



Research article

Patients' perceptions of an intensive care unit diary written by relatives: A hermeneutic phenomenological study



Anne Højager Nielsen ^{a,*}, Ingrid Egerod ^{b,c}, Sanne Angel ^d

^a Department of Anaesthesiology, Regional Hospital Holstebro, Lægårdvej 12, 7500 Holstebro, Denmark

^b University of Copenhagen, Health and Medical Sciences, Blegdamsvej 3B, 2200 Copenhagen N, Denmark

^c Intensive Care Unit 4131, Rigshospitalet, Blegdamsvej 9, 2100 Copenhagen Ø, Denmark

^d Section for Nursing, Department of Public Health, Aarhus University, Building 1260, Bartholins Allé 2, 8000 Aarhus C, Denmark

ARTICLE INFO

Article history:

Received 15 May 2019

Revised 24 July 2019

Accepted 1 August 2019

Keywords:

Critical Care Nursing

Family nursing

Hermeneutics

ICU diaries

Qualitative research

ABSTRACT

Objective: To explore patients' perceptions of an intensive care unit diary written by relatives including pictures added by staff.

Design: Ten patients were interviewed 3–6 and 8–16 months after discharge from the intensive care unit. Most patients were interviewed with a relative present. Interviews were analysed using Ricoeur's theory of interpretation.

Setting: Interviews took place in participants' homes.

Findings: Patients found the diary written by relatives with photos taken by staff to be valuable providing information that helped them understand their time in the intensive care unit. The diary text gave patients insight into relatives' experiences and suffering. Patients were touched by the love and care conveyed in the diary, however, the diaries could overwhelm the patients when they were confronted with the grief and agony endured by their relatives.

Conclusion: Although diaries kept by relatives confront patients with consequences beyond their own suffering, they are informative and promote understanding of what patient and family experienced during critical illness. The diaries expressed how much the relatives cared for the patient thus paving the way for mutual support and understanding. Diaries authored by relatives represent a new element to ICU diaries that have evolved from a nursing intervention toward family participation.

© 2019 Elsevier Ltd. All rights reserved.

Implications for Clinical Practice

- A diary written by relatives for the patient while in the intensive care unit helps the patient understand fragmented memories and piece together a story of the critical illness.
- The diary facilitates patients' understanding of relatives' feelings of distress and love for the patient.
- Nurses should guide relatives and patients on what to expect from the diary and how to use the diary as the diary can be overwhelming for the patient.

Introduction

After surviving critical illness, many patients experience a range of physical and psychological difficulties such as muscle weakness,

joint stiffness, eating difficulties, respiratory problems (Needham et al., 2012), as well as anxiety, depression and post-traumatic stress (Nikayin et al., 2016; Rabiee et al., 2016; Parker et al., 2015). The recovery process may be complicated by fragmented, distorted or lacking memories of intensive care (Jones et al., 2001), making it difficult to process what happened. Since the early 1990s critical care nurses have kept intensive care unit (ICU) diaries with the aim of helping the patient fill gaps in their memory

* Corresponding author.

E-mail addresses: annsve@rm.dk (A. Højager Nielsen), ingrid.egerod@regionh.dk (I. Egerod), angel@ph.au.dk (S. Angel).

and come to terms with their illness (Bergbom et al., 1999; Bäckman and Walther, 2001; Egerod et al., 2011) and reduce post-traumatic stress (Jones et al., 2010). ICU diaries have been appreciated by patients who have described them as extraordinary and beyond what could be expected (Storli and Lind, 2009). The diaries are typically handed over to the patient during a follow-up visit to the ICU (Egerod et al., 2011), where nurses read the diary with the patient providing the patient with a chance to ask questions. The optimal timing of the handover is difficult to determine as patient readiness to deal with the content of the diary varies (Nielsen et al., 2019c).

ICU diaries allow nurses to use their professional insight to describe patient-related events during critical illness (Ednell et al., 2017). However, when relatives have co-authored the diaries, their entries have been described as most important to the patients (Engström et al., 2009). Furthermore, research has shown that relatives may benefit from writing a diary for the critically ill patient (Jones et al., 2012; Nielsen and Angel 2015; Nielsen et al., 2019a). Writing and reading the diary during critical illness provides the relative with an opportunity to reflect on the situation and to understand what is happening (Egerod et al., 2017).

As a part of our current research, we have previously shown how patients and relatives share the ICU diary authored by the relative (Nielsen et al., 2019c). We found that the timing of the handover of the diary depended on several factors. The relative had to be ready to part with the diary, and furthermore, be able to discuss the content of the diary with the patient. In addition, the patient had to feel prepared to receive the diary. Reading the diary and talking about it allowed a shared story to develop between patient and relative (Nielsen et al., 2019c). In this paper, we move away from the shared perspective to explore the individual patient perceptions of the diary written by relatives.

Methods

Objective

The aim of the study was to explore patients' perceptions of an ICU diary written by relatives for the patient with photos added by staff.

Diary intervention

Nurses offered relatives the opportunity of writing a diary for the critically ill patient while in the ICU with the purpose of sharing the diary with the patient after discharge from the ICU. Rela-

tives received guidance from nurses on how to write the diary, and they were encouraged to find their own way of writing. Guidance was supplemented by written information pasted into the hardback diary. Nurses did not participate in writing the diary but took one or more photos of the patient. The photos were later added to the diary if the patient approved (Nielsen et al., 2018).

Setting and participants

Participants for this study were sampled from two regional mixed medical surgical ICUs in Denmark. All patients had been mechanically ventilated during their stay in the ICU. We interviewed 10 patients to achieve variation of patients' perceptions of the diary (Kvale and Brinkmann, 2009). We also wanted variation of gender, age, and relationship with the relative (Table 1).

Data collection

The study had a longitudinal descriptive design and was part of a larger study (Nielsen et al., 2019c, 2018) exploring the effect, meaning and use of diaries over time in dyadic interviews. Participants were interviewed at 3–6 months and 8–16 months to follow the use of the diary and perceptions as they evolved. All interviews were performed by the first author from September 2015 to March 2017. Most interviews took place in the participants' homes. To accommodate patients' needs, one interview took place in the hospital and one patient was interviewed by phone.

Interviews had an open and explorative approach drawing upon the thoughts of Ricoeur who describes how following a story is a complex operation, where expectations are re-adjusted as a story moves forward (Ricoeur, 1991). Therefore, to allow participants' stories to unfold the interviewer was guided by the participants' stories of how they used or perceived the diaries. A typical opening question was: "tell me about the first time you read the diary", which was followed by prompting questions like "tell me more about that" or "how did you feel about that" to elicit participants' experiences (Kvale and Brinkmann, 2009).

Recordings of interviews were transcribed verbatim by a university student; noting signs of emotions and pauses in parenthesis (Kvale and Brinkmann, 2009). Transcripts were compared to the audio recordings and checked for accuracy by the first author. One interview failed to be recorded, but a summary was dictated immediately afterwards.

Interviewing potentially vulnerable participants required the interviewer to proceed with care as participants might disclose private feelings or thoughts they later regret to have shared (Kvale

Table 1
Patients in the study.

ID	113	120	123	130	131	133	201	212	213	228
Gender	M	M	F	M	F	M	M	M	F	M
Age	68	62	47	71	77	71	35	76	76	73
Days in ICU	18	9	17	33	29	2	6	5	12	10
Hours MV**	405	193	279	756	616	11	144	51	99	72
Diary author	Wife	Daughter	Daughter	Wife	Daughter*	Wife	Mother	Wife	Daughter	Wife
Age	66	36	26	69	51	63	61	57	48	71
Entries in diary	62	16	22	75	144	9	25	7	19	10
Days covered	138	40	22	124	85	27	32	7	19	25
1. Interview										
Months post-ICU, participants	6 months Dyadic	4 months Dyadic + wife	–	3 months Dyadic	3 months Dyadic	4 months Dyadic	5 months Patient	4 months Dyadic	4 months Dyadic	4 months Dyadic
2. Interview										
Months post-ICU, participants	13 months Dyadic	12 months Dyadic + wife	9 months Patient	11 months Dyadic	9 months Dyadic	11 months Dyadic	16 months Dyadic + father	12 months Dyadic	13 months Dyadic	11 months Dyadic

* Daughter and other family members.

** MV = mechanical ventilation.

and Brinkmann, 2009). In this study, patients were interviewed in the presence of relatives. This approach may have caused some viewpoints to be suppressed (Norlyk et al., 2015). If the patient was reluctant to discuss a certain topic, the interviewer did not pursue it further. Silence and non-verbal expressions were noted in the transcripts to provide data on subjects that were sensitive or difficult to discuss.

Data analysis

Data were analysed using Ricoeur's theory of interpretation (Ricoeur, 1991). An initial naïve reading focused on appropriation of the text and therefore took the form of a "guess" (Ricoeur, 1991, p. 154) or first understanding of the text. The following structural analysis explained the text in terms of its smaller parts; asking what the text said and what the text was about. This implied holding back on the context and remaining in the suspense of the text. The final critical interpretation identified the most probable interpretation among competing interpretations serving to verify, support or modify the initial naïve interpretations in accordance with Ricoeur who states that "an interpretation must not be only probable but more probable than another" (Ricoeur, 1991, p. 155). Thereby, the final interpretation was validated and qualified by the objective and explanatory procedures of the structural analysis. During analysis and writing the paper, findings were continually discussed among authors to increase the credibility of the findings.

Ethical approval

All participants gave informed written consent to participation. Ethical approval was granted for the overarching DRIP-study by the Health Research 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). Protecting participants' confidentiality, data were anonymized and stored according to the Danish Data Protection Agency (identifier 1-16-02-30-15).

Findings

Patients found the diary valuable in relation to understanding what had happened and conveying relatives' love and support. However, reading the diary could be demanding as it confronted the patient with their own suffering and the suffering of their relatives. Our findings describe several aspects of the patient experience of the diary. The first is the confrontation with the illness experience, while the second expresses the mixed feelings being touched by the love and suffering of the relatives.

Confrontation with the illness experience

It was difficult for the patients to read the diary describing a period for which they had little or no recall and where the possibility of death was ever present. However, some patients were eager to understand what happened to them and welcomed what the diary had to offer. Patients with fragmented memory of ICU used the diary and photos as a source of information to understand disturbing recollections.

"The first time I read it (the diary), it gave me so much. I thought – was it like this, no it wasn't. It was not what I remembered, not at all. But it was. It was so interesting to read it" (201)

This shows how the diary and photos allowed the patients to piece together a story that could be combined with information from their relatives and the hospital chart available online.

However, patients were also deeply affected by the relatives' accounts. One patient described his response to reading the diary that had been lying in the living room for some time.

"Well, I probably broke down reading it" (113)

The words "broke down" opens for an understanding of the diary as demanding and difficult to read. It also shows how patients sometimes had to muster the courage to read the diary, as they feared its contents to be troubling. Thus, the unknown content of the diary could be disturbing and add to the patient's perception of the diary as difficult to approach. The pictures in the diary showed the unconscious patient in the ICU with tubes and wires. Patients expressed that looking at the pictures could be difficult and demanding because they confronted the patient with the potential risk of not surviving ICU. A few patients did not read the diary but only looked at the photos as this was less demanding than reading their relatives' account of their illness. One woman tried to explain her reluctance to reading the diary but was unable to put it into words.

"I don't know, I find it hard to say... because it's not like there's something criminal in it (the diary)" (213)

The reluctance to reading the diary suggests that the text is more difficult to confront than pictures. Perhaps the pictures represented a factual side to the illness, whereas the text represented subjective experience and private emotions of the relatives. It might have been easier for the patient to grasp the factual account of their own illness than to delve into the suffering of their relatives in the text. One patient described how the diary written by his wife was experienced as unrelated to his own illness. He did, however, acknowledge that he and his family had experienced the illness differently.

"You should ask my family how it was. I wasn't a part of it. Well it was my body, but I have no recollections of what they did and what we went through. Things first started to dawn on me after I came home" (113)

This shows how the patient slowly became aware of what had happened and cognitively tried to integrate it in to his personal story. This was difficult, as he had no memories of the time in the ICU. By the same token, it was difficult to relate to the relatives' reactions. The diary helped bridge the gap between the patient's and the relative's experiences.

Another patient disbelieved the severity of his critical illness. The diary text and pictures of him on mechanical ventilation felt surprisingly unreal. Contrary to what he expected, the pictures did not jog his memory of intensive care.

"Well, I just couldn't understand why it had gone so wrong. It's beyond my imagination... even if I look at the pictures – I still don't get it. I thought I would, but I don't" (212)

This shows that patients tried to recover their memories drawing upon the diary and its pictures, only to discover that they were unable to remember. This indicates that even when confronted with the relative's descriptions, some patients hesitated to relate to their experiences and integrate them into their own illness narrative.

Being touched by the love and suffering of the relatives

The diary conveyed a message of love and compassion, but reading the diary also provided patients with insight into relatives' feelings and experiences. As such, the diary was a testimony of the of the relatives' distress as they witnessed the patient's fight for survival. In a very emotional entry, a relative had described how

the whole family had gathered to say goodbye to the patient. The patient was deeply affected when he realized the pain his illness had inflicted on the relatives.

"Yes, I think it was when I read it (in the diary). Everyone had been down there to say their goodbyes. I think that was the hardest part, twice they had to go through that" (120)

Thus, diaries revealed the suffering of the relatives. The patient had his own suffering, but vicariously suffered with the relatives after reading the diary. Some patients even felt guilty for the distress and suffering they had caused their closest family. One patient refused to read the diary after realizing the distress he had caused.

"Yes, it's my fault and I don't want to dwell on it." (130)

This reluctance to reading the diary suggests that the relatives' suffering could be even more difficult to confront than their own critical illness and near-death experience. Other relatives wrote factual entries in the diary. Nevertheless, the patient easily related to the plight of the relatives while witnessing the patient's struggle for survival. One patient described how traces of humour disappeared from the diary as his condition deteriorated.

"It's not so much reading the diary – it's more what happened at the time. It was really a close call. That's probably it. And the way she writes – it's so easy to see if things are good or bad" (201)

This shows how patients were able to read between the lines and decode relatives' choice of words, language and even handwriting and thereby understand how relatives felt in the situation no matter how factual the entries. Thus, patients interpreted nuances in relatives' entries and understood how they really felt about the situation. This was a sign of the close relationship and intimate knowledge of each other.

The message of love comforted the patients. One woman was deeply moved by the diary's description of the care for her young son, while she herself was in the ICU with septic shock.

"The first weekend after I was put on the ventilator, I read that [my daughter] had taken [my son] home Saturday night. And he stayed with her until Sunday. And then (...) they went to a family birthday and she took care to bring him along (cries)" (123)

The care shown for her son was touching, but was also mixed with sorrow that she had been unable to take care of the boy herself. Yet she was comforted by reading how her son had been cared for.

Some diaries illustrated the close relationship between the patient and relatives. One patient remembered how his mother, upon his request, had stroked his cheek to comfort him while he was on the ventilator. When reading about this he was profoundly moved.

"But then I remember when my mother came – I think it was on the third day – I remember that I waved her closer and told her to touch my cheek. And then she wrote about it in the diary and that touched me so very much!" (201)

The gentle and caring touch of his mother in the critical situation was proof of the bond between mother and son, not only during a crisis, but in general.

Other patients had no recall of being in the ICU and were satisfied with this. Nevertheless, they treasured the diary because it described relatives' visits and greetings from visitors. One woman was uninterested in details about her own illness but reading about her grandchildren visiting touched her and was reason enough to read the diary.

"Because everything they did for me. It means so much to me" (131)

This underscores that the diary has the potential to strengthen the bond between patients and their families after critical illness and that this may be of greater importance to some patients, than factual information about illness and suffering.

Discussion

Our main findings describe the diary and photos as a source of information regarding the time in the ICU, which could feel unreal to some patients, and the diary as a key to understanding relatives' distress but also to be touched by the love shown by relatives in the diary.

The findings of the present study are supported by [Tembo \(2017\)](#) who described how being unconscious in the ICU fractures the intentionality of a human being, meaning that critical illness disturbs the experience of a continued existence. The resulting biographical disruption might alter the person's sense of identity ([Tembo, 2017](#)). It is therefore important to re-establish a continued narrative about the critical illness and the ICU stay. This is supported by [Teece and Baker \(2017\)](#) reviewing how nurses' diaries affect psychological recovery of patients. Their study showed that patients used the diaries to fill memory gaps after critical illness and helped them understand why recovery was slow ([Teece and Baker, 2017](#)). [O'Gara and Pattison \(2016\)](#) showed how nurses' diaries helped patients validate their experiences and move on after critical illness. This process of working towards an improved understanding was also explored by [Stayt et al. \(2016\)](#), who found that patients sought to complete a chronological account of events and to distinguish between real and unreal experiences. Moreover, [Stayt et al. \(2016\)](#) described the important role of the family in helping the patient complete the incomplete memories of the ICU. This supports our findings of the relatives' diary as an important source of information for patients even if difficult to confront.

The present study demonstrated the dual description of the relatives' love and distress in the diary. [Engström et al. \(2009\)](#) explored diaries co-authored by nurses and relatives and found that patients coveted the entries written by their relatives. These entries documented the relatives' presence to patients who often did not remember this ([Engström et al., 2009](#)). The study by [O'Gara and Pattison \(2016\)](#) also showed that the diary provided patients with information about relatives' experiences and distress during the patients' critical illness enabling the patients to understand the relatives. Similarly, our study described the diary as conveyor of love but also providing patients with insight into relatives' suffering. [Galvin and Todres \(2011\)](#) have proposed kinship and belonging as important for a person's sense of wellbeing. The love conveyed in the diaries may promote such a feeling of mutual understanding and belonging together. This may explain why the diary is so valued even when it confronts patients with descriptions of their relatives' distress. This points to a main difference between diaries authored predominately by nurses as shown by [Egerod and Christensen \(2009\)](#) and diaries written by relatives ([Nielsen et al., 2019b](#)) or by relatives and nurses in cooperation ([Jones et al., 2012](#); [Roulin et al., 2007](#); [Garrouste-Orgeas et al., 2012](#)) where relatives' presence is more prominent. When relatives write a diary, they express stronger feelings ([Roulin et al., 2007](#)). Moreover, they struggle to get the story right for the patient to read later on, while simultaneously trying to find meaning in the experience ([Nielsen et al., 2019b](#)). Some relatives write only very factual entries in the diary ([Nielsen et al., 2019b](#)). Nonetheless, present study showed that patients easily interpret relatives' entries, as they know the relative well and thereby grasps how the relative experienced the situation. [Page et al. \(2019\)](#) explored patients'

and relatives' different trajectories of recovery after the patients' critical illness. They found that relatives and patients had very different experiences, which had to be acknowledged by professionals and addressed in services supporting rehabilitation in patients and relatives (Page et al., 2019). The insight into relatives' suffering that came from reading the relatives' diary may help reconcile these different experiences described by Page et al. (2019) and promote a mutual understanding between relatives and patients. This way the diary may support patients' and relatives' efforts return to a life that can be lived.

Our study showed that photos were a source of information for the patients. Compared to the written text, the photos were more accessible, but for some patients, felt unreal and failed to improve memories of the time in the ICU. A mixed methods study by Åkerman et al. (2013) found that patients could feel alienated by the photos. This supports our findings of the photos as being unreal to some patients. In addition, Åkerman et al. (2013) described that photos provided patients with medical information and filled memory gaps. As such, our findings correspond well with those of Åkerman et al. (2013). However, the present study also showed that photos compared to relatives' diaries could be easier to access. This illustrates an important difference between the text and the pictures relating to the sender perspective. In contrast to the text, pictures confronted patients with their own illness; not the relatives' experiences of it. Moreover, reading a handwritten text can be more difficult than looking at a picture for patients, who may suffer from cognitive problems such as inability to concentrate for a longer time (Needham et al., 2012).

Some patients were reluctant to read the relative's diary. They felt guilty for having inflicted pain on the relative by falling critically ill. A paper by Bergbom and Askwall (2000) similarly described that patients appreciated relatives' support, but sensing relatives' suffering could evoke feelings of guilt in patients. This illustrates how critical illness may disrupt family dynamics and ability to support each other (Tembo, 2017). However, feeling guilty and avoiding the diary may also be symptoms of posttraumatic stress disorder (American Psychiatric Association, 2013), which affects about 25% of patients during the first half year after discharge from the ICU (Parker et al., 2015). Our study showed that experiences of guilt towards the relative might have prevented the patient from reading the diary, because the patient feared that the diary would overwhelm him or her emotionally. This reluctance to read the diary might conflict with the relatives' desire to share the diary with the patient (Nielsen et al., 2019c). To avoid conflicts and unnecessary strain on relatives and patients, this issue needs to be addressed when asking relatives to write diaries for critically ill patients. Based on our findings, we suggest that guidance should include the possibility of not sharing the diary if the patient expresses reluctance towards receiving it.

Limitations

The study sampled four female patients and six male patients, however, all diaries were written by female relatives. The absence of male diary authors may limit our understanding of differences relating to gender and thus be a limitation of the study. Relatives were encouraged by nurses to find their own way of writing. The different diaries resulting from this approach (Nielsen et al., 2019b) might pose another limitation of the study. The dyadic approach of interviewing might have caused some participants to not express views about the diary that would hurt relatives' feelings. However, the participants actually engaged in a dialogue with each other, which helped both converging and conflicting views to be expressed. In addition, data were sufficiently rich for patients' perceptions of relatives' ICU diaries to be described in detail.

Conclusion

Patients experienced the diary written by relatives and the photos taken by staff as a source of information about the critical time in the intensive care unit, but for some patients the diary may have been difficult to read as it confronted the patient with a difficult time. Nonetheless, the diary may help the patient understand the time of the critical illness. Photos were experienced as less demanding to grasp than reading the relatives' diary, as they did not confront the patient with the relatives suffering. The diary was an important conveyor of love and support from the relatives, which was highly valued by patients. Reading the diary written by the relatives allowed patients to understand the relatives' situation and helped reconcile the different experiences of the patient's critical illness. This improved understanding may support relatives and patients in their struggle to return to a life that can be lived.

Funding source

The study was funded by Department of Anaesthesiology, Regional Hospital Holstebro, Denmark; Aarhus University, Denmark and Health Research Fund of Central Denmark Region.

The funders did not influence the design of the study, acquisition of data, analysis, drafting of manuscript or decision to publish.

Clinical trial registration number

NCT02357680.

Declaration of Competing 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 paper.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.iccn.2019.08.001>.

References

- Åkerman, E., Ersson, A., Fridlund, B., Samuelson, K., 2013. Preferred content and usefulness of a photodiary as described by ICU-patients-A mixed method analysis. *Aust. Crit. Care* 26 (1), 29–35.
- American Psychiatric Association, 2013. Diagnostic and statistical manual of mental disorders. APA.
- Bäckman, C.G., Walther, S.M., 2001. Use of a personal diary written on the ICU during critical illness. *Intensive Care Med.* 27 (2), 426–429.
- Bergbom, I., Askwall, A., 2000. The nearest and dearest: A lifeline for ICU patients. *Intensive Crit. Care Nurs.* 16 (6), 384–395.
- Bergbom, I., Svensson, C., Berggren, E., Kamsula, M., 1999. Patients' and relatives' opinions and feelings about diaries kept by nurses in an intensive care unit: Pilot study. *Intensive Crit. Care Nurs.* 15 (4), 185–191.
- Ednell, A.K., Siljegren, S., Engström, Å., 2017. The ICU patient diary-A nursing intervention that is complicated in its simplicity: a qualitative study. *Intensive Crit. Care Nurs.* 40, 70–76.
- Egerod, I., Andersson, A.E., Fagerdahl, A.M., Knudsen, V.E., 2017. Images of suffering depicted in diaries of family caregivers in the acute stage of necrotising soft tissue infection: A content analysis. *Intensive Crit. Care Nurs.* 41, 57–62.
- Egerod, I., Christensen, D., 2009. Analysis of patient diaries in danish ICUs: a narrative approach. *Intensive Crit. Care Nurs.* 25 (5), 268–277.
- Egerod, I., Storli, S.L., Åkerman, E., 2011. Intensive care patient diaries in Scandinavia: a comparative study of emergence and evolution. *Nurs Inq.* 18 (3), 235–246.
- Engström, Å., Grip, K., Hamrén, M., 2009. Experiences of intensive care unit diaries: 'touching a tender wound'. *Nurs Crit Care.* 14 (2), 61–67.
- Galvin, K.T., Todres, L., 2011. Kinds of well-being: a conceptual framework that provides direction for caring. *Int. J. Qual. Stud. Health Well Being* 6 (4), 1–13.
- Garrouste-Orgeas, M., Coquet, I., Perier, A., Timsit, J.F., Pochard, F., Lancrin, F., et al., 2012. Impact of an intensive care unit diary on psychological distress in patients and relatives*. *Crit. Care Med.* 40 (7), 2033–2040.

- Jones, C., Griffiths, R.D., Humphris, G., Skirrow, P.M., 2001. Memory, delusions, and the development of acute posttraumatic stress disorder-related symptoms after intensive care. *Crit. Care Med.* 29 (3), 573–580.
- Jones, C., Bäckman, C., Capuzzo, M., Egerod, I., Flaatten, H., Granja, C., et al., 2010. Intensive care diaries reduce new onset post traumatic stress disorder following critical illness: a randomised, controlled trial. *Crit. Care* 14 (5), R168.
- Jones, C., Bäckman, C., Griffiths, R.D., 2012. Intensive care diaries and relatives' symptoms of posttraumatic stress disorder after critical illness: a pilot study. *Am. J. Crit. Care* 21 (3), 172–176.
- Kvale, S., Brinkmann, S., 2009. *InterViews: Learning the craft of qualitative research interviewing*. SAGE, Thousand Oaks.
- Needham, D.M., Davidson, J., Cohen, H., Hopkins, R.O., Weinert, C., Wunsch, H., et al., 2012. Improving long-term outcomes after discharge from intensive care unit: Report from a stakeholders' conference. *Crit. Care Med.* 40 (2), 502–509.
- Nielsen, A.H., Angel, S., 2015. Relatives perception of writing diaries for critically ill. A phenomenological hermeneutical study. *Nurs. Crit. Care*.
- Nielsen, A.H., Angel, S., Egerod, I., Hansen, T.B., 2018. The effect of diaries written by relatives for intensive care patients on posttraumatic stress (DRIP study): protocol for a randomized controlled trial and mixed methods study. *BMC Nurs.* 37 (17).
- Nielsen, A.H., Angel, S., Egerod, I., Lund, T.H., Renberg, M., Hansen, T.B., 2019a. The effect of family-authored diaries on posttraumatic stress disorder in intensive care unit patients and their relatives: a randomised controlled trial (DRIP-study). *Aust. Crit. Care*.
- Nielsen, A.H., Angel, S., Hansen, T.B., Egerod, I., 2019b. Structure and content of diaries written by close relatives for intensive care unit patients: a narrative approach (DRIP study). *J. Adv. Nurs.* 21.
- Nielsen, A.H., Egerod, I., Hansen, T.B., Angel, S., 2019c. Intensive care unit diaries: developing a shared story strengthens relationships between critically ill patients and their relatives: a hermeneutic-phenomenological study. *Int. J. Nurs. Stud.* 26 (92), 90–96.
- Nikayin, S., Rabiee, A., Hashem, M.D., Huang, M., Bienvenu, O.J., Turnbull, A.E., et al., 2016. Anxiety symptoms in survivors of critical illness: a systematic review and meta-analysis. *Gen Hosp Psychiatry.* 43, 23–29.
- Norlyk, A., Haahr, A., Hall, E., 2015. Interviewing with or without the partner present? – An underexposed dilemma between ethics and methodology in nursing research. *J. Adv. Nurs.*
- O'Gara, G., Pattison, N., 2016. A qualitative exploration into the long-term perspectives of patients receiving critical care diaries across the united kingdom. *Intensive Crit. Care Nurs.* 36, 1–7.
- Page, P., Simpson, A., Reynolds, L., 2019. Constructing a grounded theory of critical illness survivorship: The dualistic worlds of survivors and family members. *J. Clin. Nurs.* 28 (3–4), 603–614.
- Parker, A.M., Sricharoenchai, T., Raparla, S., Schneck, K.W., Bienvenu, O.J., Needham, D.M., 2015. Posttraumatic stress disorder in critical illness survivors: a metaanalysis. *Crit. Care Med.* 43 (5), 1121–1129.
- Rabiee, A., Nikayin, S., Hashem, M.D., Huang, M., Dinglas, V.D., Bienvenu, O.J., et al., 2016. Depressive symptoms after critical illness: a systematic review and meta-analysis. *Crit. Care Med.* 44 (9), 1744–1753.
- Ricoeur, P., 1991. *From Text to Action*. Northwestern University Press, Evanston, Ill.
- Roulin, M., Hurst, S., Spirig, R., 2007. Diaries written for ICU patients. *Qual. Health Res.* 17 (7), 893–901.
- Stayt, L.C., Seers, K., Tutton, L., 2016. Making sense of it: Intensive care patients' phenomenological accounts of story construction. *Nurs. Crit. Care* 21 (4), 225–232.
- Storli, S.L., Lind, R., 2009. The meaning of follow-up in intensive care: patients' perspective. *J. Caring Sci.* 23 (1), 45–56.
- Teece, A., Baker, J., 2017. Thematic analysis: how do patient diaries affect survivors' psychological recovery? *Intensive Crit. Care Nurs.* 41, 50–56.
- Tembo, A.C., 2017. Critical illness as a biographical disruption. *Proc. Singapore Healthcare* 26 (4), 253–259 [cited 24 September 2018].