

## The Ongoing Debate on ICU Diaries: Which Patients do Benefit?

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### ABSTRACT

*Based on the study results of the last twenty years, there has been predominantly positive experience with providing intensive care diaries for critical ill patients. But now, recent data from a large-scale, multi-center prospective randomised study has shown a rather opposite result. According to the results of this study, the most feared diseases after a time of unconsciousness due to serious illness which consequences intensive care unit (ICU) stay, like post post-traumatic stress disorder (PTSD) anxiety and depression could not be significantly affected and reduced. Thus, the effect and the efficacy of the ICU diary becomes critically questioned. Against the background of our own experiences in Cardiac Arrest Center at University Hospital of Marburg, where we see more than 250 patients with severe multiorgan dysfunction due to cardiogenic- septic shock, partly after cardiopulmonary resuscitation every year, and the results of the current literature, we will here discuss these new study results in order to ensure the best possible support for this patient cohort on ICU and their relatives in an exceptional cruel and stressful situation.*

### Keywords

Critical care medicine, Intensive care diary, Post intensive care syndrome (PICS), Post-traumatic stress disorder (PTSD).

### Introduction

The use of ICU diaries for accompanying intensive care patients has received increased attention over recent years. But a desired best possible disease course with at the end survival of the patient is not the only important goal in this situation. Secondary diseases, following an intensive care therapy which may affect patients in their relationships and work often over month or years after discharge from ICU also have to be considered in this context. These include anxiety, depression, cognitive as also physical impairments and post-traumatic stress disorder (PTSD), summarized as post intensive care syndrome (PICS) in both, patients and their relatives. Keeping an individual intensive care diary by the patients' family, the relatives and clinical staff during ICU stay should make the time of unconsciousness as transparent as possible for the patient, especially in filling memory gaps. By writing down daily events and therapy development during the intensive care treatment enables the patient to reconstruct this "empty" time period without awareness after discharge. While, so far, numerous studies have

shown quite positive effects for ICU diaries over years, data from a large-scale, multi-center, prospective randomized study on French ICUs now showed conflicting results. Does this data basically destroy the promising and convincing concept of ICU diaries? Or do we even have to better define patient collective, organizational and structural requirements.

### Background

According to the results of abundant previous studies, quite beneficial results have been published regarding the use of ICU diaries. Pattison et al. examined a cohort of 50 patients in a two-phased study including prospective diary intervention, evaluation and subsequent in-depth interviews. 95% of the patients, who complete diary evaluation, found ICU diary helpful in filling memory gaps [1]. Personally, written ICU diaries make the patients feel valuable, thus diary confirms appreciation of the patients and staff [2]. A positive effect on quality-of-life as also anxiety and depression could be determined [3]. The occurrence of a newly diagnosed PTSD after severe diseases appears reduced, so the provision of ICU diary promotes psychical recovery [4]. Next to the patients, also their relatives and families benefit from keeping a diary, especially in regard with the not to be disregarded

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risk of the occurrence of PTSD [5]. However, relevant influencing parameters in this context seems to be the severity of the disease and consequently the duration of ICU stay, the experience of the staff in keeping the diary, the age of the patients and the time of professional follow-up after discharge [6]. Furthermore, diaries reflect the commitment and care of those, who are involved in the recovery processes of the patients [7]. Indeed, to strengthen the patient's sense of coherence, follow-up visits also beyond the stay on ICU in combination with the presence of an ICU diary, have been shown to be extremely positive [8].

Recent published data of a very valuable study now fundamentally questions these results [9]. Garrouste-Oregas et al. published results from a multicenter, prospective randomized study, regarding the effect and influence of ICU diaries on the mental health of intensive care patients and their relatives. A total of 35 ICUs participated to this study, three of them routinely used ICU diaries before study start. 657 patients undergoing mechanical ventilation and 563 relatives were included. The patient age was  $\geq 18$ , the average age of the patients was 62 years and ventilation duration were  $\geq 48$ h. In the end, 339 patients (51,6%) completed the study. According to our understanding of the study design, remarkably patients with a cardiac arrest (CA) on admission and those with severe disease, considered by the investigator to be associated with a high mortality rate were excluded from the study. The primary endpoint was the occurrence of symptoms of PTSD in patients, secondary endpoint was the occurrence of PTSD in their relatives, both three months after discharge from intensive care unit. Symptoms of anxiety and depression in patients and relatives were assessed using the Hospital Anxiety and Depression Scale (HADS) [10]. The result was sobering. With regard to the frequency of PTSD, anxiety and depression, no significant benefit for keeping an ICU diary could be shown after three months in both, patients and families of this large cohort. So, can we assume and conclude now, that ICU diaries miss their purpose? Or do we have to more precisely differentiate intensive care patients and ICU settings to get the maximum benefit? Is follow-up of an intensive care patient even more complex?.

## Conclusion

Intensive care patients should return to a "normal" life as soon as possible after a serious, life-threatening event. Next the recurring examinations in literature, regarding the occurrence of PTSD, anxiety and depression, there are a number of further symptoms could be positively influenced by providing ICU diary. To be mentioned in this context have to be the actual memory, sleep quality and hyperarousal symptoms [11]. Fragmented memories in the context of delirium considerably impair the quality of life after intensive care treatment. Thereby the age of the patients (< 50 years) seems to be a major predictor of delusions associated with unexplained panic feelings. Patients suffering from these disorders are still not able to return back to work up to one year after the incident [12]. Patients suffering from symptoms like that, who would thus benefit strongly from specified support strategies, were not explicitly investigated in the study mentioned above. Due to our and other experience particularly patients surviving

cardiac arrest and their relatives suffer from the psychological consequences of intensive care situation [13]. Garrouste-Oregas et al. explicitly excluded these patients from study. Thus, in our opinion, a very significant patient group is missing in the assessment of the efficiency of an intensive care diary. Inclusion criteria in the French study was need of mechanical ventilation. Maybe this criterion alone is not sufficient for the assessment of the severity of the disease. Rather younger patients with more severe diseases and longer intensive care stay seem to benefit in particular. Unfortunately, nevertheless more than 300 patients and their relatives from 35 ICUs were included into the study there was less experience in writing a diary within the medical staff. Indeed, these phenomena could be relevant for evaluating the patients' outcome with and without ICU diary as there has been described a significant reduction in appearing PTSD in patients cared for by diary-experienced staff. Ultimately, in this context it certainly has to be discussed, if the immediate confrontation with the diary within the first three months after such a traumatic event may be at the appropriate time. The positive aspect of 'follow up visits' in conjunction with the diary suggests that intensive care patients may need more extensive follow-up than the simply handing over a diary. Systematic support in form of a "care after resuscitation" service, as first established in the United Kingdom, would be helpful in these disabled patients. As part of this project, survivors from cardiac arrest and their relatives are offered systematic psychological, cognitive and specialized medical support in the first six months after CA, a situation in which an ICU diary could be used for an additional support (14). This could be validated by means of patient interviews.

Taken together, the ICU diary may not be the "non plus ultra" that can solve any disease resulting patient problem, but nevertheless it seems to be an essential component in supporting physical and cognitive rehabilitation after a serious illness which causes a prolonged ICU stay. The positive effects of an ICU diary are manifold and in our opinion should not be limited only to the occurrence of complex PTSD, anxiety and depression. Based on our experiences and the results of many clinical studies, those younger patients who are torn out of a normal life, leading to a long intensive care unit stay and their families benefit most from providing an ICU diary. However, to get the best possible success of this supportive form of therapy, structural and organizational requirements have to be implemented on ICU before starting a diary-programm.

## References

1. Pattison N, O'Gara G, Lucas C, et al. Filling the gaps A mixed-methods study exploring the use of patient diaries in the critical care unit. *Intensive Crit Care Nurs.* 2019; 51: 27-34.
2. Strandberg S, Vesterlund L, Engström Å. The contents of a patient diary and its significance for persons cared for in an ICU: A qualitative study. *Intensive Critical Care Nurse.* 2018; 45: 31-36.
3. McIlroy PA, King RS, Garrouste-Oregas M, et al. The Effect of ICU Diaries on Psychological Outcomes and Quality of Life of Survivors of Critical Illness and Their Relatives A

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- Systematic Review and Meta-Analysis. *Crit Care Med.* 2019; 47: 273-279.
4. Jones C, Bäckman C, Capuzzo M, et al. Intensive care diaries reduce new onset post traumatic stress disorder following critical illness: a randomised, controlled trial. *Crit Care.* 2010; 14: R168.
  5. Jones C, Bäckman C, Griffiths RD. Intensive care diaries and relatives' symptoms of posttraumatic stress disorder after critical illness a pilot study. *Am J Crit Care.* 2012; 21: 172-176.
  6. Jones C, Bäckman C, Capuzzo M, et al. Intensive care diaries reduce new onset post traumatic stress disorder following critical illness a randomised controlled trial. *Crit Care.* 2010; 14: R168.
  7. Roulin MJ, Hurst S, Spirig R. Diaries written for ICU patients. *Qual Health Res.* 2007; 17: 893-901.
  8. Engström Å, Rogmalm K, Marklund L, et al. Follow-up visit in an ICU receiving a sense of coherence. *Nurs Crit Care.* 2018; 23: 308-315.
  9. Garrouste-Orgeas M, Bailly S, Timsit JF. Use of an ICU Diary and Patient Posttraumatic Stress Disorder Symptoms-Reply. *JAMA.* 2019; 322: 2025-2026.
  10. Zigmond AS, Snaith RP. Hospital Anxiety and Depression Scale HADS. The hospital anxiety and depression scale. *Acta Psychiatr Scand.* 1983; 67: 361-370.
  11. Wang S, Xin HN, Chung Lim Vico C, et al. 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.* 2020; 24: 81.
  12. Ringdal M, Johansson L, Lundberg D, et al. Delusional memories from the intensive care unit-experienced by patients with physical trauma. *Intensive Crit Care Nurs.* 2006; 22: 346-354.
  13. Wachelder EM, Moolaert VR, van Heugten C, et al. Life after survival long-term daily functioning and quality of life after an out-of-hospital cardiac arrest. *Resuscitation.* 2009; 80: 517-522.
  14. Mion M, Al-Janabi F, Islam S, et al. Care After REsuscitation Implementation of the United Kingdom's First Dedicated Multidisciplinary Follow-Up Program for Survivors of Out-of-Hospital Cardiac Arrest. *Ther Hypothermia Temp Manag.* 2020; 10: 53-59.