



## Research Article

# The Intensive Care Unit diary — A significant complement in the recovery after intensive care. A focus group study

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## ABSTRACT

**Objectives:** The aim of this study was to gain an increased understanding of the intensive care unit diary and how it affects patients' recovery after intensive care.

**Methodology/design:** The study had a qualitative design and was conducted by two focus group interviews in October 2021 and was analysed with thematic analysis.

**Setting:** Ventilator treated intensive care patients with a length of stay  $\geq 72$  hours who had received a written diary were included. The study was conducted at two university hospitals in the south of Sweden.

**Findings:** The intensive care unit diary can be an important complement to the medical record and notes taken by family members by enhancing understanding of critical illness. The patients experience several prominent feelings from reading the diary such as guilt, fear, and anxiety as well as feelings of being cared for. The design and content of the diary can be important used as a tool in patients' recovery after intensive care.

**Conclusion:** Understanding their critical illness and the time in intensive care seems important to former intensive care patients. In this respect, the intensive care unit diary on its own does not provide significant information and thus need to be complemented by information from the medical record and notes taken by family members. Therefore, the diary can be used as a complement that might increase patients' sense of coherence and facilitate recovery after intensive care.

### Implications for clinical practice

- The intensive care unit diary, together with relatives notes and the medical record, could provide patients with information to facilitate psychological recovery after intensive care.
- Bedside intensive care nurses should encourage relatives to write notes that patients can read afterwards as well as reminding patients to discuss their medical records and access if possible.
- The patients found the diary valuable, it awoke a lot of feelings and thus benefitted to be handled over and reviewed together with the intensive care unit staff.
- Fulfilling of these components appeared to be important for creating understanding and an increased sense of coherence.

### Introduction

Becoming critically ill and in need of intensive care is a form of trauma that creates stress and overwhelming emotions that has proven difficult to deal with. Of those patients who survive intensive care, physical, psychological, and cognitive problems can remain, which is

usually referred to as post-intensive care syndrome (PICS) (Harvey & Davidson, 2016). The psychological aspect of PICS includes symptoms such as anxiety, depression, and post-traumatic stress disorder (PTSD). One of five patients develops symptoms of PTSD within 12 months of the event, and PTSD is associated with a lower health-related quality of life (McIlroy et al., 2019). PTSD symptoms as reliving memories and avoiding stimuli which are reminiscent of the event can be associated with patients experiences and memories from the intensive care unit

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(ICU) (Parker et al., 2015). Activities as remembering and recreating memories can have a protective effect against developing PTSD (Nielsen et al., 2018). A diary kept by the ICU nursing staff, containing a summary from admission, daily entries, and photos of the patient (Egerod et al., 2013) can increase understanding of what has happened during the critical illness and is an important asset for the patient (Strandberg et al., 2018). The ICU diary was first implemented in the early 1990's and described as a nursing intervention to help patients fill in memory gaps, gain coherence and understanding of their critical illness and to facilitate psychological recovery (Åkerman et al., 2010; Nydahl et al., 2014). With filling in memory gaps, the diary completed a person's illness narrative by reclaiming ownership of lost time (Teece & Baker, 2017). The diary has been shown to have a positive impact on survivors' psychological rehabilitation and is also associated with a lower risk of depression and better health-related quality of life (Barreto et al., 2019). Evidence of the effect of ICU diaries in preventing and treating psychological sequelae of an ICU stay is increasing, but are still inconsistent (Garrouste-Orgeas et al., 2019; Kredentser et al., 2018; Sayde et al., 2020; Wang et al., 2020).

The diary became more important for patients and relatives during the pandemic due to visit restrictions. Nursing staff were encouraged to write daily notes and continuously take photos of the patient to put in the diary, and though relatives were not able to write in the diary due to visit restrictions, they were encouraged to take notes at home. In Sweden, during the pandemic, the healthcare guide "1177" was increasingly used by the public to obtain information about COVID-19 and recommendations to prevent the spread of infection (1177 Vårdguiden, 2021). "1177" is the national hub for information and services within healthcare in Sweden. It offers healthcare advice, information, inspiration, and e-services, patients can also obtain their own medical records. As relatives were closed off from the patient and the ward, this hub became one new source for information and communication.

Sense of coherence (SOC) a concept described by Antonovsky as a resource that enables people to manage tension, to reflect about their external and internal resources, to identify and mobilise them, to promote effective coping by finding solutions, and resolve tension in a health promoting manner. The SOC consists of three fundamental concepts: comprehensibility, manageability and meaningfulness (Antonovsky, 2005).

Engström et al., (2009) found that the diary could be a tool for enhancing a sense of coherence. It provides an increased understanding of the critical illness experience (comprehensibility) which can affect the way of managing memories and experiences by using internal and external resources (manageability) to create meaning and enhance coping with the traumatic experience (meaningfulness).

There is a lack of knowledge about the exact mechanism of how the ICU diary improves patients' recovery after intensive care. Thus, more knowledge is needed about how the ICU diary affects patients, how they use the diary and the importance of the ICU diary designed and when it is returned. The findings of this study can contribute to the understanding of the ICU diary and how it affects patients' recovery after intensive care.

## Objectives

The aim of this study was to gain an increased understanding of the ICU diary and how it affects patients' recovery after intensive care.

## Method

### Design

This study had a qualitative design. Data were collected by two focus group interviews and analysed using thematic analysis with an inductive approach according to Braun and Clarke (2006).

### Sample and setting

The study was conducted in two general intensive care units at university hospitals in Sweden during the COVID-19 pandemic.

Patients  $\geq 18$  years, Swedish speaking, ventilator treated, with an ICU stay  $\geq 72$  hours were approached for participation. As a hospital routine, approximately two months after ICU discharge, patients were invited to a post ICU clinical follow-up service to receive their diary, to review their ICU stay and to identify needs for their psychological recovery. Patients who fulfilled the inclusion-criteria were informed about the study after their post ICU clinical follow-up visit. Patients interested to participate ( $n = 22$ ), received information by mail and were subsequently contacted by phone. Twelve patients accepted to participate, but of these patients, four withdrew or were unable to participate. Finally, eight patients remained in the study.

### Data collection

Data were collected through two focus group interviews (Wibeck, 2010) with six participants in the first group and two participants in the second. The focus group interviews were held in a conference room at the follow-up clinic. The interviews were video recorded to facilitate the transcription, and to provide an in-depth understanding of the content by making body language and interaction between the participants visible. A semi-structured interview guide was designed, inspired by Antonovsky's SOC concept (Box 1). To validate the interview guide, a pilot test was conducted. Questions were tested on two patients, outside of the study, at the follow-up clinic, to see if they understood the questions. No questions were changed. Two authors participated during the focus group interviews, the first author acted as a moderator and distributed the questions and ensured that the discussions remained within the framework of the topic. The second author participated as support. The first focus group interview lasted one hour and 42 minutes and the second lasted one hour and 9 minutes.

### Data analysis

Data were analysed thematically using an inductive approach according to Braun and Clarke (2006). This model involves six steps for doing the analysis that begin with transcription and ends with the written report. To ensure adherence to the model, the 15-point checklist was used during the process, involving transcriptions, coding, analysis and written report (Braun & Clarke, 2006). Two authors were involved in the analysis process by finding themes and sub-themes and then comparing these with each other. The first author did the transcription and wrote the final report.

### Ethical considerations

This study has been approved by the Swedish Ethical Review Authority (dnr 2021-02676) and permission to conduct the study was given by the head of the department. This study was conducted in compliance with the ethical guidelines of the Declaration of Helsinki (WMA, 2008) and written consent was obtained.

### Findings

Eight patients were included in the study. Demographic and clinical characteristics for the patients are presented in Table 1.

The analysis generated three themes *understanding*, *prominent feelings* and *the design of the ICU diary* and ten sub-themes (Table 2). All three themes were important in the recovery after intensive care and affected the patient's process in varied ways.

- **Comprehensibility**  
Describe how you feel when you read the diary.  
What have you gained from reading the diary?  
Describe how you experience the content of the diary?
- **Manageability**  
Describe in what way you are using the diary.  
Describe how the diary helped you.
- **Meaningfulness**  
Describe the feelings of being critically ill and cared for in an ICU.

**Box 1.** Extracts from the interview guide.

**Table 1**  
Characteristics of the participants.

Focus Group	Age	Sex	Primary Diagnosis	Length of Stay	Mechanical Ventilation (days)
1	75	M	COVID-19	5	4
1	56	M	COVID-19	14	10
1	59	F	COVID-19	19	16
1	70	M	COVID-19	24	19
1	64	M	COVID-19	10	6
1	66	M	Larynx Edema	5	5
2	69	M	COVID-19	7	5
2	77	M	Cardiac Arrest	7	6

**Table 2**  
Themes and sub-themes.

Themes	Sub-themes
Understanding	Complement Tool for discussion Realistic goals Regain lost time
Prominent feelings	Guilt Gratitude Fear and anxiety
Design of the diary	Written content Photos Return of the diary

*Theme 1: Understanding*

The ICU diary gave an increased understanding (comprehensibility) of the critical illness and what happened while being in intensive care. Understanding what happened was considered important for letting go and to move on. The way to achieve understanding was built on four sub-themes that all had understanding as a common denominator but differed from each other and described how patients managed and processed their critical illness (manageability).

*Complement*

The ICU diary alone did not give the patients all the information they needed. After discharge, many began trying to understand what had happened by combining information from different sources. They read their medical records on the website “1177” which is freely accessible for the patient to read. However, the medical writing was difficult to understand but they compared it with notes taken by family members and the diary. The patients explained that it was therapeutic to organise data and put pieces together.

*“The combination of my daughter’s diary and the ICU diary has been valuable. I have found out a little bit more about what has happened to me. I visited the “1177” and there was a lot to read there. But after that, it was clear to me what had happened and what a job I had put down.”* (participant 1)

*“I think that building the puzzle is, that “1177” together with my wife’s notes and sms, filled the hole again.”* (participant 6)

*Tool for discussion*

The ICU diary provided information about the daily care, how the patients acted as a person and how they slowly recovered and finally were able to leave the ICU. When patients wanted to show what they had been through, the ICU diary became a foundation for the conversation, both with close relatives and with friends. It also became a way to process what had happened, to retell the story to someone else.

*“I think the most important thing for me was reading and crying a few times. Then, when you can look at it again, it becomes an important basis for discussion.”* (participant 2)

*Realistic goals*

Some read the ICU diary repeatedly to confirm for themselves what had happened and to see the progress that had been made. Patients could express frustration that they still could not do the same things as before critical illness. This made them feel sad and depressed and to lose motivation to continue training. Understanding how critically ill they have been enabled the patients to have realistic expectation on recovery and to obtain a greater ability to handle their situation.

*“It’s easy to forget... I have to be reminded why I’m not feeling well. It’s not a random thing that happened this morning, it has actually been really bad. I almost died a few times, and I need to remind myself of that.”* (participant 2)

*Regain lost time*

Gaining an understanding and knowledge of the time that you have no memory of seemed to be an important part of the recovery after intensive care. The ICU diary became a thread to follow through the critical illness period and the information in it became pieces that increased comprehensibility. Almost all patients had some form of dreams or nightmares from the ICU stay or were re-living frightening hallucinations and stories which they do not really recognise as true or not. To return to the ICU diary repeatedly strengthened the truth.

*“Yes, you have memory gaps. A whole month! You still want a description of everyday life so you can take it with you. Like the rest of your life. What everyday life was like, get a description, that’s extremely important.”* (participant 4)

## Theme 2: Prominent feelings

Several prominent feelings arose from reading the ICU diary, such as feelings of guilt, feelings of gratitude and feelings of fear and anxiety. How patients responded to their emotions and strong feelings determined how they used the ICU diary in their recovery.

### Guilt

Patients experienced feelings of guilt when they read the ICU diary. There were strong feelings about what the patient had forced his relatives to experience that they had experienced what the patient read in the ICU diary. There were also feelings of guilt for having survived, while so many others died. These feelings seemed to be overwhelming for the patients and most of them cried when talking about it. Even if they were strong feelings, they appeared to be a part of the understanding process.

*"For me, it's about guilt for my family. That they have experienced what I see in the diary."* (participant 8)

### Gratitude

Patients expressed feelings of gratitude for being taken care of in the ICU, and that nursing staff was there all the time only for them and looked after them in an intimate and careful way. It was important to see that their lives continued and that daily routines, such as washing and shaving were performed as usual. To be seen as a person, an individual, instead of any patient was surprising to them, and all of them expressed gratitude.

*"The diary is like a description of everyday life. Like the shaving... - Oh it works, I did not grow a beard! It was a small detail, but so important. That you have been taken cared of."* (participant 3)

### Fear and anxiety

Only one of the patients experienced the ICU diary as frightening and did not dare to return to it. Strong feelings of anxiety and re-living fear appeared. The group was quiet and sat with serious faces during this discussion and it appeared that it touched a tender wound for every-one.

*"I have not read it... I have planned to read it, but then not read it... I have not been able to... It was awful, all the emotions came back."* (participant 4)

## Theme 3: Design of the diary

The design and content of the ICU diary with regard to, photos, how to write, when to write and the receiving of the ICU diary was important for being helpful in a patient's recovery after intensive care. Daily notes and photos of the patient, which show warmth and compassion increased the knowledge (comprehensibility) of what happened. It seemed easier to capture the content of the ICU diary and to use it if it was received and explained during a follow-up visit. The patients returned to and read the diary over again during the recovery, it helped them to remind how critical ill they have been and find meaning of what happened (meaningfulness).

### Photos

The photos in the ICU diary made the critical illness more real, the patients realised that it really was themselves. They saw how ill they had been. Those who did not have photos in the ICU diary were disappointed when they heard that others had received it.

*"The good thing is that there are photo, because it focus on what has happened in connection with the text."* (participant 1)

## Written content

The written content of the ICU diary should reflect reality as much as possible. Both everyday chores such as washing and bedding but also how the patient behaved should be described. Since patients often are in a stage of confusion when sedation is released, it was important to describe the reality so that the patient could be helped to distinguish dreams from reality. It seemed important that the ICU diary was written in a personal way, so it emphasised that there was a connection between nursing staff and the patient. Expressing emotions was appreciated. In order to gain an increased understanding, patients thought it was important that nursing staff wrote in the ICU diary every day. No parts should be missing and the more that was described the easier it was to reconstruct the gap of lost time.

*"Thanks to the diary and the photos, I know what I was like. As long as you lie there and sleep, you don't know anything."* (participant 7)

*"The diary is a valuable tool, but there's one thing that I might be missing. I was quite unwell, confused and stuff. So it's kind of hard to figure out what really happened. I've fantasised and thought I've been at other places. So it's important that everything is included..."* (participant 5)

The diary helped the patient to move forward during recovery and find meaning in what had happened (meaningfulness).

*"You have bad days, and you think that life sucks and is unfair. Then I open the book and look at my photos. It was this bad nine months ago! And now I'm here. And by some weird logic, I feel good by seeing it. It could have been the other way around... But for me it works... The reading is crucial for me, to be able to move on..."* (participant 2)

## Returning the diary

According to the patients, the returning of the ICU diary should be done when they have returned home, and things start to sort out about how they feel psychologically and cognitively. The need for support in connection with the return varied, but the significance of the ICU diary was considered important. How it could be used and what it contained was explained in discussion with the nurse at the follow-up clinic.

*"I thought it was nice to get it back at the follow-up clinic. Because then you have time to sit down, and the content can be explained to you before you get it in your hand. I thought that was great."* (participant 2)

*"I knew I'd got the diary, it was up there in the cupboard with the other papers from the hospital, and I'd skimmed through it but didn't really understand. I thought it was like a medical record or something. But it wasn't! Now in retrospect I have read it and understood, it is not a medical record at all...it is so much more."* (participant 8)

## Discussion

This study shows that the ICU diary does not provide complete information but is a significant complement to information retrieved from the health website "1177" and from notes taken by family members, and increases patients' understanding of the critical illness and the time in the ICU. The diary as a tool to help patients during their recovery is a phenomenon that has been described in previous studies (Barreto et al., 2021; Eaton et al., 2019; Egerod & Bagger, 2010). Our study highlights a new behaviour, the need to use of additional information from a health website "1177". During the pandemic, both patients and their relatives needed information, and via other media they learned to use the "1177" website. The medical record in "1177" is protected by the persons e-identification for data security, so only the patient can log in and gain access to the medical record via "1177". Relatives were not allowed to visit the ward, and received only a daily telephone call from the physician, and nursing staff often asked relatives to keep their own notes. After discharge, patients started looking for information, and if the ICU diary was missing medical information, they were reading their

medical record in "1177". Together with information gathered by family members this increased understanding of what happened, and the ability to create a coherent story from the ICU. The level of understanding depends on comprehension, how the diary is designed, its content, and feelings arising from reading the diary. According to Antonovsky's salutogenic concept SOC (Antonovsky, 2005; Eriksson & Lindström, 2006), it could be explained as the more patients can understand and integrate their experience of critical illness (comprehensibility), the more likely they are to use all available internal and external resources (manageability) to make sense of their experience (meaningfulness). The SOC is a resource that enables people to manage tension, to reflect about their external and internal resources, to identify and mobilise them, to promote effective coping by finding solutions, and resolve tension in a health promoting manner. It follows that patients can increase their ability to develop a positive attitude towards physical and mental well-being, and therefore more likely to successfully cope with their critical illness experience.

The emotional impact when reading the diary emerged as a central theme, which could be both positive and negative when arouse feelings of fear. When patients talked about guilt and fear/anxiety, the mood was very subdued. Most patients cried. When such strong feelings are aroused by reading the ICU diary, it helped us understand that there are obstacles for patients to approach the ICU diary and to use it in their recovery. However, other studies have shown that even if it was emotional to read the diary, it helped them to accept the critical illness and to overcome the negative feelings (Barreto et al., 2021; Engström et al., 2009). Teece and Baker (2017) discussed the fact that intensive care can be a dehumanising experience in which the ICU diary helps nursing staff refocus on the patient as a person. In this study the patients experienced that nursing staff wrote in a way that made them feel cared for and important. They were seen as an individual person.

Previous studies (Åkerman et al., 2010; Barreto et al., 2022) have shown that there is difference in the design of the diary between ICUs, both pre-printed information, and whether the diary contained photos of the patient during their ICU. The same was seen between the two ICUs in this study. Patients described that the photos were important, to see themselves made the experience more realistic. The photos created an emotional connection to the text and increased the credibility to the given information. This result is in line with other studies (Barreto et al., 2021; Egerod & Bagger, 2010) and strengthens our belief that photos should be included in diaries. We believe this should be considered in other ICU's and other countries, where photos are not used routinely. However, there may be limitations in taking photos, such as access to equipment, legal restrictions, or patient autonomy. The fact that photos are a strong link representing the truth, could be significant in the recovery process, and this has been taken into account when discussing whether photos should be included or not.

The return of the diary seems to be of great importance, as well as having someone to read it with to comprehend what it says and have a person to talk to (Barreto et al., 2021; Eaton et al., 2019). Patients in this study who received the ICU diary on a follow-up visit and at the same time could talk to a specialist nurse were satisfied and had not wanted to get it back earlier as they then felt more vulnerable. However, since the study was small, it is a conclusion that should be taken with caution as individual needs should be considered and should be person-centered. Fukuda et al., (2015) found that patients required someone to give them courage for reflection. This is probably important to keep in mind, especially when patients may not want to read their ICU diary but where the nurse at the follow-up clinic sees it as a need. Missing appointments may lead to lost time in rehabilitation and perhaps a risk of developing more severe symptoms such as PTSD. However, exposing oneself to the traumatic event, to which the ICU diary corresponds, by returning to it repeatedly is one of the mechanisms in the treatment of PTSD (Knowles and Tarrier, 2009). We must not forget that there are patients who most of all want to forget what happened and have a need to move forward during the recovery process. Some patients need to focus on the present

and distance themselves from their critical illness. Reading the diary to recollect memories seems to go against their desire to turn forward to the future (Flahault et al., 2022). As patients have different ways of dealing with trauma, the diary cannot be handed over to the patients without being given the opportunity to receive support when reading the diary.

The aim of the diary is to create a narrative of the events in ICU to promote a person's sense of coherence to support understanding of the new situation. Our result was consistent with other studies (Ednell et al., 2017; McIlroy et al., 2019; Wallin et al., 2022) who stated that patients via the ICU diary were given an opportunity to understand what they have been exposed to, and that the ICU diary also could be the support patients need during recovery (Ednell et al., 2017; Wallin et al., 2022). We still do not know which individuals that are in need of information to better manage their rehabilitation. When delivering the ICU diary at the follow-up visit, nurses have to identify internal and external resources that can be helpful to the patient to manage the new situation. This necessitates awareness of resources and support factors. Gaining access to and making use of the ICU diary may empower patients, and by getting to know their story, supports constructing of meaning and coherence.

### Strength and limitations

The strength of the study is the use of focus group interviews as data collection. Together, patients reflect and provide deeper and broader information about the phenomenon (Wibeck, 2010). To increase credibility, two authors were involved in the analysis process, developing sub-themes and themes. Trustworthiness was ensured by using the 15-point checklist by Braun and Clarke (2006).

Both men and women were informed about the study, but only one woman was interested to participate. This is a limitation in this study, then it may affect the results as there can be a difference between men's and women's experiences of the diary.

The access to the medical record and the possibility to read it whenever you want, could be a Swedish phenomenon and transferability of the findings of this study depends on how easy it is to obtain the medical record in other countries.

The quotes from the interviews have been translated from Swedish to English by two English-speaking people independently from each other and then compared, although there still is a small chance that this process could have affected the meaning.

A limitation is that the patients were recruited to the study in connection with their post-ICU follow-up visit. The first author of the study works as an intensive care nurse in one of the ICUs and runs one of the follow-up clinics. To avoid patients feeling compelled to participate, the invitations were made after the meetings. One of the focus groups contained two participants. From an ethical perspective, it was important to let every-one who were invited participate in the study, and let their voices be heard (Wibeck, 2010). We chose to use data from the second focus group, despite the small number of participants, as depth in the description of the experiences could be obtained and the results are reinforced by similar results from previous studies.

### Conclusion

Understanding their critical illness and time in intensive care seems to be important for former ICU patients. The ICU diary on its own was missing important pieces and therefore needed to be complemented with more information, that patients found both in the electronic medical record ("1177") and from personal notes taken by friends and family members. The use of this new website has not been seen earlier, and its importance for patients' well-being and recovery has not been established as far as we know. Therefore, we suggest that the ICU diary can be a significant complement to medical information and notes taken by family members and might increase patients' sense of coherence and

facilitate recovery after intensive care.

This new knowledge should be considered in future follow-up of intensive care patients to improve and individually adapt the clinic to give the patients an opportunity for increased sense of coherence. We would like to see more research in this area in order to investigate how to optimise psychological recovery, with the ICU diary and supplementary information.

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## 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.2022.103337>.

## References

- 1177 Vårdguiden (2021) <<https://www.1177.se/>> accessed 2022.02.13.
- Åkerman, E., Granberg-Axell, A., Ersson, A., Fridlund, B., Bergbom, I., 2010. Use and practice of patient diaries in Swedish intensive care units: a national survey. *Nurs. Crit. Care* 15, 26–33.
- Antonovsky, A., 2005. *Hälsans mysterium [Mystery of health]*, second ed. Natur & Kultur Akademisk, Stockholm.
- Barreto, B. B., Luz, M., Lopes, A.A., Goulart Rosa, R., Gusmao-Flores, D., 2021. Exploring Patients' Perceptions on ICU Diaries: A Systematic Review and Qualitative Data Synthesis. *Crit. Care Med.* 49(7), E707–E718.
- Barreto, B. B., Luz, M., Gusmao-Flores, D., 2022. Using Qualitative Synthesis to Explore Heterogeneity of Randomized Trials on ICU Diaries. *Crit. Care Med.* Jul 22. DOI: 10.1097/CCM.0000000000005622. Epub ahead of print. PMID: 3586665.
- Barreto, B.B., Luz, M., de Oliveira Rios, M.N., Lopes, A.A., Gusmao-Flores, D., 2019. The impact of intensive care unit diaries on patients' and relatives' outcomes: a systematic review and meta-analysis. *Crit. Care* 23, 411.
- Braun, V., Clarke, V., 2006. Using thematic analysis in psychology. *Qual. Res. Psychol.* 3, 77–101.
- Eaton, T.L., McPeake, J., Rogan, J., Johnson, A., Boehm, L.M., 2019. Caring for survivors of critical illness: Current practices and the role of the nurse in intensive care unit aftercare. *Am. J. Crit. Care* 28, 481–485.
- 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., Bagger, C., 2010. Patients' experiences of intensive care diaries - A focus group study. *Intensive Crit. Care Nurs.* 26, 278–287.
- Egerod, I., Risom, S.S., Thomsen, T., Storli, S., L., Eskerud, R., S., Holme, A. N., Samuelson, K. A., 2013. ICU-recovery in Scandinavia: a comparative study of intensive care follow-up in Denmark, Norway and Sweden. *Intensive Crit. Care Nurs.* 29 (2), 103–111.
- Engström, Å., Grip, K., Hamrén, M., 2009. Experiences of intensive care unit diaries: "touching a tender wound". *Nurs. Crit. Care* 14, 61–67.
- Eriksson, M., Lindström, B., 2006. Antonovsky's sense of coherence scale and the relation with health: a systematic review. *J. Epidemiol. Community Health* 60, 376–381.
- Flahault, C., Vioulac, C., Fasse, L., Bailly, S., Timsit, J.F., Garrouste-Orgeas, M., 2022. "A Story With Gaps": An interpretative phenomenological analysis of ICU survivors' experiences. *PLOS ONE* 17 (3) ><https://doi.org/10.1371/journal.pone.0264310>.
- Fukuda, T., Inoue, T., Kinoshita, Y., Yukawa, T., 2015. Effectiveness of ICU diaries: Improving distorted memories encountered during ICU admission. *Open J. Nurs.* 5, 313–324.
- Garrouste-Orgeas, M., Flahault, C., Vinatier, I., Rigaud, J.P., Thieulot-Rolin, N., Mercier, E., Rouget, A., Grand, H., Lesieur, O., Tamion, F., Hamidfar, R., Renault, A., Parmentier-Decrucq, E., Monseau, Y., Argaud, L., Bretonnière, C., Lautrette, A., Badié, J., Boulet, E., Floccard, B., Forceville, X., Kipnis, E., Soufir, L., Valade, S., Bige, N., Gaffinel, A., Hamzaoui, O., Simon, G., Thirion, M., Bouadma, L., Large, A., Mira, J.P., Amdjar-Badidi, N., Jourdain, M., Jost, P.H., Maxime, V., Santoli, F., Ruckly, S., Vioulac, C., Leborgne, M.A., Bellalou, L., Fasse, L., Misset, B., Bailly, S., Timsit, J.F., 2019. Effect of an ICU Diary on Posttraumatic Stress Disorder Symptoms Among Patients Receiving Mechanical Ventilation: A Randomized Clinical Trial. *JAMA*, 16 (3), 229–239.
- Harvey, M.A., Davidson, J.E., 2016. Postintensive Care Syndrome: Right Care, Right Now...and Later. *Crit. Care Med.* 44, 381–385.
- Knowles, R.E., Tarrier, N., 2009. Evaluation of the effect of prospective patient diaries on emotional well-being in intensive care unit survivors: A randomized controlled trial. *Crit. Care Med.* 1, 184–191.
- Kredentser, M.S., Blouw, M., Marten, N., Sareen, J., Bienvenu, O.J., Ryu, J., Beatie, B.E., Logsetty, S., Graff, L.A., Eggertson, S., Sweatman, S., Debroni, B., Cianflone, N., Arora, R.C., Zarychanski, R., Olafson, K., 2018. Preventing Posttraumatic Stress in ICU Survivors: A Single-Center Pilot Randomized Controlled Trial of ICU Diaries and Psychoeducation. *Crit. Care Med.* 46 (12), 1914–1922.
- Mcllroy, P.A., King, R.S., Garrouste-Orgeas, M., Tabah, A., Ramanan, M., 2019. The effect of ICU diaries on psychological outcomes and quality of life of survivors of critical illness and their relatives: A systematic review and meta-analysis. *Crit. Care Med.* 2, 273–279.
- 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 Nursing* 16 (17), 37.
- Nydahl, P., Bäckman, C. G., Bereuther, J., Thelen, M., (2014) How much time do nurses need to write an ICU diary? *Nurs. Crit. Care.* 19 (5), 222–227.
- Parker, A.M., Sricharoenchai, T., Rapaola, S., Schneck, K.W., Bienvenu, J., Needham, D. M., 2015. Posttraumatic stress disorder in Critical illness survivors: A metaanalysis. *Crit. Care Med.* 5, 1121–1129.
- Sayde, G.E., Stefanescu, A., Conrad, E., Nielsen, N., Hammer, R., 2020. Implementing an intensive care unit (ICU) diary program at a large academic medical center: Results from a randomized control trial evaluating psychological morbidity associated with critical illness. *Gen. Hosp. Psychiatry* 66, 96–102.
- Strandberg, S., Vesterlund, L., Engström, Å., 2018. The content of a patient diary and Its significance for persons cared for in an ICU: A qualitative study. *Intensive Crit. Care Nurs.* 45, 31–36.
- Teece, A., Baker, J., 2017. Thematic Analysis: How do patient diaries affect survivors' psychological recovery? *Intensive Crit. Care Nurs.* 41, 50–56.
- Wallin, E., Hultström, M., Lipcsey, M., Frithiof, R., Rubertsson, S., Larsson, I.M., 2022. Intensive care-treated COVID-19 patients' perception of their illness and remaining symptoms. *Acta Anaesthesiol. Scand.* 66, 240–247.
- Wang, S., Xin, H.N., Vico, C.C.L., Liao, J.H., Li, S.L., Xie, N.M., Hu, R.F., 2020. Effect of an ICU diary on psychiatric disorders, quality of life, and sleep quality among adult cardiac surgical ICU survivors: a randomized controlled trial. *Crit. Care* 24 (1), 81.
- Wibeck, V., 2010. Fokusgrupper. Om fokuserade gruppintervjuer som undersökningsmetod [Focus groups. About focused group interviews as a research method], second ed. Studentlitteratur, Lund.
- World Medical Association Declaration of Helsinki - WMA (2008), [https://www.wma.net/wp-content/uploads/2016/11/Ethics\\_manual\\_3rd\\_Nov2015\\_en.pdf](https://www.wma.net/wp-content/uploads/2016/11/Ethics_manual_3rd_Nov2015_en.pdf) < accessed 2021.10.25.