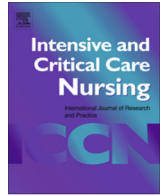




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## Research article

## Nurses' experiences of ICU diaries following implementation of national recommendations for diaries in intensive care units: A quality improvement project

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## ABSTRACT

**Objectives:** To evaluate critical care nurses' experiences of ICU diaries following the implementation of national recommendations for the use of diaries for critically ill patients.**Design:** A quality improvement project describing the development and implementation of national recommendations (2011), as well as the assessment of the use of diaries in intensive care nursing practice (2014).**Setting:** Norwegian intensive care units (ICUs).**Participants:** Thirty-nine Norwegian ICUs took part in the study.**Intervention:** A multi-component process for developing national recommendations for the use of diaries in Norwegian ICUs, including recommendations for the target group, when to start, health professionals as authors, diary content, structure, language, use of photographs, handover, access and storage within patient medical records.**Main outcome measure:** A questionnaire asking about experiences of implementing national recommendations on diaries in Norwegian ICUs, as well as their impact and how they are used.**Results:** Three years after the implementation of the national recommendations, diaries were provided in 24 (61.5%) of the responding ICUs. Fifty-six per cent of the ICUs had revised their routines, of which 62% had updated and 38% had developed new protocols. Most ICUs kept the diary along with other medical information describing patient care, but only 50% of the ICUs scanned handwritten diaries into the electronic medical records before handing them over to patients or the bereaved. ICU nurses reported that implementing national recommendations had increased their awareness and knowledge on patient and family needs, as well as the long-term effects of critical illness.**Conclusion:** The results of this quality improvement project indicate that access to national recommendations on the use of diaries for critically ill patients have a potential of changing routines and increase standardisation.© 2020 The Authors. Published by Elsevier Ltd. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

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## Implications for clinical practice

- National recommendations on the use of diaries change critical care nursing practice.
- Nurses consider the use of diaries important for the quality of nursing care.
- The process of development and key elements of the Norwegian national recommendations could be used to facilitate similar processes in other countries and reduce variations in nursing care.

## Introduction

Critical illness and advanced medical treatment in technological ICU environments have been associated with physical, cognitive and mental side effects, including symptoms of traumatic stress (Karnatovskaia et al., 2015; Needham et al., 2012; Parker et al., 2015; Wolters et al., 2013). New or worsening impairments in health status, arising after critical illness and continuing beyond hospitalisation, are known as Post-Intensive Care Syndrome (Needham et al., 2012). Care beyond hospital stays and follow-up after discharge have therefore been considered vital for the quality of critical care (Inoue et al., 2019; Jones, 2014). Hence, more studies have been advocated on interventions to improve important patient outcomes in the critical post-ICU period (Gaudry et al., 2017).

A nurse-led initiative consisting of diaries written to patients during their ICU stay has been shown to be valuable for both patients and their next of kin in the aftermath of critical illness (Backman et al., 2010; Inoue et al., 2019; Jones et al., 2010; Knowles and Tarrier, 2009). Sedation during the period of treatment, loss of memory and recurrent memories of delusions or hallucinations, make ICU patients particularly prone to post-traumatic stress disorder (PTSD) (Parker et al., 2015). In addition, diaries have been reported to reduce PTSD, anxiety and depression (Garroute-Orgeas et al., 2012; Jones et al., 2010; Knowles and Tarrier, 2009; Kredentser et al., 2018). However, a French multicentre study found that diaries written by both family and health professionals during a hospital stay had no effect on patient and family mental health three months after discharge. There was no follow-up consultation based on the diaries (Garroute-Orgeas et al., 2019). Findings from other studies, however, revealed that diaries written by health-care personnel and family had positive effects (Jones et al., 2010; Kredentser et al., 2018). These studies included patients with longer stays of >72 hours, the diary was handed over to the patient one month after ICU discharge and the patients were also offered a face-to-face or telephone review of the diary content. Moreover, a systematic review and a recent RCT (Drip-study – using diaries authored by relatives) have demonstrated that receiving a diary had a positive effect on PTSD in family members (Hojager Nielsen et al., 2019a; Ullman et al., 2014). Diaries written by relatives may also facilitate mutual understanding within the family of what happened during the ICU stay (Hojager Nielsen et al., 2019b). While studies on the effects of follow-up on patient and family outcomes have shown some variation in results, qualitative studies on patient experiences of receiving a diary have been more unambiguous, reporting that patients appreciated the diary and that the diary gave them a better understanding of their period of critical illness (Akerman et al., 2013; O’Gara and Pattison, 2016; Strandberg et al., 2018). Studies on post-discharge, nurse-led follow-up without a diary from Denmark and Iceland have reported no effects or very short-term effects on patients’ mental health (Jensen et al., 2016; Jonasdottir et al., 2018a,b). The Danish multicentre study, RAPIT, included three consultations, the first face-to-face one to three months post-ICU, followed by two consultations at five and ten months by telephone (Jensen et al., 2016). The nurse-led follow-up study from Iceland involved two ward visits during the first 24 hours post-ICU, a phone call the first week

after discharge, and an appointment together with family members three months post-discharge (Jonasdottir et al., 2018a,b). Taken together, this indicates that protocols for future studies on improved ICU patient outcomes should include a diary and that the written material should optimally be handed over during a consultation.

A theoretical foundation and guidelines for the use of diaries have been requested over time (Aitken et al., 2013; Johansson et al., 2019; Phillips, 2011; Strandberg et al., 2018). The ICU diary has its origin in Scandinavia (Ewens et al., 2015), and has been used for several decades in many European countries (Gjengedal et al., 2010; Heindl et al., 2019; Nydahl et al., 2015). On behalf of the Nordic Association for Intensive Care Nursing Research (NOFI), studies were initiated in 2006–08, which aimed to describe the use of diaries in Scandinavian ICUs (Akerman et al., 2010; Egerod et al., 2007; Gjengedal et al., 2010). These studies were undertaken in Denmark, Sweden and Norway and provided an overview of diary practices with an opportunity for comparison between countries (Egerod et al., 2011, 2013).

In Norway, nurses started writing diaries for ICU patients as early as the beginning of the 1990s. This began as a “bottom-up initiative”, inspired by idealist nurses who wanted to offer patients a tool for processing their memories of their stay in the ICU, theoretically underpinning diaries both in terms of care and therapy. The use of diaries was a response to an increasing body of research which reported on ventilator patients’ own experiences from their ICU stay, including the burden of stress symptoms and depression (Gjengedal, 1994; Storli et al., 2007, 2008). The practice of providing a diary soon became a regular part of the follow-up initiatives at many Norwegian ICUs. However, an interview study demonstrated significant procedural variations and the participating nurses asked for more guidance through national recommendations (Gjengedal et al., 2010). Ethical and legal aspects of the diaries were considered some of the most challenging issues to take into consideration. This initiated a quality improvement process and the development of Norwegian recommendations.

Today, it has been suggested that the use of diaries is perhaps the best evidence-based initiative for improving mental health outcomes after critical illness (Lasiter et al., 2016; Mehlhorn et al., 2014), as well as being easy and cost-effective to deliver (Ewens et al., 2015). Based on national and international requests for increased standardisation of this practice, the purpose of this project was to describe the process of development and to assess nurses’ experiences of ICU diaries following the implementation of national recommendations for the use of diaries for intensive care patients in Norway.

## Methods

### Design

This study is a quality improvement project describing the development and implementation of the use of diaries in Norwegian ICUs, as well as the assessment of the use of diaries in intensive care nursing practice. The recommendations from the Agree Collaboration and the Norwegian Board of Health Supervision

(Statens Helsetilsyn, 2002; Agree Collaboration, 2001) were used to develop the diary recommendations. After implementation in 2011, all Norwegian ICUs were in 2014 invited to participate in a survey, asking how they used diaries, and what their experiences were of implementing the national recommendations (for details see below). The diary questions were part of a larger survey asking about nurse-led follow-up in Norwegian ICUs (Moi et al., 2018).

#### *The process of developing and implementing diary recommendations*

National and international guidelines (Statens Helsetilsyn, 2002; Agree Collaboration, 2001) informed the development of national recommendations for the practice of using diaries. The guidelines offered a stepwise procedure for the development process, which included engaging a working group, defining and formulating goals and target groups, improving knowledge, formulating recommendations, planning for implementation, planning for evaluation and revision, and undertaking evaluations and revisions. Moreover, a systematic search was conducted in 2009 to summarise current research evidence (Storli et al., 2011). The search was conducted in CINAHL, British Nursing Index, Ovid MEDLINE, PsycINFO and PubMed using the terms “intensive care”, “critical care” and “ICU” in combination with a) “patient experience\*”, “patient perspective\*”, “patient perception\*”, “memory”, b) “anxiety”, “depression”, “emotional outcome”, “posttraumatic stress”, “PTSD”, “health-related quality of life” and c) “diary”, “diaries”, “intensive care diary”, “patient diary”, “narratives”, “follow-up” and “nurse-led program”. At the time, although several publications described various procedures for the use of diaries for ICU patients, only one national guideline was identified (Egerod, 2008). This Danish guideline inspired the development of the Norwegian recommendations. Today, several recommendations are available (see e.g. [www.icu-diary.org](http://www.icu-diary.org)).

In collaboration with the Norwegian Association of Critical Care Nurses (NSFLIS), a working group was given a mandate to authorise national recommendations on the use of diaries for patients in Norwegian ICUs. Included in the working group were nurse researchers experienced in critical care, ICU nurses and a board member from NSFLIS. The working group arranged 16 meetings over a period of one and a half years. In addition, a reference group was established, which brought comprehensive competence in nursing research, critical care nursing, legislation, medicine and ethics. The referents advised and supervised the working group during the process of developing the recommendations for safe diary practice. Discussions between clinicians and researchers, both within the working group and between working group and referents, were significant throughout the process. The work was funded by the Norwegian Nursing Association (NSF) and NSFLIS (Storli et al., 2011).

Feedback on the recommendations were sought from the Norwegian Board of Health Supervision, the Department of Professional Policy within the NSF, the NSF Nursing Ethics Committee, the local and national boards of NSFLIS, the Norwegian Society of Anaesthesiology and several patient organisations. In general, the recommendations were considered to be positive for critical care, and grounded in research, legislation and ethical reasoning. The Norwegian recommendations were published in 2011 and distributed to all ICUs in the country. They were posted on the NSFLIS website in 2012, as well as presented at national conferences on critical care nursing and cardiac nursing in 2012 and 2013.

#### *The national recommendations on the use of diaries in ICUs*

The normative status of the recommendations is emphasised, as well as the need for regular revisions.

**Organisation and leadership:** This recommendation stresses that the formal leadership in the ICU department needs to agree on a

diary routine. It is recommended that resources and time be made available to allow a group of nurses to take daily responsibility for diary activity in the department, including a duty to approve the quality of the diary content before handing the diary over to the patient. Leadership responsibilities include systematic teaching, training and supervision of employees in terms of writing diaries, registering diary activity in the unit, organising handovers and undertaking regular evaluations.

**Target group:** Diaries should be written primarily for patients in need of ventilator support and patients who are expected to have longer stays in the ICU. Patients receiving non-invasive respiratory support and who are disoriented because of their current illness, should also be considered for a diary. The multi-disciplinary team should discuss the benefit of particularly vulnerable patients receiving a diary, i.e. patients with dementia or patients who have attempted suicide. Parents must give their approval for diaries to be written for children under the age of 16.

**Start-up and access:** The first diary entry should be written as early as possible after ICU admission and the next of kin should be informed about the initiation and purpose of the diary. Nurses should write the daily diary notes primarily, though other professionals can also write them. Next of kin are encouraged to write their own diaries. When a patient is discharged to another department or hospital, the diary should be finalised.

**Layout, language, content and photographs:** A diary should have a standard introduction written in everyday, personal language, but also reflecting a professional approach. The purpose of the diary notes should be to promote patients' understanding of their ICU trajectory, including giving meaning and coherence to their experiences. Incidents should be included, describing both setbacks and progress. Any photographs used should be realistic, but not frightening, and their context should be clear from the text. Including photographs of medical equipment surrounding the patient during their stay is also recommended, as these are important signs of the severity of their illness and the steps to recovery.

**Storage:** It is recommended that the diary be incorporated into a patient's medical records and there should be close collaboration with the staff responsible for the medical records system at each hospital. The diary can be written electronically or by hand, and should be stored safely together with other health-related information on patients. Diaries written by hand should be securely stored and scanned into a patient's records before the diary is handed over to the patient.

**Handover:** When patients are ready to receive the diary, the timing of the handover should be adjusted to suit the patients. Preferably, the diary should be handed over during a consultation with their primary-contact nurse, offered to them while they are still hospitalised. Handing diaries over to patients under the age of 16 must be agreed with their parents. ICUs are advised to have routines for handovers when patients are transferred to other hospitals, in order to make handovers easier. Patients and their next of kin should be offered a follow-up conversation based on the diary at some time after discharge. Close relatives should be offered the diary after a patient dies if there is no significant reason to withhold it.

#### *Survey on the experience of implementation*

According to the Norwegian Board of Health Supervision, an integral part of implementing quality initiatives is to evaluate their use. In this case, the evaluation specifically included the extent to which the national recommendations had been put into practical use and whether they had led to changes in diary practice in Norwegian ICUs (Statens Helsetilsyn, 2002).

**Setting and participants:** In 2014, a questionnaire was sent to 66 Norwegian ICUs. Thirty-nine ICUs replied, giving a response rate of 59%. The ICUs were located at university hospitals (14) regional

hospitals (10) and local hospitals (15) and included general and mixed ICUs (28) medical ICUs (7), three specialised ICUs (neuro- and burns) and one postoperative department (Moi et al., 2018). Health care workers who were engaged and well-acquainted with the follow-up offer in the unit answered the questionnaires (Table 1). The responding ICUs had an average number of 7 ICU beds and 40 full-time nursing positions (for details see Moi et al., 2018).

**Data collection:** The questionnaire contained 49 questions concerning diaries, both open ended and closed, divided into two domains: i) The current diary protocol, actual use and the ICU nurses' experience of writing and providing diaries and ii) specific questions concerning changes in routines, practice, attitudes, knowledge, as well as the nurses experiences following implementation of the national recommendations. The questionnaire content was based on an earlier interview study on the use of diaries at Norwegian ICUs (Gjengedal et al., 2010) and the questions covered all topics of the national recommendations (Storli et al., 2011) including the ICU's diary routines, the diary protocol, the patient target group, when diaries were initiated, what motivated them, who wrote them, what was written, whether and how they used photographs, routines for quality assurance, storage and scanning to medical records, handover to patients and bereaved, as well as the use of time, resources and leadership commitment.

#### Data analysis

The quantitative questionnaire data were analysed by descriptive statistics, frequencies and percentages, supported by the "Statistical Package of Social Sciences version 19 (SPSS Inc.). The qualitative data, i.e. answers as text, were thematised, summarised and given without further analysis.

#### Ethical considerations

The quality improvement project was approved by the Norwegian Centre for Research Data (ID 2014-37924). A letter of invitation describing the study purpose, together with the questionnaire and a form for informed consent, were sent to all Norwegian ICUs identified through the Norwegian Intensive Care Registry (<https://helsebergen.no/norsk-intensivregister-nir>).

#### Results

In 2014, three years after the implementation of the national recommendations, diaries were used for critically ill patients in 24 of the 39 responding ICUs (61.5%) (Moi et al., 2018). Fifty-six per cent of the units had changed their practice, of which 38% had developed new protocols and 62% had revised their earlier protocols according to the recommendations. The diaries were still mostly written by nurses (96%) in their own handwriting (68%). In line with the recommendations, the diary was written primarily for adult ICU patients treated with mechanical ventilation (77%) (Moi et al., 2018). The responding ICUs considered that the national

recommendations had increased their knowledge on the long-term effects of critical illness (56%), the diary itself (70%) and the recommended routines for the use of diaries (82%). Moreover, the impact of the recommendations on the general attitude towards using diaries was reported to be more positive in 60% of the ICUs.

In general, the routines for assessing and storing the diaries were improved in 26% of the units after implementing the national guidelines, but only about 50% of the ICUs scanned handwritten diaries into patient medical records. The timing when the diaries were offered patients, or their family varied greatly. The diary was offered the patients within the first days or months after discharge from the ICU and offered the bereaved family members two weeks to three months after the patients had died. Handwritten diaries were destroyed when patients or the bereaved family did not wish to keep the diary after an ICU stay. However, if scanned into the patient medical records, the diary is available for both patients and bereaved for as long as legally justified.

The respondents experienced that the diary largely had a positive impact on the patients (88%) and their family (62%) (Moi et al., 2018). All ICUs reported that they seldom or never had experienced negative impacts of the diary. Further details on these experiences were provided by answers to open-ended questions, in which the respondents described changes to nursing care brought about through the use of diaries. These suggested that nurses had become more aware of needs in terms of preventing post-ICU complications. Moreover, the human beings behind all the technology became more prominent - including their upbringing, work, social life and culture, as well as their wishes and needs. Writing the diary encouraged staff to reflect on what patients might be experiencing and made the nurses more focused and aware of their role. It strengthened the caring aspects of nursing, including elements of family care. Furthermore, the diary facilitated prolonged contact with the patients, giving the nurses a sense of achievement when patients were satisfied with the care they had received. The respondents reported that most of the nursing staff were generally positive to the use of diaries, even though some experienced difficulty in writing them or felt that they did not have enough time. After implementing the national guidelines, 82% of the ICUs reported that there were no changes in resources for the facilitation of diary activity, either in terms of dedicated time or positions. Moreover, the heads of department seldom or never initiated the process of starting a diary (78%), and seldom (67%) advocated that diary notes be written to patients.

#### Discussion

Survivors of critical illness will be in need of rehabilitation and follow-up, because of cognitive, physical and mental challenges post-discharge (Needham et al., 2012). The two assessments of the use of diaries in Norway, in 2009 and 2014, revealed that diaries were written in 31 (44.2%) and 24 (61.5%) departments respectively (Gjengedal et al., 2010; Moi et al., 2018). This may indicate that the use of diaries for ICU patients increased after implementation of the national guidelines in Norway.

The results of the study revealed that writing diaries for critically ill patients is a widespread nursing activity in Norwegian ICUs, even though the recommendations specified that it was not a required duty (Storli et al., 2011). Following the implementation of national recommendations on the use of diaries, more than 50% of the units had either developed new protocols or revised their earlier protocols according to the recommendations, indicating that nurses mainly appreciated the improved standardisation. The departments which reported little change may also have had well-integrated routines before the new recommendations were introduced.

**Table 1**  
The positions of the respondents answering the survey on behalf of the ICU.

	N*	Per cent*
Registered nurse (RN)	2	5.1
Critical care nurse	22	56.4
Head nurse or assistant head nurse	22	56.4
Diary resource group member	11	28.2
Quality improvement nurse	4	10.2
Consultant physician	1	2.5

\*The participants could hold more than one position.

The most significant change in diary practice to be introduced by the national recommendations was to incorporate the diary into patients' medical records. The decision was based on legal advice and changed the status of the diary from being an unofficial gift from the nurses to the patient, to become a legal document and an integral part of patients' medical records. This also led to obligations about the use, storage, documentation and handover of diaries to the patients. More reflection on issues of privacy or medical-legal risks has also been requested internationally (Beg et al., 2016), and the risks attached to data being used outside the medical records has been seen as a potential issue. According to the Norwegian recommendations, diaries should be part of a patient's medical records and the use of diaries should be seen as a caring initiative in line with the rest of the total critical care offered at the intensive care unit. In response to questions from one Norwegian health enterprise in 2015, the Norwegian Directorate of Health confirmed in writing that they considered the diary to be part of patients' medical records. Thus, the legislation governing access to the diary was changed, giving both patients and the bereaved legal rights of access to the content of the diary in line with other parts of the medical records.

In 2014, at the time of this survey, all ICUs in Norway had electronic medical records. This means that if adhering to the national recommendation, all units should have scanned handwritten diaries before handing them over to patients or bereaved. Since handwritten diaries were destroyed if patients or bereaved did not want to receive the diary and only about 50% of the units scanned the handwritten diaries, it possible that patients or bereaved that later changed their mind, were unable to obtain a copy of the diary. Hence, it is our opinion that all Norwegian ICUs should adhere to the national recommendations and scan handwritten diaries so that they are documented as an integrated part of the patient's medical records for the future.

Despite the new legal status of the diary, many nurses continued to write it by hand, just as they had done in the 1990s. Hence, about two-thirds of the diaries were still handwritten in 2014. This may reflect a wish to allow for a closer and more personal relationship with the patients in the diary than is common with other aspects of the medical records. The qualitative comments made by the nurses in our study also indicated that they considered the diary to promote more person-centred care for critically ill patients.

In accordance with earlier studies, the ICU leaders seldom initiated diary activity, which seemed very much dependent on a patient's primary critical care nurse and other staff committed to the idea (Gjengedal et al., 2010). This makes this practice of writing diaries vulnerable to inconsistency, and the Norwegian recommendations advocate incorporating the practice into the formal leadership of ICUs to make it more effective (Storli et al., 2011).

Standards and guidelines regulating diary practices have been recommended internationally to support systematic evaluations and quality improvements, since the current variations limit the possibility of comparisons between countries (Aitken et al., 2013; Ewens et al., 2015; Johansson et al., 2019; Strandberg et al., 2018). The systematic process followed in developing the "National recommendations for the use of diaries in Norwegian ICUs" has been pivotal in anchoring them in research-based knowledge and multi-disciplinary expertise.

### Limitations

Possible limitations of the described quality improvement process include that patients and their next of kin were not involved, and the fact that different methods were used in contacting the

ICUs in 2009 (telephone) and in 2014 (postal questionnaire). Moreover, Norwegian hospitals have centralised the care for patients in need of ventilator support in recent years, reducing the number of departments treating the main target group for receiving an ICU diary.

### Conclusion

National recommendations for diaries in intensive care units were developed and implemented in Norway in 2011. Three years after the implementation, more than half of the ICUs using diaries had either made new or updated their diary procedures. Writing diaries was still mostly based on the initiative from the ICU nurses, and the majority of ICUs reported that there had been no changes in resources for the facilitation of diary activity. The process of development and key elements of the Norwegian national recommendations could be used to facilitate similar processes in other countries, allowing for increased standardization, but also taking national and cultural characteristics into account.

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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.

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