

# ICU Survivors Experience of ICU Diaries: An Ancillary Qualitative Analysis of the ICU Diary Study

**OBJECTIVES:** To investigate patients' experience of ICU diaries 6 months after ICU discharge among survivors. This study was designed to add insight into a large randomized study, which found no benefit of the ICU diary to post-traumatic stress disorder among critically ill patients having received mechanical ventilation.

**DESIGN:** A preplanned qualitative substudy of patients receiving an ICU diary written by ICU caregivers and families. Six months after ICU discharge, survivors were contacted by a psychologist for a telephone interview using a semi-directive guide.

**SETTING:** Thirty-five French ICUs.

**PATIENTS:** All ICU survivors having received an ICU diary.

**INTERVENTION:** An ICU diary written by both ICU staff and families.

**MEASUREMENTS AND MAIN RESULTS:** Among the 332 patients randomized in the intervention group (having had an ICU diary filled by both ICU staff and families), 191 (57.7%) were alive at 6 months and 101 of 191 (52.9%) participated in a telephone interview. They were (median [interquartile range]) 64 years old (53–70 yr old); 65 (64.4%) were men, and 79 (78.2%) were medical patients. Duration of ICU stay was 13 days (8–21 d). Three themes were derived from the thematic analysis: 1) reading the diary: between emotion and pain, 2) how the diary helped, and 3) the bittersweet representation of the diary. For half of the patients, the diary is a good memory of difficult times (55/101, 54.5%), others seem to be more ambivalent about it (28/101, 27.8%), and 37 of 101, 36.6% see it as a painful representation of a time to be forgotten.

**CONCLUSIONS:** When reading their ICU diaries, ICU survivors experienced mixed emotions, related to family messages, medical caregiving, and to the severity of their illness. Patients described diaries as a help or a hindrance to recovery, depending on their wish to remember the period or move on from it.

**KEY WORDS:** intensive care; intensive care unit diary; post-traumatic stress disorder; psychological interview; qualitative research

Hospitalization in ICUs is a stressful experience for patients. ICU memories are recalled as positive and/or negative. Patient's perceptions are related to physical symptoms like pain, thirst, sleep disturbances, respiratory discomfort of mechanical ventilation, and inability of maintaining daily activities (1). Negative experiences are in relation with noise, lack of privacy, lack of

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DOI: 10.1097/CCE.0000000000000384

understanding of the situation, and being cared for by an unfamiliar staff. Positive experiences exist as being in a safe environment and cared for by an empathic staff.

Substantial morbidity after ICU was identified as post-intensive care syndrome, which includes physical, cognitive, and psychological impairments (2). Most ICU survivors experience a lack of factual memories, the presence of distorted or delusional memories, which could be involved in the development of post-traumatic stress disorders (PTSDs) (3, 4), and other comorbid psychological symptoms such as anxiety and depression (5–7). Qualitative studies have reported that after ICU discharge, sepsis survivors strived to a return to normal life, or what is considered normal for their age, regardless of their specific impairment (8).

To minimize ICU stay consequences and particularly the distress induced by memory impairment, several countries have used an ICU diary to recall ICU story and events (9–12). ICU diaries filled-out by both ICU staff and families attempted to reduce survivors' memory gaps, to give a sense of reality, bring them to understand the severity of their illness, and to set realistic goals to achieve meaningful recovery (13). Currently, the effectiveness of diaries is a matter of debate (14–16). In 2019, we published a randomized multicenter study to explore the effect of an ICU diary, provided to survivors at ICU discharge, on the presence of PTSDs, anxiety and depression symptoms, in patients and families (17). We observed that ICU diaries did not decrease either post-traumatic stress or anxiety and depression symptoms in patients 3 months after discharge.

The aim of this study was therefore to provide insight into our randomized multicenter trial by qualitatively exploring survivors' perceptions of their diary.

## PATIENTS AND METHODS

### Patients

Patients were those of the initial ICU diary study (17). The protocol and results of the study were reported elsewhere (17, 18). Briefly, the study was a randomized (allocation 1:1) multicenter study in 35 ICUs in France. An ICU diary was written for patients who had been mechanically ventilated for over 48 hours within the 48 hours after ICU admission. A description for the diary is reported in the **Supplemental Digital Content** (<http://links.lww.com/CCX/A571>). Guidelines for writing and contents of the ICU diary were reported elsewhere (17).

An audit of the content of a random sample of ICU diaries was performed and published elsewhere (17). Of the 709 eligible patients, 657 were randomized (332 in the intervention group receiving an ICU diary, 335 in the control group with usual care without an ICU diary). Survivors at 6 months of the intervention group were included for a telephone interview.

### Ethics

The study (No. 2015-A00700-49) was approved by the ethics committee of the Necker University Hospital, Paris, France (2015-05-01-SC), by the Commission Nationale de l'Informatique et des Libertés (No. HZB1693034n), and by the Comité Consultatif sur les Traitements de l'Information en matière de Recherche dans le domaine de la Santé (No. 15.1004).

### Data Collection and Analysis Procedures

Semi-structured interviews were conducted by telephone by a psychologist (C.V.) hired for the study. Patients having received an ICU diary were called 6 months after ICU discharge (17). Prior to the interview, each participant gave oral informed consent to the audio-recorded interview. The interview guide and principles of inductive thematic analysis are reported in the Supplemental Digital Content (<http://links.lww.com/CCX/A571>).

In our study, the transcription of the interviews was done by the researcher psychologist who has interviewed the participants. A thematic analysis using the CAQDAS NVivo 10 package (QSR international, Melbourne, VIC, Australia) was carried out on verbatim contents once transcribed. The software enabled a statistical analysis on qualitative data, focusing on word distribution in the patients' discourse, and unveiling links between emerging themes. Coding was done following Braun and Clarke's (19) recommendations for thematic analysis, as described in a six-step guide: 1) familiarizing oneself with the data, 2) generating initial codes, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes (against the coded data and against the entire data set), and 6) producing the report into a detailed description of the results. Coding, manual identification of themes and subthemes, as well as results interpretation, were conducted by a research psychologist trained in qualitative analysis (M.S.) and a student (M.T.) in Masters in Psychology supervised by a senior researcher in psychology trained in qualitative methods

(C.F.), and then discussed within the research team, in order to minimize possible bias of interpretation.

## RESULTS

### Participants

**Figure 1** shows the study flow chart. Of the 332 patients randomized in the intervention group, 191 (57.5%) were alive at 6 months. Interviews were conducted with 101 of 191 patients (52.9%). The median (interquartile range) of the interviews was 22.2 minutes (17–30 min). They were performed between October 2018 and March 2019. There were no significant differences in the baseline characteristics and the outcomes assessed on day 90 between the 101 patients who were interviewed at 6 months and the 164 patients who participated in the quantitative evaluation of psychological consequences at 3 months (**Supplemental Digital Content, Tables 1 and 2**, <http://links.lww.com/CCX/A571>).

### Main Findings

Three themes emerged from the analysis: 1) reading the diary: between emotion and pain, 2) how the diary helped, and 3) the bittersweet representation of the diary.

**Reading the Diary: Between Emotion and Pain.** Many patients described an overwhelming emotion when reading the diary, as they realize what they had gone through (76/101, 75.2%) and linked to the messages and attention from relatives and the medical teams (47/101, 46.5%) to whom they express strong gratitude (18/101, 17.9%):

I was quite moved in fact. I became aware of everything that had happened. So, I was very moved. I didn't think that ... it actually had happened. I was not conscious of that.

(Patient 1 female, 38 yr old).

I am extremely grateful for the medical staff, whom I admire. You know, when you're hospitalized, you're plugged in everywhere. And they wash you, and (help you) for basic needs, all these people are admirable. (...) And it touched me.

(Patient 2 male, 84 yr old).

Messages from relatives and friends are most often associated with positive emotional reactions (66/101, 65.3%) (**Supplemental Digital Content, Table 3, number 1**, <http://links.lww.com/CCX/A571>), although several patients mentioned that what prevented them from further reading the diary was their emotion when

reading their relatives' messages in the diary and the pain they have been through (5/101, 5%).

It was moving (to read) all the messages from the nurses and my family (...) and the love they gave me and also the messages from the ICU team. (...). It was tremendously touched to see how they fought to keep me alive

(Patient 4 male, 55 yr old).

The diary can be seen by some patients as a painful experience, either because patients realize how severe their condition was (40/101, 39.6%), or because it brings back difficult memories (30/101, 29.7%):

(I was depressed) because I was thinking about everything (that had happened). I realized it when I read the diary. I realized that I had almost died. It really shook me.

(Patient 4 male, 55 yr old) and **Supplemental Digital Content, Table 3, verbatims number 2** (<http://links.lww.com/CCX/A571>).

Finally, a few patients (9/101, 8.9%) shared their impression of strangeness when reading the diary, an impression of dissociation from the experience:

(The diary is) a rather unpleasant experience. (...) I did not have the impression that what was described actually happened to me. It was almost like it was not about me. I know it is a part of me, (...) but somehow, I did not really experience it, it is as if I was out of it. (...)

(Patient 5 male, 67 yr old).

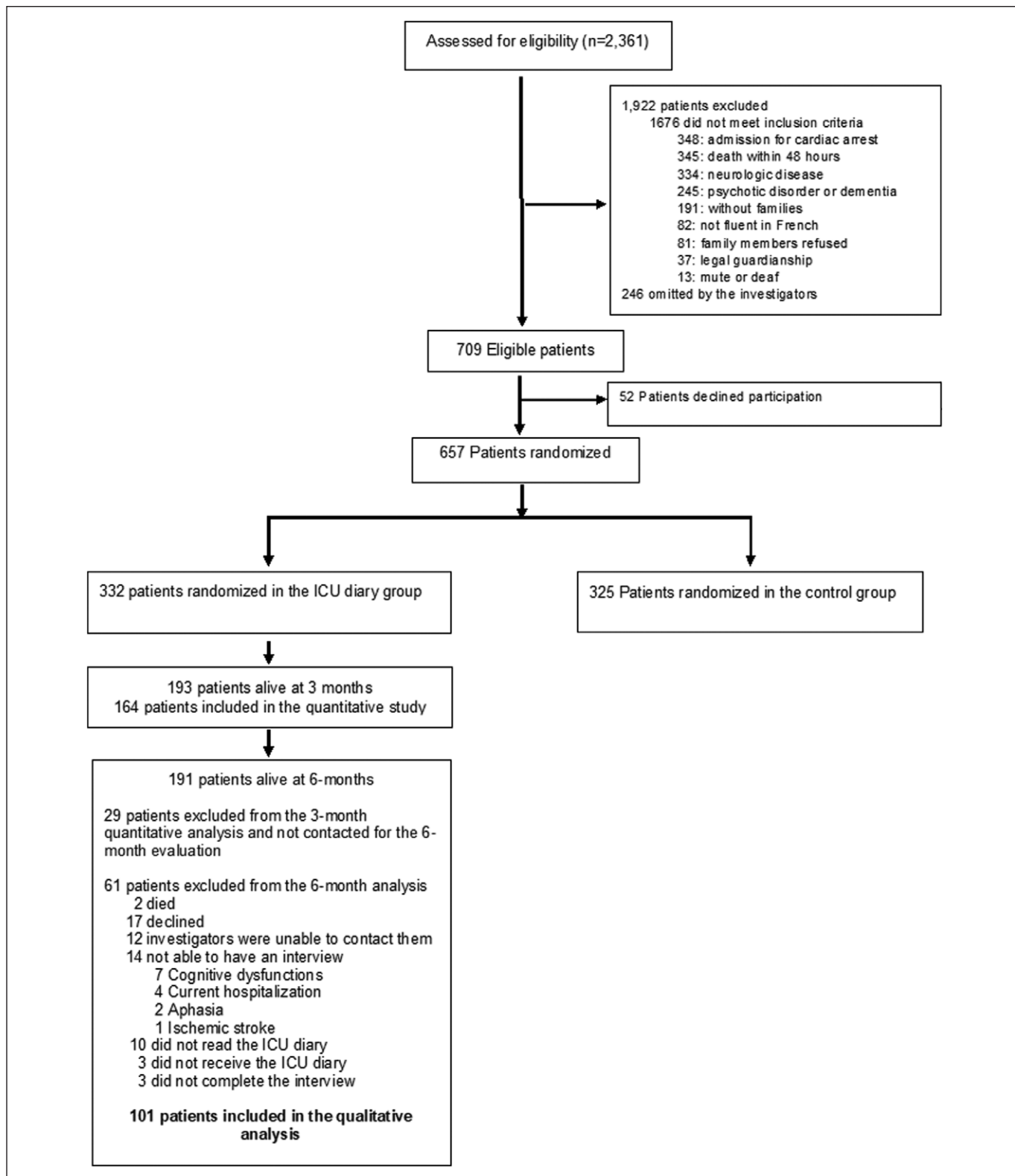
**How the Diary Helped.** The diary is seen as a testimony to a particular period of their existence (52/101, 51.4%), for which they have no memories:

I now have a trace of how they saved me, (...), what was tried, not tried, failures and successes. (...) It is a good memory. It is the testimony of the medical teams and of my family."

(Patient 6 male, 72 yr old) and **Supplemental Digital Content, Table 4, verbatims number 1 and 2** (<http://links.lww.com/CCX/A571>).

The written form of the diary gives patients a sense of ownership and permanence of the experience (10/101, 10%), which, for some, is what allows them to set difficult ICU memories aside and move on:

Because something was written, I have a trace of something. But there is a piece of writing. The diary lays next to me on my bedside table. When



**Figure 1.** Flow chart of the quantitative (17) and qualitative study.

I look at it, I know everything I've been through. It is a piece of writing, it will remain as is. Words, memories fade away.

(Patient 8 male, 54 yr old) and **Supplemental Digital Content, Table 4, number 3** (<http://links.lww.com/CCX/A571>).

The diary is mostly cited for its informative function (66/101, 65.3%). It provides medical information about their time in the ICU (64/101, 63.3%), a chronology for the organization of care and details on the evolution of their health (13/101, 12.8%), which come as a complement to the information given by relatives or medical teams (15/101, 14.8%). However, half of the patients (53/101, 52.5%) did not describe the information given in the diary as helping them remember what happened in the ICU (**Supplemental Digital Content, Table 4, numbers 4–6**, <http://links.lww.com/CCX/A571>).

The diary has also been used by some medical teams as a tool to inform relatives during hospitalization: (16/101, 15.8%).

What I liked most was the fact that the nurses would mark down what the doctors said about my health every day for my daughters to be always updated. (...) They would write down what had happened during the day, and my children would read it in the evening.

(Patient 12 female, 68 yr old).

The diary brings patients to the abrupt realization of the severity of their situation (45/101, 44.6%) and gratitude towards the medical teams (29/101, 28.7%):

(The diary) helped me realize that I had almost died. If I hadn't had it, I wouldn't have believed the severity of my case.

(Patient 7 male, 57 yr old) and **Supplemental Digital Content, Table 4, numbers 7 and 8** (<http://links.lww.com/CCX/A571>). But by giving precise, chronological and factual information to patients, the diary has helped some patients bridging anxiety-inducing memory gaps, thereby providing them with reassurance: 22/101, 21.8%) (**Supplemental Digital Content, Table 4, numbers 9 and 10**, <http://links.lww.com/CCX/A571>).

The diary seems to help subjects realize the strength of their bond to others (29/101, 28.7%), mainly loved ones, but also value the central role of medical caregivers. They report being touched by the attention and care they receive from both the medical staff and their families, and feel less isolated (12/101, 11.9%), recognized (6/101, 6%), and strengthened by it:

I have tears in my eyes often, and when I read it again, I tell myself that I am not alone on earth

and that there are people who love me and who take care of me.

(Patient 16 male, 70 yr old) and **Supplemental Digital Content, Table 4, numbers 11–14** (<http://links.lww.com/CCX/A571>).

This attention, materialized by the diary, is reported as comforting and an essential support in motivation throughout recovery (41/101, 40.6%), that is, during the hospitalization, but also afterward:

When ... when I was not well, or when I was in pain, for example...in these moments, I would re-read the diary and I re-read what my granddaughter had written to me. It would give me strength; it would boost me.

(Patient 15 female, 65 yr old) and **Supplemental Digital Content, Table 4, numbers 15–17** (<http://links.lww.com/CCX/A571>).

*The Bittersweet Representation of the Diary.* For most patients, the diary is a good memory of difficult times (55/101, 54.5%), while others seem to be more ambivalent about it (28/101, 27.8%), and 37/101 (36.6%) see it as a painful representation of a time to be forgotten. To patients having a positive image of the diary, this latter is often emotionally invested (20/101, 19.8%) and generally seen as being a human touch in the highly technical environment of intensive care (11/101, 10.9%) (**Supplemental Digital Content, Table 5, numbers 1–3**, <http://links.lww.com/CCX/A571>).

As such, the diary is seen by these patients as a good memory, either because it withholds expressions of love and attention from relatives and friends or because it shows professional caregivers' commitment to saving their lives and is a symbol for their survival. The diary seems to have allowed some patients to move on:

(The diary) saved me. It allowed me to find freedom. (...) He led me to imperatively want to retrace my journey, and that was an essential thing to do, otherwise there would be lots of things that I would not have understood, and that would have disturbed me in the long run. It saved me, because he freed me from my ties.

(Patient 14 female, 71 yr old).

Some patients seem to have developed a certain attachment to the object of the diary, which becomes an anchor symbol for a turning point of their lives. It creates a transition between the acute experience of the ICU and the lasting time of recovery:

I brought this diary from the hospital to my home. I bring it back into my daily life and my private life, and I use it as a link between both worlds.

(Patient 20 male, 38 yr old) and **Supplemental Digital Content, Table 5, numbers 3 and 4** (<http://links.lww.com/CCX/A571>).

The diary is also feared as stirring up painful memories, and therefore seen as an image of the sometimes traumatic experience of the ICU to be distanced from (37/101, 36.7%). Reading the diary is seen by some as a hindrance to recovery.

I am keeping (my diary) in a cupboard in the dining room. It's still in sight, I haven't buried it. As long as I don't open it, nothing happens. But when I open it, everything opens up again ... I am too afraid to read it a second time, for fear of going through what happened again.

(Patient 22 male, 66 yr old) and **Supplemental Digital Content, Table 5, numbers 5–9** (<http://links.lww.com/CCX/A571>).

Some patients showed disinterest for the diary (12/101, 12%), which is trivialized as is the entire ICU experience (**Supplemental Digital Content, Table 5, numbers 10–13**, <http://links.lww.com/CCX/A571>).

## DISCUSSION

We investigated experience of ICU-patient related to ICU diaries, how they react to and appropriate the diary. We identified three main themes: 1) reading the diary: between emotion and pain, 2) how the diary helped, and 3) the bittersweet representation of the diary.

Long-term support of psychological recovery after critical illnesses is an increasing focus of care (20). Tested strategies have given controversial results (21–23). ICU diaries have been used to mitigate psychological consequences (15, 24, 25). Until now, five randomized studies focused on patients' PTSD and symptoms of anxiety and depression, have been published, and did not allow a conclusion about its efficacy (17, 26). Lack of effectiveness may be explained by patient's residual problems, which may be more multifactorial and complex than anticipated (27). Our research is the largest qualitative study with patients, of diverse age and demographical characteristics, on the experience of the ICU diary. It offers insight into our large, randomized study that showed a noneffectiveness of ICU diaries on PTSD-related symptoms (17).

The findings of this study reported results widely published in other qualitative studies (13, 28–30). The ICU diary provided patients with a chronology of events and with an account of families' and medical caregivers' support (13, 31). For patients struggling with distorted memories of their stay (13), the diary did not seem to improve memories "per se" (30) but was used as a transitional object throughout recovery and into a newly reinvested life (28). Besides, the written form of the diary conveys an image of permanence, a testimony of what they have been through. In this case, the diary comes as a way to gain closure on their experience and liberate them from it. It is therefore read, used, closed, and stored, with an intention to open it in the future "if and when needed."

Our study however also reported several negative findings about the ICU diary, which triggers several comments. First, reading the ICU diary was not a neutral experience for patients. Reactions to and use of the diary differed greatly from one patient to another. The patient's understanding of the diary could depend on his or her cognitive function and capacity to revisit potentially negative experiences (30). It seems that the emotional reaction to reading the diary partly determined the future perception and use of it, either as a hindrance to or as a support for recovery. Interviewees often described an emotional reaction when reading messages from relatives and medical caregivers, resulting in expressions of gratitude toward the latter, and increased connections with families and close friends (32). Second, the diary also seemed to bring patients to become aware of the severity of their medical condition. Others describe an unsettling feeling of dissociation from the ICU experience, with the impression that the diary is telling someone else's story. Patients' emotional experience could also be partly determined by the way the diaries were shared or not between patients and relatives (33). The most appropriate way to deliver and share the diaries with the patient is still unknown and should be further evaluated to better understand the controversial effects of the diaries on psychological sequelae (14). Third, the diary was described by many subjects as a symbol of their survival, which is two-fold, containing both ideas of death and aliveness, and was therefore perceived by them as bittersweet. In that, the diary was often seen as stirring painful memories, with which patients do not necessarily wish to reconnect, at a time they were

trying to move away from their difficult experience at the hospital and resume “normal” lives. This was also reported by a recent study by Castillo et al (34) finding that when patients had the choice, they chose a discharge summary rather than the ICU diary, with half of the patients reporting distress reading the ICU diary. It is possible that, in some patients, the distress induced by the traumatic event would lead to avoidant coping strategies (35, 36), expressed in a certain “desire to forget,” that is challenged by the diary. These patients would therefore defensively disregard or misuse the diary. This may be particularly true for patients suffering from PTSD symptoms, for whom avoidant coping strategies may be a mediator between peritraumatic dissociation consequent to the traumatic event and PTSD (37). The use of the diary would antagonize avoidance strategies, and would therefore be dismissed, which could explain the absence of effect of the diary intervention on PTSD symptoms (14, 17). The main findings of our main study demonstrated that ICU diaries did not efficiently prevent PTSD in a general population of ICU patients and that their implementation deserves more precise investigations.

The main strength of this study is its large sample of patients and multicenter design. Only 13 of 191 (7%) had not read or received the diary. This study, with a high number of interviews, unusual for qualitative studies, has the advantage of providing a detailed picture of patients’ perceptions on the diary, with a broad range of patients’ demographic, education, social, and location characteristics. This study has however several limitations. First, our study explored the use and the representations of the diary in the rather short term (6 mo after ICU discharge). Now, survivors can report various symptoms and emotional reactions months or even years after their hospital discharge. Our results did not reflect reactions, patient’s adjustment strategies and perception of the ICU diary in the long term. Second, all patients were hospitalized in France, these results may therefore not be generalized to other countries.

In conclusion, this study showed that ICU survivors reported both discomfort and benefit in reading their ICU diaries. There are discrepancies in benefits reported by patients; while ICU diaries could beneficially be included in patient’s recovery process, their place remains to be defined.

## ACKNOWLEDGMENTS

The authors thank Céline Féger, MD (EMIBiotech) for her editorial support.

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*Trial registration NCT02519725: <https://clinicaltrials.gov/ct2/show/NCT02519725?cond=ICU+diary&rank=21>.*

*Supplemental digital content is available for this article. Direct URL citations appear in the printed text and are provided in the HTML and PDF versions of this article on the journal’s website (<http://journals.lww.com/ccejournal>).*

*Supported, by a grant from the Fondation de France (ENG 50328).*

*The authors have disclosed that they do not have any potential conflicts of interest.*

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