

# Report on the Third International Intensive Care Unit Diary Conference

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**TOPIC** Many patients in intensive care units have frightening experiences and memories and subsequent post-intensive care syndrome, with psychiatric morbidity including depression, anxiety, and posttraumatic stress disorder. Intensive care unit diaries, written by staff members and families, support patients' understanding of what occurred and may alleviate their psychological suffering.

**CLINICAL RELEVANCE** An increasing number of critical care nurses in the United States and elsewhere are implementing intensive care unit diaries, but implementation remains challenging.

**PURPOSE** To address emerging questions and support implementation in the United States, we held the Third International Intensive Care Unit Diary Conference as a 1-day preconference during the Seventh Annual Johns Hopkins Critical Care Rehabilitation Conference on November 1, 2018, in Baltimore, Maryland. This article summarizes the conference.

**CONTENT COVERED** Conference presentations included intensive care unit-related experiences of patients and families, psychosocial aspects of post-intensive care syndrome, the evolution of diaries, implementation strategies for intensive care unit diaries, special topics (eg, legal issues, electronic vs handwritten diaries, pediatric diaries, and time of handover), and psychosocial recovery. (*Critical Care Nurse*. 2020;40[5]:e18-e25)

## CE 1.0 hour, CERP B

This article has been designated for CE contact hour(s). The evaluation tests your knowledge of the following objectives:

1. Describe the development of diaries, written for patients in intensive care units (ICUs).
2. Describe common barriers during implementation and use of ICU diaries.
3. Describe the aim of ICU diaries in the pediatric setting.

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**I**ncreasing numbers of patients are surviving critical illnesses, but serious consequences, collectively termed *post-intensive care syndrome (PICS)*,<sup>1</sup> are common. One important aspect of PICS is clinically significant psychiatric morbidity, including posttraumatic stress disorder (PTSD),<sup>2</sup> depression,<sup>3</sup> and/or anxiety<sup>4</sup> symptoms. Using intensive care unit (ICU) diaries may reduce these problems for both patients and their families.<sup>5</sup>

Intensive care unit staff members (eg, nurses) and/or family members can contribute to ICU diaries. Writers make daily entries in the diary throughout the ICU stay, addressed to the critically ill patient in everyday language. Entries in the diary, starting from day 1 in the ICU, provide a narrative account of events from hospital admission until ICU discharge so that patients can understand their own illness, which they may not be able to remember. Intensive care unit diaries provide a context for distorted memories that patients and others can discuss later. The evidence for the benefits of diaries in preventing and treating the psychosocial sequelae of an ICU stay is increasing<sup>6-8</sup>; nevertheless, discussion regarding their specific benefits is ongoing.<sup>9,10</sup>

Nurses in Scandinavia (Denmark, Norway, and Sweden)<sup>11,12</sup> initiated the use of ICU diaries, and the practice spread to other countries in Europe, Australia, and South America (see Figure). In recent years, clinicians from North

America have shown an interest in ICU diaries and conducted implementation studies.<sup>13</sup> To support this interest and to increase knowledge and motivation, an international group of ICU diarists decided to hold their conference in the United States. The diary conference, held on November 1, 2018, was a 1-day preconference to the Seventh Annual Johns Hopkins Critical Care Rehabilitation Conference. Nearly 80 clinicians from 13 countries participated, including 61 from the United States. Most participants were nurses, followed by physical therapists, psychologists, and other professionals.

## The ICU Diary Conference

The 1-day conference included 4 sessions comprising basic information on PICS, implementation strategies for ICU diary programs, special topics, and psychosocial rehabilitation (see Table). In this article we summarize the lectures and provide helpful references to disseminate the knowledge gleaned from this conference.

## Rationale for ICU Diaries Experiences of ICU Patients

Critically ill patients face tremendous physical and emotional challenges. These challenges include dyspnea, a powerful driver of anxiety, as well as painful procedures, such as endotracheal intubation, suctioning, and arterial catheter placement. In addition, because of organ dysfunction and the use of sedating medications, critically ill patients often have acute brain dysfunction (delirium and/or coma).

Delirium is frequently associated with hallucinations (eg, seeing children without faces or blood dripping from the walls), delusions (eg, that physicians and nurses are conspiring to harm or kill the patient), and misperceptions of the immediate environment (eg, mistaking urinary catheter placement for rape). These stressors occur in the context of complete dependence on others (loss of autonomy) and a limited ability to communicate normally due to acute brain dysfunction, the presence of endotracheal tubes, and weakness, leading to a profound sense of isolation and anxiety.<sup>14</sup> A study of non-pharmacological interventions suggested that moderate

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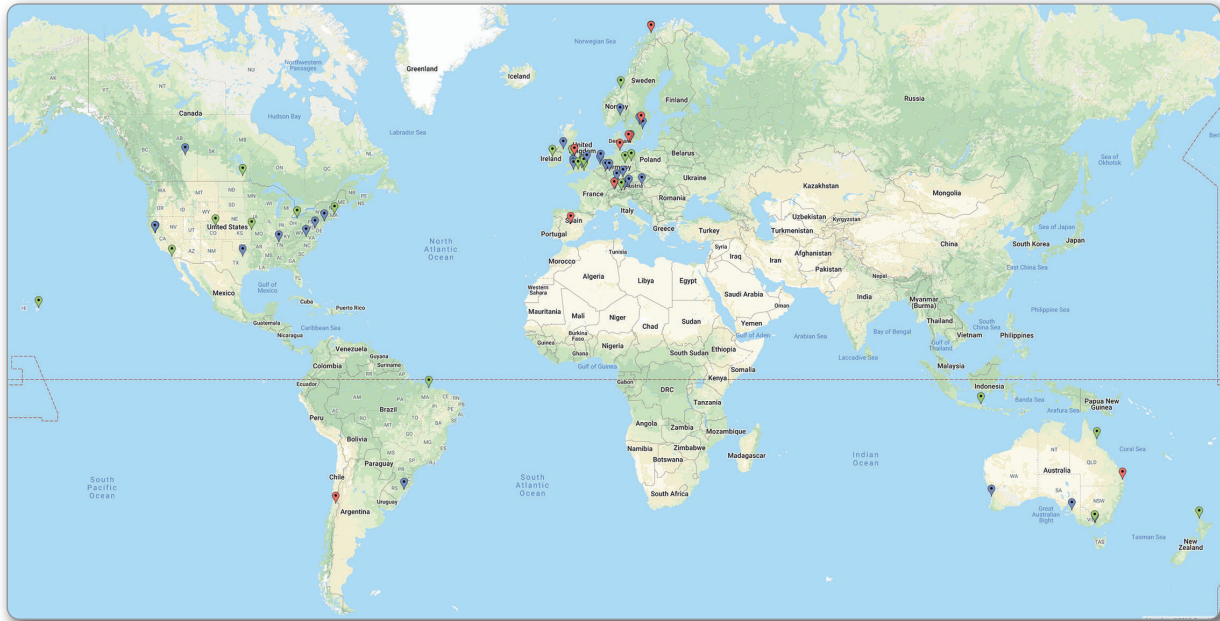
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**Figure** Intensive care unit (ICU) diary network. Red dots represent contact persons, blue dots represent ICU diaries, and green dots represent ICUs starting to implement ICU diaries.

levels of anxiety occur in 50% of critically ill patients randomized to a control condition.<sup>15</sup> Qualitative studies emphasize patients' sense of vulnerability, helplessness, and uncertainty.<sup>16</sup>

### Post-Intensive Care Syndrome

The term *PICS* refers to new or worsening mental health, cognitive, and/or physical sequelae arising after critical illness and persisting beyond discharge from the acute care setting.<sup>1</sup> Roughly 25% of critical illness survivors experience PTSD, 34% depression, and 40% anxiety within the first 6 months after ICU discharge.<sup>2-4</sup> Previous psychiatric history increases risk for these phenomena, as in the case of other severe stressors.<sup>2-4</sup> Critical illness and intensive care risk factors (or markers of risk) include higher doses of benzodiazepines and opiates in the ICU, as well as early post-ICU memories of frightening ICU experiences (eg, disturbing visual hallucinations, persecutory delusions, nightmare-like experiences, and dyspnea).<sup>2-4</sup> Early post-ICU psychiatric morbidity tends to co-occur across mental health domains,<sup>2-4,17</sup> and it can persist for years.<sup>18</sup> Use of mechanical ventilation is an additional risk factor for new-onset mental health problems beyond critical illness per se.<sup>19</sup> Reviewing ICU diaries can supplement other psychotherapeutic interventions (eg, traditional

### Table Program of 1-day conference

**Session 1:** Rationale for Intensive Care Unit (ICU) Diaries  
Experiences of ICU Patients  
Post-Intensive Care Syndrome  
Post-Intensive Care Syndrome-Family  
Emergence and Development of ICU Diaries  
Evidence for ICU Diaries

**Session 2:** Understanding Barriers to Implementation:  
International  
Germany  
Sweden  
Australia  
United Kingdom  
United States  
Chile

**Session 3:** Special Considerations  
Legal and Risk Management  
Hand Written Versus Electronic Diaries  
Development of the ICUsteps Electronic Patient Diary App  
Pediatric ICU  
Timing of Sharing a Diary With a Patient

**Session 4:** Psychosocial Recovery  
Family Member Diary Writing  
ICUtogether: A Web-Based Recovery Program  
Impact on Psychological Outcomes in the First Year After Discharge

trauma-focused cognitive-behavioral therapy or interpersonal therapy) and/or antidepressant medication to prevent persistent mental health problems in critical illness survivors.<sup>20</sup>

## Post-Intensive Care Syndrome-Family

Critical illness can also have long-term effects on family members (ie, PICS-F).<sup>5</sup> Family members can experience both psychiatric morbidity (anxiety, depression, PTSD, complicated grief) and physical morbidity (sleep disturbance, fatigue, exacerbation of preexisting physical problems) that can negatively influence quality of life.<sup>21</sup> Having a loved one who is or has recently been critically ill can increase the risk of impaired family integrity, job strain or loss, impaired caregiving ability, interpersonal conflict, and financial distress.<sup>22</sup> To reduce these risks, rehabilitation bundles should incorporate family-centered care, including promotion of relatives' sleep hygiene, open visitation policies, family involvement in rounds, informational brochures, and ICU diaries.<sup>13</sup>

## Emergence and Development of ICU Diaries

In 1985, nurses in Denmark introduced "open nursing notes" to encourage patient involvement,<sup>23</sup> and this inspired Norwegian nurses in the 1990s to create diaries for critically ill patients in intensive care. This practice led to a debate about how and why to use diaries. For example, should nurses write "for/to/about" or "with" the patient? In addition, were diaries considered therapeutic, informational, or a vehicle for clinician-patient communication? In Sweden, the ICU diary became a "photo diary" aiming to orient patients to the reality of what happened to them in the ICU. By 2000, nurses in the United Kingdom started using ICU diaries to help patients fill their memory gaps and come to terms with their illnesses. Diary writing became a more open practice, integrating notes from various hospital staff members, family, and friends. By the time Swiss clinicians adopted ICU diaries, the practice had evolved to help not only the patient but also the family.<sup>23,24</sup>

In a Danish study in which 48 Danish ICUs were surveyed and 19 ICU nurses were interviewed, the researchers examined writers' rationales for using ICU diaries.<sup>25</sup> The diary was seen as a therapeutic instrument, an act of caring, an expression of empathy, or a hybrid of these. As the practice evolved, ICU diaries became integrated with ICU aftercare, where diaries were presented to the patient during a visit to the hospital some weeks or months after hospital discharge.<sup>26</sup> Diary practice is still evolving in different cultures. In Austria, diaries were described as providing a human aspect to the technological environment in the ICU.<sup>27</sup> In the United States, clinicians

regard diaries as a tool for maintaining a patient's personhood during acute and critical illness. An ongoing study is examining the potential benefit of diaries written exclusively by family members, rather than including professionals.<sup>28</sup> The use of ICU diaries seems to promote humanism and understanding of the patient perspective.

## Evidence for ICU Diaries

Critical illness survivors often experience distress related to their lack of autobiographical memory from the ICU, and memories of terrifying experiences are associated with substantial emotional distress during recovery.<sup>29</sup> An ICU diary can be a powerful rehabilitation tool. Studies suggest that diaries may improve psychological recovery by promoting a better understanding of frightening experiences, thus reducing anxiety and depression,<sup>6</sup> halving the rate of new-onset PTSD,<sup>7</sup> and reducing PTSD-related symptoms.<sup>8</sup> However, in a recent meta-analysis on the effectiveness of ICU diaries, the investigators reported that the intervention was associated with a nonsignificant reduction in PTSD but a significant reduction in anxiety and depression. In contrast, the investigators reported that family members had a significant

improvement in PTSD and health-related quality of

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life, although the heterogeneous impact of ICU diaries on patients may be due to factors such as timing, assessment method, and diary-related contents (wording, photographs, etc).<sup>9,30</sup> Regardless of patient effects, however, family members appear to benefit substantially,<sup>9,31</sup> possibly through acquiring a better understanding of the critical illness and intensive care provided, or possibly through their expression and processing of feelings.

## Understanding Barriers to Implementation: International Germany

German clinicians began implementing ICU diary programs in 2008. This process was facilitated in part through a knowledge dissemination project led by Peter Nydahl and Dirk Knueck that included a website, frequent newsletters, and email support.<sup>32</sup> Commonly reported

barriers to diary implementation programs included “time constraints” and “bureaucratic difficulties.”<sup>33</sup> However, results of a study showed that 5 minutes per day was sufficient to make useful diary entries.<sup>34</sup> In addition, Nydahl and colleagues developed and uploaded ICU diary policy templates on a German website ([www.intensivtagebuch.de](http://www.intensivtagebuch.de)), with recommendations for making entries to avoid legal problems. A follow-up survey in 2014 showed that approximately 20% of German ICUs had ICU diary programs.<sup>35</sup>

### Sweden

In Sweden, nurses have a long tradition of writing diaries, although this is a voluntary practice. Research suggests that Swedish nurses prefer to make 3 entries per day, invite the family to participate, and include photos of patients on an individualized basis according to nurse preference.<sup>34</sup> Staff members treat the ICU diary as the patient’s property, which they hand over to the patient upon discharge. Through follow-up services—meetings with patients 2 weeks after discharge to discuss their experiences and recovery—nurses receive feedback from patients and families, increasing their job satisfaction.<sup>34</sup> Interviewed nurses mention the challenge of finding the right balance between professionalism, empathy, and privacy. One interviewed patient suggested, “Not too private, absolutely no lovey-dovey daze or hearts or too many hugs or nicknames.”<sup>34</sup> Swedish clinicians would benefit from training in diary writing (eg, with a guideline). So far, only Denmark and Norway have national diary guidelines.<sup>34</sup>

### Australia

When surveyed, Australian ICU nurses expressed skepticism and concerns about diaries, as well as lack of knowledge regarding the ICU recovery process and common post-ICU morbidity.<sup>36</sup> Australian clinicians have few guidelines, publications, or networks regarding diaries. Typically, a few nurses with personal interest drive ICU diary practice there. Nevertheless, diary research is currently under way in Australia, and implementation is currently in progress.<sup>9,37</sup>

### United Kingdom

Creating ICU diaries for all of the long-term patients in intensive care is too much work for a single clinician. Although one nurse might know a patient better than

another nurse does, making entries should ideally be a team effort. The ICU diary program at Whiston Hospital in the United Kingdom began with a group of interested nurses.<sup>38</sup> This group wrote guidelines for staff members and relatives on how and when to write in the diary, how to take respectful photographs, and how diaries should be stored. On the advice of the legal department, staff members copied all completed diaries and filed them with patients’ charts. Staff members also requested retrospective informed consent from patients they photographed in the ICU in order to include photographs in the diaries. Diaries were notebooks protected by plastic covers. A copy of the diary guidelines was available at each bed. Staff members provided an informational leaflet to family members with suggestions for how to write in the diary and a recommendation to include patient-related information about the family, home, interests, and work.<sup>38</sup> Excerpts, templates, guidelines, and other information are available at [www.icu-diary.org](http://www.icu-diary.org).

### United States

Diary implementation in the United States is a relatively recent development.<sup>39</sup> Nonpharmacological interventions show promise in preventing delirium, and diaries appear to aid in prevention of long-term PTSD. Hence, a group of clinicians in a New York hospital enacted a project combining delirium screening and diary implementation in all of the hospital’s ICUs. An interdisciplinary committee developed a nonpharmacological delirium bundle that included the ICU diary. Diary concerns included writing style and legal issues. Local champions invited family participation and motivated staff members. Future evaluations from families, patients, and staff members are planned.<sup>39</sup>

### Chile

Narratives shape memories and contribute to a person’s identity. After an illness involving memory impairment, diaries might help patients reconstruct their identities. The speaker started an ICU diary team in 2017 as a quality improvement project.<sup>40</sup> She and her colleagues collaborated with the Chilean Society of Critical Care Medicine and provided educational material in the Spanish language, incorporating a unique graphic design. The speaker contacted the international ICU Diary Network to identify interested clinicians in other Spanish-speaking countries, and she visited the

United States, the United Kingdom, and Sweden to meet experts and discuss her implementation project. She and her colleagues completed their first diary in August 2018 and proceeded with implementation. The speaker learned that shared knowledge and experience within a global network help single clinicians implement new ideas in their particular environments.<sup>40</sup>

## Special Considerations

### Legal and Risk Management

In a southern California hospital, ICU diaries are not a part of the patient's medical record. Because diaries have multiple authors, create transparency with patients and families, and include written messages of hope and caring, a risk-benefit analysis showed that diaries are not likely to provoke undue legal scrutiny. The speaker recommended avoiding discussions of diagnosis or prognosis, as well as performing the "social media test." (Should this information be shared on Twitter or Facebook? If the answer is "No," then it should not be included.) The complete risk discussion is available at [www.icu-diary.org/diary/support.html](http://www.icu-diary.org/diary/support.html).

### Handwritten Versus Electronic Diaries

With the increasing use of smartphones and tablet computers, electronic diaries are an emerging topic.<sup>41</sup> The speaker and her team set a goal to implement ICU diaries for patient electronic medical records in a 21-hospital health care system in California. The speaker received a grant to establish an interdisciplinary team that creatively used existing technologies. The team constructed an ICU diary prototype using a storyboard and tested its feasibility and practicability, incorporating user feedback to improve usability. The diary includes a glossary with medical information, and clinicians and family members can make entries. Pilot evaluation with patients' families is promising.

### Development of the ICUsteps Electronic Patient Diary App

ICUsteps, a charity organization and support group in the United Kingdom, is developing an ICU diary app, which is now 80% complete. The goal is to provide a free patient-oriented app that includes a timeline with texts and photos, with clinician and family input. The speaker, chair and founder of ICUsteps, shared his experience of surviving and recovering after a critical illness.

During his recovery, he found it difficult to talk with others about his ICU experiences. With the help of others, he established a post-ICU support group for former ICU patients and families to meet and exchange experiences, with the involvement of health care professionals.<sup>42</sup> ICUsteps has developed several helpful tools, including patient and relative booklets that, among other things, provide information about critical illness and recovery ([www.icusteps.org](http://www.icusteps.org)).

### Pediatric ICU

Intensive care unit diaries are also useful in the pediatric setting, although clinicians and relatives are encouraged to include more pictures, drawings, and simple wording. In the case of very young children, diaries support the coping of parents and siblings, and they should be kept for

years to support the future understanding of then-grown children. The speakers intro-

duced the pediatric form of PICS, which can affect the child, parents, siblings, and others.<sup>43</sup> In a qualitative study from a pediatric ICU in Scandinavia, children and family members found diaries helpful for understanding and coping.<sup>44</sup> The speakers shared their experiences implementing diaries in the pediatric ICU at Johns Hopkins Hospital.<sup>45</sup> Future studies on the long-term impact of pediatric ICU diaries are necessary.

### Timing of Sharing a Diary With a Patient

Views differ about the ideal time to hand over an ICU diary to a patient: when the patient is still in the ICU, at ICU discharge, shortly after ICU discharge, or weeks to months later.<sup>6-8,23</sup> Although patients may be deeply touched and gain a sense of coherence with an ICU diary, the content could also bring emotional pain.<sup>46</sup> The speaker recommended that clinicians or family members share the diary with the patient when (1) the patient is fully awake, conscious, and emotionally stable; (2) the potential traumatic situation is resolved (ie, the patient is no longer critically ill); and (3) the patient is interested in the illness and the process of recovery, asking questions such as "What happened to me?" "How long [have I been or] was I in the ICU?" or "Why am I so weak?"

## Psychosocial Recovery

### Family Member Diary Writing

Research suggests the importance of family members' writing in ICU diaries.<sup>47-49</sup> Usually, both clinicians and relatives make diary entries. Nurses often report on medical status, examinations, or developments, whereas family members often describe feelings, relationships, and news from home. Hence, diaries written by nurses versus relatives can be slightly different. A diary allows relatives to express emotions, develop an understanding of intensive care, and participate in the journey of the critical illness. Further, a diary maintains contact with the patient, documents family presence, and expresses support for the patient.

### ICUTogether: A Web-Based Recovery Program

A group in Australia developed a web-based ICU recovery program called ICUTogether that includes diaries. In a qualitative study on the perception and use of ICU diaries, the speaker found that patients felt unprepared for recovery and required both verbal and written information.<sup>50</sup> For many patients, critical illness and intensive care are traumatic events, especially when accompanied by delirium. Patients appreciated the diary, but they reported that reading it led to mixed emotions. The diary helped fill memory gaps regarding their ICU experience and recovery but also led to temporary discomfort.

### Impact on Psychological Outcomes in the First Year After Discharge

The last speaker is currently implementing an ICU follow-up project that includes diaries and aims to reduce PTSD and other elements of PICS in military personnel and their families.<sup>51</sup> Her team also developed brochures and a video ([youtu.be/VUfjzf\\_ixEo](https://youtu.be/VUfjzf_ixEo)) and identified suitable screening tools for patients and families at risk for PICS to improve coordination of care.<sup>47</sup> The speaker reported that her group will assess patients' and families' quality of life after 12 months to determine the effect of this program, which includes diaries, other educational materials, and screening.

## Conclusion

Critically ill patients and their families have substantial burdens, including grief, PTSD, depression, and anxiety. Intensive care unit diaries show promise for preventing persistent psychiatric morbidity in patients and family

members, although more research is necessary to assess benefits for patients themselves. At this international conference, speakers discussed using ICU diaries in a variety of countries with varying practices, and they discussed the barriers the speakers and their colleagues have faced. Across settings, legal considerations varied, and in most settings ICU diaries are separate from the medical record (although sometimes attached to it). Computerized (electronic) diaries and apps are currently being developed and tested. Critical illness survivors report both discomfort in and benefit from reading their own diaries. In summary, the field has progressed, although questions remain. In the meantime, we hope that this conference and report stimulate implementation, networking, collaboration, and further research. **CCN**

### Financial Disclosures

All authors received honoraria related to presentations and/or organizational aspects of the conference reported on in this article. Dr Needham was the activity director for this Johns Hopkins University School of Medicine continuing medical education conference.

### See also

To learn more about ICU diaries, read "Intensive Care Unit Diaries, Part 2: Impact of Diaries and Follow-up Consultation on Post-Intensive Care Syndrome" by Halm in the *American Journal of Critical Care*, November 2019;28(6):488-492. Available at [www.ajconline.org](http://www.ajconline.org).

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