) We like to explain the things we do. The diary is sort of a channel where we can have this communication. If not only for my own sake, if that's not too selfish of me?*” (1:1)

1.2 *Adjusting to a change of reader*

A major challenge for the nurses was the uncertainty of the patient's survival and, consequently, who would actually read the

Table 2
Focus group demographics.

Focus groups	1 (pilot) (n = 5)	2 (n = 7)	3 (n = 5)	4 (n = 6)
Mean age and range	52 (34–61)	42 (26–60)	43 (29–61)	45 (31–59)
Mean years of ICU experience and range	22 (8–30)	13 (3–30)	12 (2–28)	19 (7–32)
Mean years of diary experience and range	10 (5–28)	6 (3–10)	10 (2–16)	14 (5–22)
Interview length	60 min	70 min	76 min	65 min

ICU, intensive care unit.

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Table 3
Themes and subthemes.

Overarching theme: "Finding the right words"			
Theme 1	Theme 2	Theme 3	Theme 4
Forging a relationship with the patient	Collaborating with colleagues	Comforting the family	Closing the book
Subthemes			
1.1 Creating a channel of communication 1.2 Adjusting to a change of reader	2.1 Creating a caring culture 2.2 Promoting intercollegial inspiration	3.1 Negotiating hope and reality 3.2 Demonstrating good end-of-life care 3.3 Reducing the family burden	4.1 Compensating for hopelessness 4.2 Managing a difficult situation

diary. Uncertainty meant that the tone of the text and the information needed to be adjusted.

"*...in severe cerebral haemorrhages or heart attacks, for example, with poor outcome and major hypoxic injuries, (...) I feel it's futile to start a diary. I've had that thought.*" (3:14)

Several participants explained that they changed direction when the patient deteriorated and then aimed their narrative at the family rather than the patient. Switching to an uncertain or unknown reader was difficult, and some nurses ceased to write because they found it futile.

"*It's a bit difficult because you always write to the patient, but then if things don't go well, then eventually it can be hard to find the words, especially if there's a withdrawal of treatment. Because then you actually write more to the family, or the bereaved.... Then it can be difficult to find the right words, I mean (...) who's going to read this after all?*" (1:2)

2.0 Collaborating with colleagues

The collective effort made by the nurses to develop and maintain a high standard in diary writing was described with pride. This second theme expresses the collaboration that nurses had with their nurse colleagues where the practice of writing diaries promoted a culture of awareness of the patient as a person, leading to increased empathy and the feeling of enhancing nursing care.

2.1 *Creating a caring culture*

Keeping a diary was made possible by nursing teams that respected and enabled the practice. The nurses described how they needed to find a certain mode of communication that encouraged reflection on the patient experience. It was easier to find that mode during quiet night shifts than during busy day shifts.

"*I need some peace and quiet to write (...). During the night shift, I get this peace of mind where I can think things through.*" (4:20)

This type of writing was described as "coming from the heart", and nurses felt it brought them closer to the patients.

"*I think there's something intimate about writing in the diary. And it's bound to make us provide better care. I really mean that.*" (2:11)

The nurses felt that the diary had a humanising effect on nursing care in the unit and described it as a "culture of caring". This caring culture was not limited to patients receiving a diary but included all patients in the unit.

"*I see it [diary writing] as a benefit for all patients, because there's something about the way we view our patients, and we talk a lot about the need to be aware of who the person in the bed is, not just a 'case'. I believe writing the diaries has helped us achieve that.*" (4:19)

2.2 *Promoting intercollegial inspiration*

The nurses talked about how they were inspired by their colleagues' writing and how they learned from each other. Nurses with good writing skills were said to set the standard for others, and the best diaries were described as the ones where the nurse chose to address difficult situations and writing that required emotional involvement.

"*And it's kind of brave too, because ... it's so hard to go into such a difficult process. And you actually dare to be close in your writing when it's so difficult and emotional. I think that's pretty tough. I think those are the best diaries.*" (1:2)

In cases of patients with an uncertain chance of survival, some nurses got a second opinion from a colleague to ensure an appropriate narrative in the diary.

"*I have someone else look at it, if it looks okay, you know. Can I write like this, or what ...? We look at it together. You become very aware of how you express yourself.*" (2:6)

3.0 Comforting the family

The third theme describes the shift of focus to comforting the family rather than informing the patient when treatment was withdrawn. The tone of the text and the information level shifted to accommodate the grieving family.

3.1 *Negotiating hope and reality*

When chances of patient survival were slim, the narrative had to be composed with special care. The nurses weighed every word they wrote and described how these particular diaries needed to be beautiful and cautiously written. When discussing a particular patient, one of the nurses remarked,

"*I also wrote in that diary when I didn't think he was going to make it, and then I wrote a little more thoughtfully, I think. (...) I took more care with how I wrote. Shouldn't there be something beautiful about it too?*" (1:2)

In the nurses' opinion, a diary should always be honest and correspond to the medical record. Nurses referred to results of medical tests and the information already given to the relatives when the condition of the patient deteriorated. They had to strike a balance between sustaining marginal hope and facing the reality of the situation.

"*When we know the person is never going to wake up, I wouldn't write things that could..., well, it may be okay to write that you've*

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> *had hope, but without suggesting things like 'Oh, soon you'll wake up, and everything will be just fine', you know.*" (2:9)

3.2 *Demonstrating good end-of-life care*

During a discussion of a diary for a dying teenager, one of the nurses described the change of focus that occurred: "*It's more like you describe how much your mother and father love you*" (2:11). Love from the family, which was normally not a topic in the diary, was emphasised, and as one nurse put it, "*Time passes at a slower pace, giving more space for details*" (2:11). Describing attentive personal care, such as using a fragrant lotion or washing the patient's hair, could be a message to the family that the patient was receiving good end-of-life care.

> "*We often focus more on describing care, that they get good care 'today we have washed your hair', things like that, so that when relatives read it later, they see that we treated them very well and with respect.*" (2:9)

3.3 *Reducing the family burden*

It was crucial to the nurses that a diary should never add to the family's burden after the patient died. Although they knew the patient was dying, they tried to maintain a slight hope to show that they had not given up too soon.

> "*Like a small strand of hope…? Because you know the family will read that diary afterwards, and they'll definitely use it a lot. And if you've written something sort of thoughtlessly … that's not okay, you have to be very careful.*" (1:3)

Efforts made by the members of the medical team to save the patient were described. It was important to show that everything possible had been done. When death was inevitable, one nurse described how she wrote to lessen the suffering of the family:

> "*Yes, … I wrote 'you look peaceful' and 'I can see your face is relaxed', somehow to show those left behind that the patient didn't suffer.*" (3:15).

4.0 Closing the book

The fourth theme describes the efforts of nurses to create meaning and end the diary in the phase when there was no hope left of survival. When the patient died, the diary was a tool for the nurses to achieve closure in the patient—family—nurse triad. The task of creating a special diary in this difficult situation was meaningful to the nurses.

4.1 *Compensating for hopelessness*

The participants referred to diaries that were particularly well written when patients were dying. These diaries were not intended for the patient, but for those left behind. They evidently also gave meaning to the nurses, who had put an effort into creating something special.

> "*We have written diaries for some young patients in a very sad situation…. where we actually just waited to see if they could become organ donors or not. And we did everything in our power to make it a really beautiful diary.*" (2:3)

One nurse added the patient's handprint to the diary. Other nurses described diaries that had been translated by nurse colleagues into other languages for family members unable to travel to Norway to see their dying relative. Such extraordinary diaries for the bereaved were perhaps seen as a way for nurses to acknowledge the loss of a loved one and compensate for the impossibility of saving the life of the patient. In a hopeless situation where few practical things could be done to help, the creation of a special diary was a tangible task that became meaningful also for the nurses.

4.2 *Managing a difficult situation*

Writing a diary enabled the nurses to manage their own emotions in demanding situations. They could reflect upon what had been done, which they considered helpful.

> "*It's kind of a process for us too, at least if it's a tough situation or really sad. Then I think it might help me a bit as well. Writing about it, you really think about how to express yourself … what to write … and, yes, I think it helps in a way … to deal with things.*" (2:9)

Some nurses wrote an epilogue at the end of the diary after the death of a patient. This gesture could be a way to end the relationship with the patient and the family and promote closure.

> "*And then we sum it up in the end, after the passing, by writing a kind of epilogue in the diary, in some sense we send our greetings to the family, you see… and thank them for our time together here …*" (2:10)

The nurses here described a need to thank the families for the opportunity to take part in their difficult but important time in the ICU and also to give them their condolences and best wishes for the future.

4. Discussion

Our main findings were that the nurses strove to find the right words in the diary, adapting their writing to the assumed reader, and that they made adjustments when the patient was unlikely to survive. The purpose of the diary was expanded to comfort the family when the patient was dying; then the nurses put an extra effort into making the diary something special, which was also a meaningful activity for the nurses themselves. The change in focus from the patient to family when the patient did not survive has been described in previous research. Both Johansson[8] and Ednell[5] found that the nurses kept writing for the sake of the relatives when the patient was dying. However, the nurses' reflections on this particular writing have not been described in detail previously.

4.1. Finding the right words

Our study demonstrated that writing a patient diary is a particular nursing skill. Writing the diary was not taken lightly, as indicated by the overarching theme. Nurses were careful to find the right words in the diary to set the right tone. This is in accordance with Johansson who described that nurses weigh every word to get the right balance.[8] Initially, the diaries in this study were written for the patients, but as the prognosis changed for the worse, the intended reader changed from the patient to family. This situation is not described in the Norwegian diary recommendations, but nurses appear to develop a tacit understanding based on the patient's trajectory. The challenge of shifting from one implied reader to another might be discussed by using Chatman's narrative communication diagram (Fig. 1).[27] Unlike most diaries, the ICU

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Fig. 1. Simplified version of Chatman's narrative communication diagram (Chatman, 1978, p. 151).

diary has several narrators (all the nurses involved) and starts out with the patient as the intended or "implied reader", to use Chatman's term, i.e., the person for whom the text is written. Each entry has one single "real author", namely the nurse who writes it. As the patient trajectory evolves, the narrators might change, as some nurses may cease to write in the diary. The "real reader" is the person who actually reads the diary and might change from the patient to a relative if the patient's situation becomes hopeless. This naturally has implications for the narrative.

We found that writing for a dying patient was considered a very special task. It was important for the nurses that the diary should never give the relatives an additional burden but potentially offer comfort in their grief. It was, however, easier to write after the withdrawal of treatment than in situations when survival was uncertain. This may be explained by the uncertainty in unresolved situations, where the ultimate "real reader" was uncertain. Concurrently with the change in care to end-of-life care, the purpose of writing changed to being directed to the relatives, who then became the implied readers, i.e., those for whom the diary was written.

The term "implied author" describes a notion of the real author reconstructed through the values and norms that are communicated through the text.[27] When the nurses collaborated and sought inspiration from each other, they strove to set a high standard for the writing, and by doing so, they created a norm for the nursing practice, communicated through the diary entries. In our study, the best diaries were described as diaries in which nurses took part in difficult situations, rather than distancing themselves.

The nurses furthermore stated that their writing should "come from the heart". This calls for a close relationship in the nurse−patient−family triad. Close involvement, as described here, could increase professional motivation and job satisfaction according to the concept described as "compassion satisfaction".[28,29] Compassion satisfaction could be regarded as the reward for caring, whereas the opposite, compassion fatigue represents the cost of caring.[30] Compassion fatigue is especially relevant among critical care nurses who face suffering and stress on a daily basis. Personal involvement carries the risk of crossing professional boundaries and might contribute to the development of compassion fatigue.[31,32] Whether diary writing is associated with compassion satisfaction or compassion fatigue may, among other factors, depend on the nurses' professional boundaries.[31] These boundaries appear to be at stake in the emotional involvement required in diary writing. It is difficult to predict whether the act of writing a diary for a dying patient will lead to compassion satisfaction, compassion fatigue, or a mix. The nurses in our study, however, did not emphasise the risk of compassion fatigue, which is in accordance with findings by Johansson et al.[8] that diary writing by "doing good" might promote work satisfaction. The diary acts as a tool to promote both a relationship and communication with the patient and family was among the findings in this study. It is important, however, to keep in mind that the diaries were written by nurses and hence were the nurses' story of what happened. Even though the nurses here described the diary as a "channel of communication", this is a one-sided communication. This special form of communication has been elaborated in previous studies.[33,34]

Writing an extraordinary diary in perceived hopeless situations was a noteworthy finding in our study. The nurses appeared to put an extra effort into the creation of the diary to compensate for the futility of further treatment. Writing these diaries also appeared to be meaningful for the nurses themselves. The concept of empowerment might explain this finding. A concept analysis suggested that nurses are empowered by "doing good" and by meaningful experiences that increase their motivation.[35] Being emotionally moved by caring for patients and families has been found by Flinterud et al.[36] to be a motivation for nurses to initiate activities such as diary writing. Memory-making as part of end-of-life care in an ICU setting has proven to be valuable for bereaved families[37,38] and can help a bereaved person construct meaningful memories about a deceased person.[39,40] Making tangible keepsakes such as creating handprints or keeping locks of hair is an example of memory-making, and ICU diaries have been described as memory-making objects.[38] In a study of newborns, nurses' memory-making activities were considered by the parents as providing care beyond clinical standards.[41] The example of an extraordinary beautifully made diary, which also includes keepsakes like a handprint, is beyond what is expected in a Norwegian adult ICU context. However, for the relatives of a dying patient, it might be regarded as important memory-making.

Writing an epilogue for the relatives appeared to be a way to say goodbye and end the relationship with both the patient and the family. This activity of "closing the book" might bring closure to nurses, but how it affects the family remains uncertain. A French study found that a handwritten letter of condolence sent to the relatives after the patient died in an ICU was associated with higher prevalence of symptoms of depression and posttraumatic stress disorder among the bereaved.[42] Although the condolence letter may not equal the more contextualised epilogue, this calls for further research among bereaved families with regard to specific diary content. Moreover, a systematic review concluded that diaries delivered postmortem were generally considered positive as they might bring comfort and help the family to cope with their loss.[43]

The Norwegian diary practice, where only healthcare personnel write in the diary, differs from practice in many other countries where the family coauthors the diary and has access to it in the ICU or until it is handed over to the patient.[3,4] Since the diary is a part of the medical record in Norway, family members are not allowed to write in or read the diary during the hospital stay. Patient- and family-centred care (PFCC) as a concept to improve care in the ICU is gaining acceptance worldwide.[44] According to the Institute for Patient and Family-Centered Care in the US, the core concepts are respect and dignity, information sharing, participation, and collaboration.[45] Diary writing has been described as an intervention to promote PFCC[46] and a tool for information sharing, participation, and collaboration when both family and healthcare personnel have access to the diary.[47] By excluding the family from participating in the creation of the diary, the Norwegian practice does not encourage PFCC. However, nurses in this study chose an alternative route for family involvement by writing to comfort the family after the death of the patient, although this is not described in the national recommendations.

5. Limitations

This study has some limitations. It is a small sample study from a Norwegian context. However, the inclusion of participants from six different ICUs provided rich data from a community with a

long and varied experience of diary writing, and the findings concur with previous studies. The discussions were lively, and the participants shared personal experiences openly, adding richness to the data. A further limitation was that LMH had previous professional involvement with four of the 23 participants as a spokeswoman for the practice of diary writing. This may have affected the participants' openness about possible negative attitudes. Attempts were made to take account of this during recruitment and interviews.

6. Conclusions

Nurses strive to find the right words in the diary when patients are unlikely to survive. The purpose of the diary might shift when the patient deteriorates or dies, to concentrate on comfort for the bereaved family. The study suggests that making a special effort to create a diary for the family may also be meaningful for nurses in managing care of the dying patient. Diaries may therefore serve other purposes than helping patients to understand their critical illness trajectory.

7. Implications for practice

This study provides inputs for reviewing diary writing practices both in Norway and internationally. The role of relatives in diary writing needs to be carefully considered when establishing or reviewing diary writing practices. In line with interpretive description methodology, the findings in this study will be returned to practice and will hopefully initiate a review of the Norwegian recommendation that currently neither encourage nor legally permit family members to participate in diary writing.

Diaries may serve other purposes than helping patients to understand their critical illness trajectory, and findings from this study acknowledge diary writing as a meaningful humanising activity for ICU nurses. In a time of global shortage of ICU nurses, activities that may contribute to compassion satisfaction and possibly job satisfaction among nurses are of importance. Since writing is described as a special skill, investing time and resources needed for new nurses to learn this skill may also be of value. Whether this diary practice with another purpose than helping patients to understand the critical illness trajectory can be justified needs to be further investigated.

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CRediT authorship contribution statement

Lisa Maria Högvall: Conceptualisation; Formal analysis; Investigation; Methodology; Project administration; Roles/Writing - original draft; Writing - review & editing. **Ingrid Egerod**: Conceptualisation; Formal analysis; Investigation; Methodology; Supervision; Roles/Writing - review & editing. **Suzanne Forsyth Herling**: Conceptualisation; Formal analysis; Investigation; Methodology; Supervision; Roles/Writing - review & editing. **Tone Rustøen**: Conceptualisation; Formal analysis; Investigation; Methodology; Project administration; Supervision; Roles/Writing - review & editing. **Helene Berntzen**: Conceptualisation; Formal analysis; Investigation; Methodology; Project administration; Supervision; Roles/Writing - original draft; Writing - review & editing.

Conflict of interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this manuscript.

Data availability statement

Data collected in this study are not available without special permission from the data protection officer of the participating hospitals.

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