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Intensive care unit diaries: Developing a shared story strengthens relationships between critically ill patients and their relatives: A hermeneutic-phenomenological study☆

Anne Højager Nielsen[a,b,*], Ingrid Egerod[c,d], Torben Bæk Hansen[e], Sanne Angel[f]

[a] Department of Anesthesiology, Regional Hospital Holstebro, Lægårdvej 12, 7500 Holstebro, Denmark
[b] Department of Clinical Medicine, Aarhus University, Incuba/Skejby, Building 2, Palle Juul-Jensens Boulevard 82, 8200 Aarhus N, Denmark
[c] University of Copenhagen, Health and Medical Sciences, Blegdamsvej 3B, 2200 Copenhagen N, Denmark
[d] Intensive Care Unit 4131, Rigshospitalet, Blegdamsvej 9, 2100 Copenhagen Ø, Denmark
[e] University Clinic for Hand, Hip and Knee Surgery, Regional Hospital Holstebro, Aarhus University, Lægårdvej 12, 7500 Holstebro, Denmark
[f] Section for Nursing, Department of Public Health, Aarhus University, Building 1260, Bartholins Allé 2, 8000 Aarhus C, Denmark

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ABSTRACT

Background: After discharge from the intensive care unit, patients and relatives struggle to rebuild their lives while suffering from fatigue and distress. Intensive care unit diaries written by relatives are a novel approach that may help relatives and patients process the critical illness experience together.
Objectives: To explore patients' and relatives' perceptions and use of a diary written by relatives for the critically ill patient.
Design: Hermeneutical-phenomenological interview study.
Setting: Two regional mixed surgical/medical intensive care units in a regional hospital.
Participants: 10 critically ill patients and 13 relatives. All participants were 18 years or older, all patients had undergone mechanical ventilation.
Methods: Dyadic, in-depth interviews conducted at 3–6 months and 8–16 months after discharge from the intensive care unit in 2015–2017. Interviews were analyzed using Ricoeur's theory of interpretation; a three-step process initiated by a naïve reading; followed by a structural analysis exploring the internal relations of the text, and finally, a critical interpretation to identify the most probable interpretation.
Results: Before sharing the intensive care unit diary, relatives had to feel able to give the diary to the patient, which meant separating themselves from the diary and being available for discussions with the patient. Likewise, the patients had to be prepared to receive the diary and to acknowledge relatives' efforts. Sharing the diary included interpreting the content of the diary, and developing a re-configured story based on the diary.
Conclusion: The diary written by relatives for the critically ill patient was fulfilled when the diary was shared between the authoring relative and patient and a re-configured story was developed. This enabled a strengthened relationship between patient and relative. Not sharing could be disappointing to the relative, but did not preclude discussion of the experience of critical illness.
This study provides professionals with knowledge about supporting patients and relatives through intensive care unit diaries written by relatives. Relatives need guidance on when to share the diary with the patient and how to accept patient rejection.

What is already known about the topic?

- Diaries by critical care nurses can improve patients' understanding of the time in the intensive care unit.
- Intensive care unit diaries written by nurses may remind patients of a difficult experience and may be painful to review.
- Relatives express feelings and feels connected with the patient when writing diaries for the patient in the intensive care unit.

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* Corresponding author at: Department of Anesthesiology, Regional Hospital Holstebro, Lægårdvej 12, 7500 Holstebro, Denmark.
E-mail addresses: annsve@rm.dk (A.H. Nielsen), ingrid.egerod@regionh.dk (I. Egerod), torbehns@rm.dk (T.B. Hansen), angel@ph.au.dk (S. Angel).

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What this paper adds

- The intensive care unit diary can be written by a relative instead of nurses.
- The shared story developed in the context of the diary helped relatives and patients process the critical illness experience together.
- Some patients find it difficult to receive the diary from the relative and therefore relatives need guidance on when and how to share the diary and to accept if the patient rejects the diary.

1. Introduction

In Scandinavia, intensive care unit nurses have written diaries for critically ill patients since the early 1990′s. The aim has been to promote the patient's psychosocial recovery after the experience of critical illness and intensive care (Egerod et al., 2011b). Involving relatives in keeping a diary for the critically ill patient helps relatives express their care for the patient and reading this is greatly appreciated by patients. (Nielsen and Angel, 2015; Engström et al., 2009). Moreover, asking relatives to write the diary instead of nurses may be a way to overcome legal issues related to what can be disclosed in the diary. Thus, family diaries may offer patients and relatives a more personal narrative, but their use of this personal diary needs further exploration to inform clinical practice about its advantages and disadvantages.

2. Background

After discharge from the intensive care unit, patients struggle to recover their former lives (Ågård et al., 2012; Stayt et al., 2016) but symptoms of anxiety, depression and posttraumatic stress symptoms (Parker et al., 2015; Huang et al., 2016) may complicate the recovery process (Needham et al., 2012). Incorporating the experience of critical illness into a personal narrative can be a way to deal with posttraumatic stress symptoms (Ehlers and Clark, 2000), albeit, this may be difficult when memories of critical care are lacking, fragmented or distorted (Jones et al., 2001). During recovery, patients are highly dependent on their relatives (Ågård et al., 2015), but relatives could also suffer from fatigue (Choi et al., 2014), anxiety, depression and posttraumatic stress after discharge from the intensive care unit (Davidson et al., 2012).

Diaries have been suggested, as a supportive measure to reduce distress and helping patients and relatives to understand and accept what happened in the intensive care unit (Jones et al., 2010; Garrouste-Orgeas et al., 2012). A pilot study showed that a diary reduced posttraumatic stress in relatives (Jones et al., 2012), whereas the effect on patients remains contested (Jones et al., 2010; Ullman et al., 2014; Nydahl et al., 2018). A recent study showed that unrelated to the experience of distress; most patients and relatives would have liked to receive a diary (Aitken et al., 2017b). This supports the idea that diaries have a broader application than preventing posttraumatic stress. In line with this, Egerod et al. suggested that diaries written by intensive care nurses for critically ill patients provided patients and relatives with a narrative framework for discussing and understanding the experience of being in the intensive care unit (Egerod et al., 2011a). Moreover, patients were grateful for diaries written by nurses even if reading the diary confronted the patient with a difficult story about their own illness (Engström et al., 2009). Most importantly, when relatives were invited to co-author the diaries, patients coveted these entries that signified the love from their family (Engström et al., 2009).

Relatives find writing a diary highly meaningful (Nielsen and Angel, 2015). In the diary, difficult emotions could be expressed and the process of writing created a distance that allowed for reflection and understanding (Nielsen and Angel, 2015). Moreover, diaries co-authored between relatives and staff provided relatives with an opportunity to support the patient and remain in contact (Johansson et al., 2015).

For this study, we therefore propose that diaries authored by relatives are a way to support both relative *and* patient, and help them process the experience together, but, transferring authorship from nurses to relative may change the intervention significantly. Nevertheless, while the diary may benefit the relative, its influence on the patient-relative relationship remains unexplored. As diaries about critical illness may remind relatives and patients of a distressing time in their lives, a more comprehensive understanding of the process of sharing the diary is needed.

3. Aim

The aim of this study was to explore patients' and relatives' perceptions and use of a diary written by relatives for the critically ill patient.

4. Methods

4.1. Design

The study was a hermeneutical phenomenological interview study inspired by the work of Ricoeur (1991b). The participants were sampled from the intervention group of a larger randomized, controlled trial of diaries written by relatives for critically ill patients (Nielsen et al., 2018).

4.2. Intervention

Within the first few days of the patients' stay in the intensive care unit, a relative was invited to participate in the diary intervention and were introduced to it by specially trained nurses. Information on how to write and eventually share the diary with the patient was pasted into the diary. Relatives were guided to find their own way of diarizing, although guidance was given within the flexible framework of the written information (Nielsen et al., 2018).

4.3. Participants

All patients and relatives (a family member or close friend) were 18 years or older. Patients were anticipated to stay in the intensive care unit for more than 48 h and to be mechanically ventilated longer than 24 h. A total of 12 patients and 12 relatives were included to achieve sufficient variation of different relationships to enable a comprehensive understanding of the diary experiences (Patton, 2015). One patient died before interviewed while two additional relatives were allowed to be present during interviews. One dyad was excluded from the study, as the relative had not written a diary for the patient (Table 1).

4.4. Data collection

From September 2015–March 2017, the first author collected data by dyadic in-depth interviews of relatives and patients. The plan was to interview each dyad of patient and relative at 3–4 months and 7–12 months after discharge from the intensive care unit to capture changes during the first year. However, the timing of the interviews was adjusted due to the prolonged recovery of some patients or busy schedules of participants. Interviews were carried out in the private home of participants to make them feel safe (Kvale and Brinkmann, 2009). To accommodate needs of participants; 7 interviews were scheduled as single interviews;

Table 1
Participant demographics.

ID	113	120	121	123	125	130	131	133	201	212	213	228
PATIENTS												
Sex	M	M	M	F	M	M	F	M	M	M	F	M
Age	68	62	63	47	65	71	77	71	35	76	76	73
SAPS-II[1]	90	77	33	61	35	33	76	37	38	45	33	46
ICU STAY												
Days in ICU	18	9	32	17	2	33	29	2	6	5	12	10
Hours MV[2]	405	193	728	279	38	756	616	11	144	51	99	72
RELATIVES (diary author)												
Relationship	Wife	Daughter	Wife	Daughter	Daughter	Wife	Daughter[3]	Wife	Mother	Wife	Daughter	Wife
Age	66	36	62	26	39	69	51	63	61	57	48	71
DIARY												
Entries no	62	16	51	22	–	75	144	9	25	7	19	10
Days covered	138	40	69	22	–	124	85	27	32	7	19	25
INTERVIEWS												
1. interview months post-ICU, participants	6 months Dyadic	4 months Dyadic + Wife	6 months Wife only	4 months Daughter only	–	3 months Dyadic	3 months Dyadic	4 months Dyadic	5 months Mother + father 5 months Patient	4 months Dyadic	3 months Daughter only 4 months Dyadic	4 months Dyadic
2. interview months post-ICU, participants	13 months Dyadic	12 months Dyadic + wife	15 months Wife only	9 months Patient only	8 months Dyadic	11 months Dyadic	9 months Dyadic	11 months Dyadic	16 months Dyadic + father	12 months Dyadic	13 months Dyadic	11 months Dyadic

[1] SAPS-II – Simplified acute physiology score (Le Gall et al., 1993).
[2] MV = mechanical ventilation.
[3] Daughter + family.

one interview was carried out at the hospital and one interview on the phone (Table 1).

Interviews were open and explorative in nature; guided by the participants' experiences of using of the diary. This approach was inspired by Ricoeur who describes how following a story is a complex undertaking (Ricoeur, 1991a) because expectations are readjusted as the story moves to an end. Therefore, to allow participants' stories to unfold, we refrained from using an interview guide. However, a typical opening question could be "tell me about the time, when you started the diary in the intensive care unit". Exploring questions like "tell me about the first time you read the diary" and probing questions like "can you tell me more about that" were used to further elicit participants' experiences of using the diary (Kvale and Brinkmann, 2009). Interviews were digitally recorded and transcribed verbatim by a university student under supervision of the first author. Pauses and signs of emotions were noted in parenthesis (Kvale and Brinkmann, 2009). Transcripts were checked for accuracy by the first author.

4.5. Data analysis

Ricoeur's hermeneutical-phenomenological theory of interpretation was used for the analysis (Ricoeur, 1991b). This three-step process was initiated by a thorough reading of all interviews to become familiarized with the data. A naïve interpretation was formulated for each interview reflecting an overall understanding of the data. In the following structural analysis, the text was divided into units minimally the size of a sentence (Ricoeur, 1991b). Each unit was described in terms of what it said and what the text was about (Ricoeur, 1991b). Moving back and forth in the data, the structural analysis brought out the logic of the text and explained the data in terms of the relations between its smaller parts (Ricoeur, 1991b). The critical interpretation identified the most probable interpretation (Ricoeur, 1991b). The analysis was managed in NVIVO 12.

4.6. Rigor and transparency

In the interviews, the first author strove for an open and interested attitude, while aware of preconceptions being present (Kvale and Brinkmann, 2009). These preconceptions came from experiences of being a mother, a wife, a relative of sick parents, an experienced intensive care nurse and a researcher and from literature. This profound knowledge of the field provided AHN with a sensitivity to what mattered to participants (Kvale and Brinkmann, 2009), but belonging to the field also provided limitations as to which questions could be asked (Ricoeur, 1991b).

The depth of the analysis was achieved by thoroughly reading the text, carefully listening to what it said, thus allowing the structures to emerge (Ricoeur, 1991b). Dialectically moving between explanation by the structural analysis and understanding in the critical interpretation provided rigor as well as transparency of the analysis. The most probable interpretation was validated by the structural analysis (Ricoeur, 1991b). Furthermore, the analysis was continually discussed with the other authors as well as peers, and patients and relatives outside the study (Kvale and Brinkmann, 2009). These discussions provided important critical perspectives on the analysis.

4.7. Ethical considerations

An interview study with potentially vulnerable participants requires the researcher to proceed with caution as participants may disclose thoughts and feelings they later regret to have expressed (Kvale and Brinkmann, 2009). Additionally, the dyadic interviews and presence of other relatives could influence the interview situation in ways not known beforehand (Norlyk et al., 2015). Therefore, participants were not pushed too hard if the interviewer sensed hesitation to answer a question. To diminish the stress of the situation, the first author strove to build a trusting relationship during the interviews. However, telling their stories to an interested listener could also be a rewarding experience for the participants (Kvale and Brinkmann, 2009).

All participants gave informed, written consent to participation. To protect confidentiality, all participants were anonymized and data were stored according to the Danish Data Protection Agency (identifier 1-16-02-30-15). Ethical approval for the overarching DRIP study was granted by Health Research Ethics Committee of Region Central Jutland (identifier 1-10-72-371-14). The study was carried out in accordance with the Helsinki Declaration (The World Medical Association, 2013).

5. Findings

In the process of recovering from critical illness and restoring life as it was, the intensive care unit diary could be understood as a first draft of what would later become a shared story of patient and relative. Prerequisites for *developing a shared story* based on the diary included f*eeling able to give the diary* to the patient and *being prepared to receive the diary* from the relative.

5.1. Feeling able to give the diary to the patient

Fulfillment of relatives' intentions of writing the diary was achieved by handing over the diary to the patient and later sharing the diary. Feeling able to part with the diary and letting go on were necessary for this to occur.

5.1.1. Separating oneself from the diary and letting go

The diary had been a companion to the relative during the patient's critical illness and before passing it on; they needed to separate themselves from the diary. This implied feeling able to stop the process of writing and reading the diary. Difficulties with separating from the diary particularly applied to relatives living apart from the patient. Keeping the diary close for continued reading comforted relatives. Consequently, some made a photocopy for themselves or made the patient promise to keep the diary for future reference. This need for the diary showed that the diary had become an object that secured their memories of the critical time and potentially would help them understand.

Handing over the diary required the relatives to open themselves to the patients; making themselves available for explanations and discussions about the critical time. To do this, relatives needed to have the physical and mental resources to be ready to start a dialogue with the patient about the diary. Otherwise, the diary would not be given to the patient. Some relatives acknowledged that they found it difficult to find the resources for this, as they struggled to recover from the experience themselves. A daughter who wrote the diary for her mother explained:

> "So if it hadn't been such a rough time for me, she probably would have liked to see it (the diary) 'cause she is curious about these things." Relative 213

The inability to pass on the diary even though the patient was ready to receive the diary opens for an understanding of the potential asynchrony between the needs of patients and relatives. This may strain relatives, who are not ready to part with the diary or have the resources for explaining the diary to the patient. This shows that the diary besides being an object also is a collaborative process between relative and patient.

5.1.2. Facing the risk of rejection

Preparing for the diary handover made relatives feel both vulnerable, anxious and exited about giving the diary containing their innermost thoughts and feelings to the patient. The vulnerability came from being uncertain about how the diary would be received by the patient. As the diary conveyed intense feelings, criticism or rejection from the patient would be painful. Therefore, the risk of rejection was perceived as a real by the relative. A daughter described how she felt, when she was preparing to share the diary with her father:

> "I had butterflies in my stomach, I was nervous. I was afraid how he would react and how I would react (laughs). But I was also anxious and exited and looking forward to see if he would be pleased. It was a very strange day". Relative 120

These intertwined positive and negative feelings and expectations opened for an understanding of how critical the handover of the diary was to the relative. A rejection of the diary and its emotion laden content would be hurtful to relatives who had written the diary with sincere intentions of helping the patient recover after the critical illness.

5.1.3. Assessing patient's readiness to receive the diary

In preparation for the handover, relatives tried to assess the patient's readiness to receive the diary before they could give the diary to the patient. Thus, relatives sensed the difficulties related to the diary even before sharing the diary with the patient.

> "Sometimes when we discussed something about the hospital, he would suddenly shut down saying – 'it's enough now". Then I thought that he probably wasn't ready to hear what I wrote in the diary". Relative 120

Determining the optimal time for the handover was a critical part of feeling able to give the diary to the patient. Optimal timing could promote patient acceptance. Some relatives, however, merely passed on the diary to the patient, believing that the patient was strong enough to receive the diary. Alas, not all relatives were equally aware of the impact the diary might have on the patient and some diaries might have been shown to the patient too soon.

Feeling able to hand over the diary was an integral part of fulfilling the intentions of writing a diary for the patient. However, parting with the diary could be difficult as the diary had become an object that secured their memories and potentially would help them understand. Relatives were anxious to achieve a successful handover of the diary, as rejection would be detrimental.

5.2. Being prepared to receive the diary from the relative

The handover of the diary required the patient to accept the diary when offered by the relative. By accepting, patients acknowledged and appreciated the relative's endeavors in writing the diary regardless of its content.

5.2.1. Acknowledging the relative's vulnerability

Patients understood that the relative had made great efforts in writing the diary and were eager to share the diary with them. One patient was more concerned about his daughter's experience of handing over the diary and less about his own perceptions of it:

> "I told her I would be ready whenever she was. I let it be up to her. She also needs to take care of her family, so I didn't want her to come home totally wasted after we had read the diary together. I wanted her go home with a good feeling inside" Patient 120

Receiving the diary in a respectful manner became a way of both appreciating the care shown by the relative and accepting the thoughts and emotions shared by the relative in the diary. Thus, the patient acknowledged the vulnerability of the relative and this allowed patients to reach out to help the relative recover from the experience of critical illness.

5.2.2. Accepting the diary

Patients could show their acceptance of the diary on different levels. The content of the diary could be accepted and embraced or

the diary could merely be accepted as a symbol of the care shown by the relative for the patient. One patient read the diary right away and accepted the diary content as his mother's account of what happened:

"Well, the first time I read it – It was so enlightening. It was not what I remembered – not at all. But it was so interesting! Patient 201

Although the content of the diary differed from his own memories of intensive care, it was accepted by the patient as a true version of the story of what happened. By accepting the content of the diary, the patient showed appreciation for the diary as well as for the relative's work that helped him build his own story of the stay in the intensive care unit.

Other patients would find the diary more difficult to read but could still accept the diary as a symbol of the care shown by relative. One woman was given the diary from her daughter but never read more than the first page and a half. Despite her reluctance to read the diary, she continued to voice her intentions to do it and thereby conveyed her acceptance of the diary as an object that signified care and love from her daughter. By accepting the diary as a symbol of care, rather than relating to its content, patients were able to respectfully appreciate the relative's endeavors. Most importantly, this was possible without reading the diary, which could be difficult for patients.

5.2.3. Rejecting the diary

Rejection of the diary was also a possibility. A patient refused to be confronted with the content of the diary written by his wife, claiming that he would much rather look towards the future than linger on the past.

"Yeah but I must admit that I prefer not to dwell on the past – I'd much rather dwell on the future if you know what I mean?" Patient 130

The content of diary could be rejected by the patient as too emotional and difficult to be confronted with. The relative might accept this, but repeatedly raise the topic, trying to persuade the patient to see the diary. The disappointment of not being able to share the diary could put pressure on the patient and spark a conflict between patient and relative. Rejecting the diary and its content could also cause the relative to feel hurt. Although this was not directly spoken of in the interviews, rejecting the diary implied a rejection of the emotional and personal content within the diary. This could be interpreted as a rejection of the relative's effort to help the patient altogether.

Thus, the diary could be accepted with or without reading it or rejected altogether by the patient. However, acceptance of the diary would be a prerequisite for sharing the diary and working towards a shared story based on it.

5.3. Developing a shared story based on the diary

Sharing the diary was preceded by feeling able to give the diary to the patient and being prepared to receive the diary from the relative. The three aspects of sharing the diary was so closely interrelated that none of them could occur in isolation, they were in fact the prerequisites of each other. Sharing the diary implied sharing information, interpreting memories and sensations as meaningful and in this way working towards a shared story about the time the patient was critically ill.

5.3.1. Sharing information and interpretation of the story

Patients' either read the diary on their own or had the relatives read it aloud for them. The relative would read from the diary but often be interrupted by the patient's need to ask questions and discuss the content:

"When I read the diary, he stops me and goes 'I need to ask something about this or that' and I do remember more than I wrote in the diary. This way more things comes up and then we talk and then we go on reading". Relative 228

This process of interrupted reading allowed patients and relatives to share information and clarify what happened. When reading and talking about the diary the patient would compare his or her own fragmented, incomplete or distorted memories with the chronologic accounts in the diary. When the diary verified the patient's memories, this would allow the patient to trust these memories and consider them as real:

"There was one thing, when I was put on the ventilator. I had a feeling about it for some time . . . There were two doctors at my bed and they said 'don't think he's will make it' [..] but then I found out that there was probably some truth to what I remembered". Patient 120

The diary helped patients interpret strange and incomprehensible memories and sensations as meaningful and perhaps accept how seriously ill he or she had been. This could be difficult, as most patients had only very limited memories of intensive care.

A shared interpretation would also be formed between relative and patient when they read the diary together. The relative and patient would try to interpret the delirious experience in relation to their knowledge of the patient when the diary described delirious episodes of the patient. One patient had a recurring nightmare about being trapped in his hospital bed in a small room. His wife had described in the diary how he had undergone different procedures. When talking and reading the diary together, she helped him interpret the nightmare as a reflection of the many small rooms he had been in during his hospital stay. The process of sharing the diary became a dialogue, where patient and relative co-interpreted disturbing memories in the context of the diary into a coherent narrative that was meaningful to both patient and relative. Moreover, this process of developing a shared story gave participants valuable insights into each other's experiences and strengthened their bonds.

Thus, sharing information and interpretation of the diary helped patients and relatives incorporate the diary narrative, the relatives' recollections and the patients' memories, however fragmented or disturbed into a re-configured, shared story strengthening their relationship.

5.3.2. Being unable to share, but still communicating

Sharing the diary was not always possible. Sometimes the diary was too intense for the patient and relative to read and discuss but they would then talk about what happened drawing on their recollections of the time in the intensive care unit.

"No, but we found it easier just to talk about it than me reading it". Relative 212

Talking about the critical time was less intense than sharing the diary. The direction of the conversation could constantly be modified and altered according to responses of the patient and relative whereas the content of the diary fixed in writing could not be modified; only interpreted. Thus, the diary narrative was a configured story that initially could not be modified but eventually through sharing would be interpreted and built into a re-configured and shared story about the experience of critical illness.

6. Discussion

In this study, we found that giving the diary to the patient and accepting the diary from the relative were prerequisites for patient

and relative to develop a shared and re-configured story based on the diary. The shared story strengthened the bond between relative and patient.

In a study by Egerod et al. (2011a), patients drew on both relatives and the diary in their endeavor of building a coherent narrative of the critical illness experience. Relatives supported the patient in this process of information acquisition but also helped themselves by reading the diary (Egerod et al., 2011a). The present study expands this understanding, as we found that the support between relative and patient also yielded a *shared* story. This was brought on by the joint reading of the diary, revealing the relatives' vulnerability to the patient and thus enabling mutual support. Egerod et al. (2011a) furthermore described how the diary written by nurses allowed patients to acknowledge their delusional memories as unreal. This supports our findings, were relatives and patients were able to co-interpret the nature of the patient's fragmented memories and nightmares and place them within a coherent narrative.

Developing a shared story reflects the general need for interpreting and configuring some sort of narrative about the critical time. According to Frank, narratives can repair the damage that illness has done to the person's sense of direction in life (Frank, 1995). Thus, narratives have the ability to point out a livable future for the patient and relatives as narratives are not only retrospective and unidirectional accounts of what happened, but also prospective, providing a new interpretation of the future. Sharing diaries and developing a shared story can be understood as such a narrative activity that will help relatives and patients to position themselves in life. Furthermore, this may allow them to identify the meaning the situation and promote a feeling of connectedness.

In present study, most patients accepted the diary and thereby appreciated the relatives' efforts. This is supported by Engström et al. (2009) who similarly described the patient's appreciation of the relatives' participation in diaries co-authored by staff and relatives. However, Engström et al. (2009) showed that reading the diary was difficult and touching to most patients, confronting them with their critical illness. This may in part explain why the diary was rejected by some of the patients in our study. Avoidance is not an uncommon response to critical illness, but we found that not sharing the diary did not preclude discussion of the time in the intensive care unit; patient and relative could still approach the sensitive subject in their own pace. Nevertheless, the rejection of the diary could potentially be disappointing or painful for the relatives. The risk of rejection this should therefore be addressed when asking relatives to author a diary.

Concerns about the confrontational nature of intensive care unit diaries has also been raised (Aitken et al., 2017a), and predicting the optimal handover time of the diary has proved difficult (Egerod et al., 2011a). We found that some relatives were intuitively aware of this issue and tried patient readiness, whereas others did not. Consequently, some patients may have received the diary earlier than they whished for. To avoid harming the patient in the future, relatives should be guided on how to determine the optimal handover. Drawing on our findings, we suggest that the relative should talk with the patient about the time in the intensive care unit and about what to expect from the diary. If the patient responds with interest, the diary may be shared, provided the relative feels ready to discuss the content of the diary.

Our analysis unfolded a dual perspective of the diary being both an object that could be *given* but also a process of *sharing* the diary. In comparison, Storli and Lind (2009) described how patients perceived a diary written by nurses as an unexpected gift. It conveyed care from the nursing staff to patients, but a shared story between nurses and patients was not intended. Attempting to understand the nature of gift giving, Mauss (2002), described gift giving as giving something of oneself to the other. In our study this applied to the personal content of the diaries that were given to the patient. However, giving a gift must be reciprocated to avoid being indebted (Mauss, 2002). The expected reciprocity was achieved when the patient accepted the diary and contributed to the process of developing the joint story. Thus sharing the diary became a two-way process between patients and relatives that fulfilled the diary more than merely transferring the diary from the relative to the patient as an object. However, not accepting the diary offered by the relative implied a rejection of the relatives' intentions to help the patient. This suggests that a family diary may not be suitable for all relatives and patients and consequently, this should be a concern when asking relatives to author a diary for the patient while critically ill.

6.1. Limitations

We set out to interview all participants as dyads and sought to elicit their shared experiences of using a diary. Dyad interviewing includes the risk of one participant dominating over the other and conflicting points of view to be suppressed (Norlyk et al., 2015). Our experience was, however, that the participants often helped each other tell their story, but also challenge each other when not agreeing. This allowed nuances between relative and patient to come forward. As it were, no male relatives accepted our invitation to take part in the study. Therefore, we are unable to say if male relatives might add other perspectives to writing and sharing a diary. This study focused on the shared use of the diary from 3 months post-discharge and onwards, however, exploring patients' use of the diary in the early recovery phase could have provided additional perspectives on how patients perceive the relatives diary.

7. Conclusion

The process of writing a diary for a critically ill patient was fulfilled when the diary was shared between relative and patient and a shared story was developed. For this to occur; relatives needed to feel able to give the diary to the patient and the patient needed to receive and accept the diary from the relative. Sharing the diary enabled mutual support, the development of a shared story and strengthened bond between patient and relative. Not sharing the diary could be a disappointment to the relative, but did not preclude a discussion of the experience of critical illness.

7.1. Relevance to clinical practice

Diaries written by relatives for patients may be authored by relatives instead of nurses as it support the relative in the intensive care unit and moreover facilitates support between patient and relative in the recovery period. However, as our findings showed that some patients found it difficult to receive the diary, we suggest that guidance to relatives on how to use the diary should include advice on how and when to share the diary with the patient and to accept patient refusal. Moreover, nurses should be sensible towards relatives' preferences when proposing a family diary to promote individualized care and family well-being.

8. Conflict of interest

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