

**ORIGINAL ARTICLE**

# The provision of nurse-led follow-up at Norwegian intensive care units

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**Aims and objectives:** To describe the prevalence, content and administration of intensive care unit diaries and follow-up practices offered to patients and their families in Norway.

**Background:** Intensive care treatment has been associated with risks for new or increased health impairments affecting both patients and their families. These impairments have the potential of continuing beyond the acute phase of treatment. In parallel, preventive actions have gradually become an integrated part of critical care nursing, and in Norway, national recommendations for the use of intensive care unit diaries have been established.

**Design and methods:** A survey was conducted in Norwegian intensive care units offering care for adult patients, using a questionnaire asking about the frequency, administration and content of the follow-up offered to patients, their relatives, as well as bereaved family members.

**Results:** Thirty-nine of 66 (59.1%) invited intensive care units answered the questionnaire. The majority ( $n = 33$ , 84.6%) of the responding units had follow-up routines. The provision of diaries was the most frequent follow-up activity ( $n = 24$ , 61.5%), and consultations postdischarge formed an integrated part of the diary practice. Consultations with bereaved were conducted in 21 (53.8%) of the intensive care units. About one quarter of the responding intensive care units had positions for follow-up nursing staff.

**Conclusion:** Nurse-led follow-up after critical care was a common activity in Norwegian intensive care units, comprising diaries and consultations offered to patients and family members. The follow-up was mainly driven by bottom-up processes conducted by dedicated nurses motivated by the patients' and their families' situation and feedback.

**Relevance to clinical practice:** Adherence to recommendations, as well as the availability of defined positions for aftercare nurses or teams, may improve the implementation of follow-up practices and reduce suffering after discharge from Norwegian intensive care units.

## KEYWORDS

bereavement, diary, intensive care, nursing, support

## 1 | INTRODUCTION

Alongside the successes of modern critical care, a growing body of evidence has revealed physical, mental and cognitive side effects in both patients and their family members after intensive care unit (ICU) hospitalisation (Needham et al., 2012). The prevention of harm and restoration of health, functioning, comfort and self-fulfilment have been recognised as fundamental parts of nursing (Meleis, 2012). Accordingly, nurses have developed follow-up initiatives specifically aimed at supporting both patients and their families through the trajectory of critical illness and recovery. Moreover, patient diaries and follow-up conversations with patients and their families have become an increasingly important part of critical care nursing (Egerod et al., 2013).

The burden of recovery after critical care has both physical and psychosocial dimensions. Symptoms of intensive care unit acquired weakness (ICUAW) are among the most commonly reported physical health limitations, and up to 80% of ICU patients develop some kind of neuromuscular dysfunction (Jolley, Bunnell, & Hough, 2016). ICUAW has been documented to increase 1-year mortality in patients requiring long ICU stays (>8 days) and to be a significant threat to functioning and activities even years after discharge (Herridge et al., 2011; Schandl et al., 2011). After hospitalisation, a majority of critically ill patients will need long-term follow-up in a rehabilitation facility: community-based physical rehabilitation or home-based assistance with care (Agard, Lomborg, Tonnesen, & Egerod, 2014; Griffiths et al., 2013). The patients themselves describe the first year after discharge as a struggle to regain physical strength, functioning and domestic roles (Agard, Egerod, Tonnesen, & Lomborg, 2012).

Another burden associated with critical illness is cognitive impairment, which is reported in 4%–62% of general intensive care patients after a follow-up between 2–156 months (Wolters, Slooter, van der Kooi, & van Dijk, 2013). Patients often describe disturbed memories, delusions and illusions after critical illness, which may be associated with delirium, a frequent complication reported in as much as 80% of patients in need of mechanical ventilation (Karnatovskaia, Johnson, Benzo, & Gajic, 2015). Delirium has been associated with impaired cognitive functioning 12 months after discharge from hospital, in both medical and general ICU populations (Girard et al., 2010; Wolters et al., 2014).

New or increased psychosocial problems are prevalent in both patients and their next of kin following treatment in an ICU department (Agard et al., 2014; van Beusekom, Bakhshi-Raiez, de Keizer, Dongelmans, & van der Schaaf, 2016; Schandl et al., 2011). Pain and sleep disturbances affecting health are common

### What does this paper contribute to the wider global clinical community?

- Follow-up activities at Norwegian intensive care unit (ICUs) for patients and their next of kin are driven and led by dedicated nurses.
- The use of ICU diaries is the most common follow-up activity in Norwegian ICUs and serves as an integrated part of the follow-up consultations with patients, relatives and bereaved families.
- Lack of positions for aftercare nurses or teams may reduce the implementation of these follow-up practices.

(McKinley, Fien, Elliott, & Elliott, 2013, 2016). The first year after critical illness, the prevalence of post-traumatic stress disorder (PTSD) has been estimated to affect 4%–62% of patients and anxiety to affect 62% (Karnatovskaia et al., 2015; Parker et al., 2015). In this respect, frightening delusions and hallucinations have been recognised as potentially more traumatising than real events. Moreover, one-third of the patient population has been reported to experience depression at the 1-year follow-up (Rabiee et al., 2016). Factors associated with depression were pre-ICU psychological illnesses, mood symptoms, stressful experiences in the ICU, delusional memories and lack of factual memories while hospitalised. Overall, distress and the impact of delusional memories, or lack of factual memories, seem to play a significant role in emotional and cognitive outcome after critical illness (Karnatovskaia et al., 2015).

Informal caregivers also experience psychological problems after ICU discharge and sometimes even comparable or worse levels of PTSD, anxiety and depression than patients (van Beusekom et al., 2016; Fumis, Ranzani, Martins, & Schettino, 2015). Overall, the health deficits after critical illness severely effect social functioning in terms of employment status in both patients and their partners (Agard et al., 2014; Griffiths et al., 2013).

To raise awareness of post-ICU impairment, a stakeholder's conference in 2010 agreed upon the terminology postintensive care syndrome (PICS) as a new concept to describe "new or worsening impairments in physical, cognitive or mental health status arising after critical illness and persisting beyond the acute care hospitalisation" (Needham et al., 2012, pp. 505). Furthermore, the term was applicable to both patients (PICS) and family members (PICS-F). While knowledge about long-term consequences of critical illness is increasing, less is known about the implications for follow-up and clinical nursing practice.

## 2 | BACKGROUND

Knowledge of successful rehabilitation programmes for the adult ICU population is still sparse, but nurse-led follow-up practices including the use of diaries have been stated to be the best evidence-based initiative for positive mental health after critical illness (Lasiter, Oles, Mundell, London, & Khan, 2016; Mehlhorn et al., 2014). For about three decades, nurses working at intensive care units have written diaries as part of caring for the critically ill patient and their next of kin. The diaries have been used to fill in gaps in patients' memories from their stay in ICUs and combine text and photographs to show significant situations and changes in the patient's condition (Jones, 2014). Egerod and co-workers compared the practices related to nurse-led aftercare in Scandinavia and found diaries to be an integral part of ICU follow-up (Egerod et al., 2013). During the hospital stay, nurses, and sometimes also family members, wrote in the diaries daily, describing the illness trajectory from the perspective of what patients would appreciate and benefit from remembering if they had been fully awake. After transfer to step-down units or regular wards, nurses visited patients at the wards and offered follow-up conversations at a later stage. The use of diaries has now become a worldwide activity (Jones, 2014).

A national recommendation for the use of patient diaries was published in Norway in 2011 (Storli, Eskerud, Gjengedal, Holme, & Synnevåg, 2011). This was based on a need for more standardisation revealed by a Norwegian study of use of diaries (Gjengedal, Storli, Holme, & Eskerud, 2010).

The Norwegian recommendations for the use of diaries give Norwegian nurses advice on topics such as target group for the diary, when to start, health professionals as authors, access, structure and language, content, use of photographs, handover process and storing as part of the medical record. Norwegian nurses at ICUs that used diaries, described the diary practice in 2010 as a nursing caring act, anchored in the organisational leadership of the department. Moreover, having a resource group that led the initiative on a daily basis was important for keeping a high level of diary activity (Gjengedal et al., 2010). Other nurse-led follow-up practices for patients and their relatives may include short-term follow-up and ward visits, and long-term follow-up in terms of phone calls and appointments, return visits to the ICU room, drop in meetings outside the hospital, for example at ICU cafés to share experiences with others (Jonasdottir, Klinke, & Jonsdottir, 2016; Svenningsen, Langhorn, Agard, & Dreyer, 2015). Follow-up of the relatives' grieving process after losing one of their loved ones in the ICU has also been part of nurse-led follow-up. Experiencing a high risk of death, often sudden and unexpected, puts a lot of strain on family members in the ICU, and nurses have provided support afterwards in terms of condolence cards, brochures, phone calls and follow-up appointments (McAdam, Dracup, White, Fontaine, & Puntillo, 2010; McAdam & Erikson, 2016).

Today, a general consensus exists on the need for systematic and comprehensive rehabilitation and follow-up programmes supporting both patients and family members following critical care

(Svenningsen et al., 2015). Nevertheless, large diversities still exist in follow-up practices both within and between countries. Moreover, the content of these follow-up programmes is not standardised.

The aim of this study was to describe the prevalence and content of nurse-led follow-up practices after critical care hospitalisation in Norway, including the use of follow-up consultations and patient diaries in the ICUs.

## 3 | METHODS

This study has a survey design using a questionnaire developed by the study authors through a process of consensus. The questionnaire comprised both closed and open-ended questions asking about nurse-led follow-up practices at Norwegian intensive care units. The open-ended questions were mainly used to specify or deepen answers given to the close-ended questions in order to facilitate the interpretation of findings. First, information about the project and an invitation to participate were sent to departments included in the Norwegian Intensive Care Registry (<https://helsebergen.no/norsk-intensivregister-nir>). Members from the research group identified additional units. The inclusion criteria were departments offering mechanical ventilation (CPAP, NIV or positive pressure ventilation) for more than 24 hr and included surgical, medical, specialised and postoperative intensive care units. Neonatal and paediatric intensive care units were excluded, as these units were expected to have different practices for nurse-led follow-up.

### 3.1 | Data collection

After approval from the head of the departments, nurses working in an ICU, and having a particular responsibility for the diaries and follow-up practices of patients and their families, were asked to fill in a questionnaire on behalf of their units. The questionnaire comprised 110 items in six domains: ICU characteristics, follow-up consultations with patients and family, follow-up with bereaved family members, the use of patient diaries, the use of Norwegian National Recommendations for Diaries (Storli et al., 2011) and a report on the numbers of follow-up consultations and diaries from 2013. The questionnaire content was based on an earlier interview study on the use of diaries at Norwegian ICUs and the subsequent Norwegian recommendations (Gjengedal et al., 2010; Storli et al., 2011). After the questionnaire content had reached consensus in the research group, three units, from two university hospitals and one local hospital, were asked to review the questionnaire for face validity, resulting in some minor linguistic corrections. Overall, the questionnaire was easy to understand and fill in. The most difficult part was the objective information about unit characteristics and the actual treatment offered throughout the year 2013 (e.g., number of patients receiving mechanical ventilation or noninvasive ventilation).

### 3.2 | Analysis

Descriptive analyses, frequencies and percentages for the categorical data, and mean, standard deviation and range for the continuous numerical data, were used to describe the nurse-led follow-up activity. The statistical package SPSS version 19 (SPSS Inc.) was used for the descriptive statistics. Two of the authors (ALM and ANH) cross-checked the entering of data into SPSS.

### 3.3 | Ethics and approvals

The questionnaire was sent together with a letter of invitation and an informed consent form to the identified units in late spring 2014. Nonresponding units were given four reminders, one by mail, two by telephone and one by email. The participating units were informed that their given information would be treated confidentially and anonymously. The data analyses were conducted on a password-protected research server. The Norwegian Centre for Research Data approved the study (ID 2014-37924).

## 4 | RESULTS

### 4.1 | ICU characteristics

In total, 39 of the 66 invited ICUs answered the questionnaire, giving a response rate of 59.1%. These included units at university hospitals ( $n = 14$ ), regional hospitals ( $n = 10$ ) and local hospitals ( $n = 15$ ). The majority of units were general intensive or mixed ICUs ( $n = 28$ ), whereas the others included medical ICUs ( $n = 7$ ), specialised ICUs (i.e., neurointensive and burn units) ( $n = 3$ ) and one postoperative ICU. The nonresponding ICUs did not differ from those responding with regard to type of ICU and type of hospital (not shown).

The number of full-time critical care nurses employed was on average 39.9, and the mean number of intensive care beds was 7.2 (Table 1). The mean number of patients treated in 2013 was 1,214.7, of whom, 163.4 (mean) received invasive ventilator support for on average 4.0 days. Noninvasive ventilator support was given to 154.4 patients (mean), lasting on average for 0.9 days (Table 1).

### 4.2 | Follow-up interventions and routines

In total, 33 (84.6%) of the 39 responding ICUs offered follow-up to patients or bereaved family members, and 31 (79.5%) units had written protocols regulating this activity. Twenty-seven (69.2%) ICUs offered follow-up for patients. Twenty-four (61.5%) of these used patient diaries as an important part of their follow-up, whereas three ICUs (7.6%) used follow-up consultations only. Twenty-one ICUs (53.8%) offered follow-up to bereaved family members. Six of these ICUs (15.4%) offered follow-up to bereaved only and not to survivors.

The follow-up interventions with patients or bereaved family were mainly based on preventive, caring and therapeutic

**TABLE 1** Intensive care unit (ICU) departments and patients

	<i>n</i>	Mean (SD)	Min–Max
Number of ICU beds	34	7.2 (3.0)	2–15
Number of full-time nursing positions	29	39.9 (26.8)	5–108
Number of patients admitted	24	1,214.7 (1,183.4)	129–4,525
Adults	19	1,028.7 (1,040.3)	125–4,167
Children <18 years	15	53.9 (85.1)	4–352
Patient age	18	62.2 (5.3)	0–101.9
Length of stay (days)	24	2.8 (1.4)	0.007–94
Invasive ventilator support (number of patients)	29	163.4 (191.1)	0–700
Invasive ventilator support time (days per patient)	17	4.0 (1.6)	0.013–72
Noninvasive ventilator support (number of patients)	22	154.4 (101.1)	20–402
Noninvasive ventilator support time (days per patient)	12	0.9 (0.9)	0.007–66

perspectives. Moreover, the purpose was to fill needs for information, support the processing of memories and receive feedback on care and treatment (Figure 1). Systematic assessments using standardised questionnaires for quality improvement projects or research were seldom part of the follow-up interventions (Figure 1).

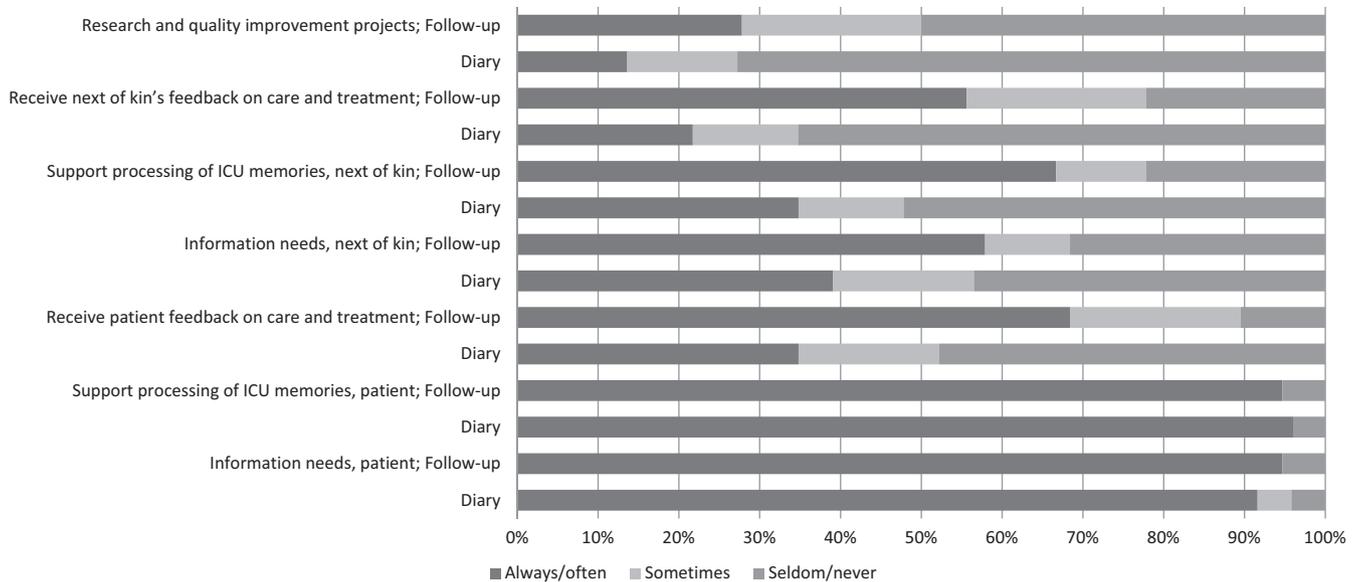
Even though many units did not register their follow-up activity, seven units reported they had performed on average 32.1 (4–67) follow-up consultations in 2013, while 46.3 (4–116) patients had received an invitation to take part. Furthermore, eleven units had invited 37.5 (6–75) bereaved and had performed on average 20.5 (2–59) consultations with next of kin after a patient had died in the ICU.

### 4.3 | Patient diaries and follow-up consultations

The responding ICUs had introduced patient diaries between 1990–2012 and had used diaries routinely for on average 12.0 (SD 6.0) years. Of the 24 ICUs that offered patient diaries, 23 (95.8%) had protocols for when to start writing and for the handover procedure. Twenty-two ICUs (91.7%) had predefined the target group, and 16 (66.7%) had established procedures for quality checks.

The main target group for diaries was adult patients (76.9%) who had been treated with invasive mechanical ventilation (Table 2). Diaries were seldom or never written in the following cases: patients speaking foreign languages, after suicide attempts, when patients were intellectually disabled or suffering from dementia or severe mental illness, or when a patient had been considered as organ donor (Table 2). In most ICUs, the nurses discussed the initiation of use of the ICU diary for particularly vulnerable patients with the rest of the multidisciplinary team. The reported purpose of diaries was mainly to meet patient needs for information and to support processing of memories from the stay in the ICU (Figure 1).

In 91.3% of the responding units, the recommendations for use of diaries advocated writing the first note within 3 days after patient



**FIGURE 1** Purposes for the use of diaries and follow-up consultations

admission. The diary content comprised the patients' ICU environment, important transitions in care and procedures, as well as visits from family or friends (Figure 2). It was common to use photographs, and 21 (80%) departments reported using photographs always or often.

The average time used for the first diary entry was 24.3 (*SD* 10.3) minutes and for the daily notetaking 15.9 (*SD* 6.9) minutes. Mainly nurses (96.2%) wrote the diary notes. However, family members were given the opportunity to write in the diary in 42% of the units. The handover process differed greatly between hospitals, but was most often performed in hospital as part of a follow-up conversation (34.6%), or as part of the transfer from the ICU to step-down units or other hospitals (30.8%).

Twenty units reported using follow-up consultations as part of the process of using diaries. The follow-up conversation had more focus on next of kin compared with the written diary (Figure 1). It was common to invite family, and only three units never invited next of kin to follow-up conversations with the patient. In nearly 90% of the ICUs, the follow-up consultation was an open face-to-face dialogue based on the patients' needs, whereas nearly 60% (58.8%) sometimes performed a follow-up by telephone. A consultation guide was used in 47.1% of the units.

All but two units offered visits to the ICUs in connection with the follow-up consultations to allow patients to meet staff that had cared for them, and re-experience equipment, sounds, smells and atmosphere in order to establish a more accurate memory of their ICU stay.

The majority of the follow-up consultations were performed within the first 3 months after discharge (80%). Moreover, a second follow-up consultation was offered at five units, either within the first 3 months (two units) or between the fourth and sixth months (three units).

In about two-thirds of the units, the diaries were offered to the bereaved next of kin after a patient had died in the ICU. Eighty-eight per cent of the units experienced the diaries to be positive for

patients, and 62% found them positive for next of kin. No units reported a perceived negative impact of the diaries on patients or their families.

#### 4.4 | Consultations with bereaved

The majority (76%) of the ICUs contacted the next of kin between 3 weeks and 2 months after the patient had died, and the consultations were mainly conducted during the same time period (88%). The target group consisted of almost all bereaved and was independent of the illness trajectory (Table 2). The purpose of the consultation was to give the next of kin a possibility for processing their experiences (100%) and to supply information according to their needs (92%). In 66.7% of the units, feedback on treatment and care was part of the purpose of the follow-up. The needs of the bereaved formed the basis for the dialogues (95.7%), which were mainly conducted face-to-face (63.6%) or by telephone (61.9%).

#### 4.5 | Nurses' role in the follow-up

Only nine departments (23.1%) had a defined position of aftercare nurse, and only eight (20.5%) had a resource group organising the follow-up activities. The diary group and resource group often consisted of the same persons. Nurses participated (84.2%) and led the follow-up conversations (83.3%) most often; this also applied to consultations with the bereaved next of kin, with 96.2% and 75.0% for participation and leadership, respectively. Beside nurses, medical doctors were the profession that participated the most, especially in follow-up consultations after patients had died (72.0%). The patients' primary care nurse had an important role, being the person that most frequently initiated the use of a diary (73.1%), and that participated most in both follow-up consultations (72.2%) and consultations with the bereaved (87.0%).

**TABLE 2** Follow-up target populations

Follow-up consultations				
	<i>n</i>	Always/often <i>n</i> (%)	Some times <i>n</i> (%)	Seldom/never <i>n</i> (%)
<b>Intensive care unit (ICU) departments (<i>n</i> = 39)</b>				
All patients	18	1 (5.6)	1 (5.6)	16 (88.9)
Patients on invasive mechanical ventilation	16	7 (43.8)	3 (18.8)	6 (37.5)
Patients having long-lasting ICU stays	15	7 (46.7)	3 (20.0)	5 (33.3)
Patients having short ICU stays	15	0	5 (33.3)	10 (66.7)
Patients having short, acute and dramatic ICU stays	14	3 (21.4)	4 (28.6)	7 (50.0)
Patients having a written diary	15	11 (73.3)	2 (13.3)	2 (13.3)
Patients <16 years and their next of kin <sup>a</sup>	20	5 (7.6)	4 (6.1)	0
<b>Diaries</b>				
Patients expected to survive	24	16 (66.7)	5 (20.8)	3 (12.5)
Patients who were awake	24	10 (41.7)	4 (16.7)	10 (41.7)
Patients on invasive mechanical ventilation	25	17 (68.0)	6 (24.0)	2 (8.0)
Patients on noninvasive mechanical ventilation	26	6 (23.1)	10 (38.5)	10 (38.5)
Patients who made a suicide attempt	25	3 (12.0)	5 (20.0)	17 (68.0)
Patients having severe mental illness	25	2 (8.0)	5 (20.0)	18 (72.0)
Patients having severe mental retardation	25	1 (4.0)	3 (12.0)	21 (84.0)
Patients having dementia	25	1 (4.0)	3 (12.0)	21 (84.0)
Patients having severe head injury	25	9 (36.0)	4 (16.0)	12 (48.0)
Possible organ donation	25	2 (8.0)	1 (4.0)	22 (88.0)
Not speaking Norwegian	25	3 (12.0)	3 (12.0)	19 (76.0)
<b>Consultations with bereaved</b>				
All bereaved	25	21 (84.0)	3 (12.0)	1 (4.0)
Long-lasting ICU stays	17	14 (82.4)	3 (17.6)	0
Short ICU stays	17	13 (76.5)	3 (17.6)	1 (5.9)
Short, acute and dramatic ICU stays	17	14 (82.4)	2 (11.8)	1 (5.9)
Bereaved persons whose deceased family members had a written diary	14	10 (71.4)	4 (28.6)	0
Bereaved persons whose deceased family members had been organ donors	16	14 (87.5)	0	2 (12.5)

<sup>a</sup>Not relevant for 11 units not caring for children.

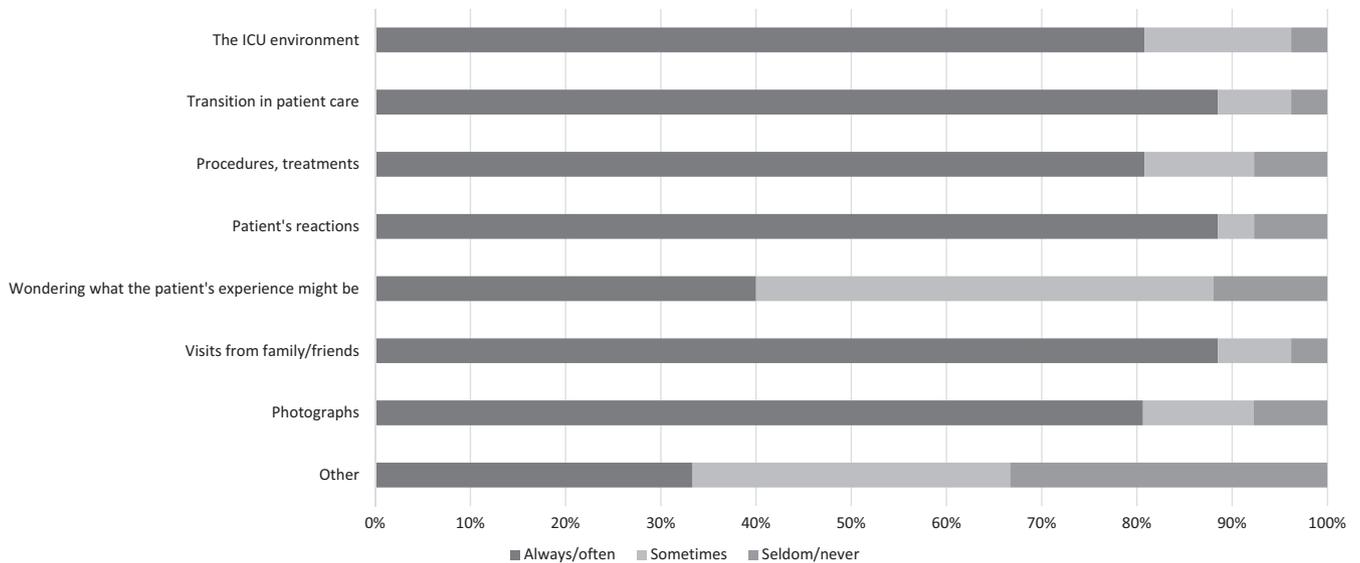
Nurses became motivated to write diaries through caring for patients (96%), knowledge gained from research and conferences (72%), the diary resource group (70%), through patients' next of kin (50%) and their leaders (25%). The use of diaries was facilitated through written recommendations (88.5%) that described the layout, content and language. A diary nurse usually checked the quality of the diary before the handover (62.5%), mainly for content, photographs and ethics, but also for structure and language.

## 5 | DISCUSSION

This study describes the frequent use of nurse-led follow-up, including the use of ICU diaries at Norwegian intensive care units. About 50% of the invited units and 80% of the responding units had nurse-led follow-up to support patients and their next of kin after their ICU stay. Thus, many Norwegian critical care nurses have recognised the potential long-term harm and effects related to the

intensive care experience and have integrated supportive and preventive caring initiatives into their nursing practice (Gjengedal et al., 2010; Needham et al., 2012). The present study showed that the follow-up was predominantly driven by bottom-up processes implemented by dedicated critical care nurses working at the bedside or in teams, and taking special responsibility for the after care of critical care patients and their families, confirming earlier reports (Heindl, Bachlechner, Nydahl, & Egerod, 2016; Nydahl, Kneuck, & Egerod, 2015).

The use of ICU diaries was the most frequently occurring part of the follow-up activity in Norway, and based on data from this and an earlier study, it was implemented in about 40% of the ICUs. A review of nurse-led follow-up practices in Scandinavia has shown that diaries were written in about two-thirds of the Swedish units and about half of the Danish ICUs (Egerod et al., 2013). Scandinavian nurses started writing ICU diaries in the early 1990s, and still this initiative seems to be more widespread in Scandinavia compared with other countries where diaries have been introduced more



**FIGURE 2** The contents of diaries

recently (Egerod, Storli, & Akerman, 2011; Heindl et al., 2016; Nair, Mitchell, & Keogh, 2015; Nydahl et al., 2015).

Over the years, ICU diaries have been used as part of the patient and family follow-up at Norwegian ICUs, but still the provision seems to be characterised by variations in both frequency and routines. This has been found in other studies, describing the voluntary nature of nurse-led follow-up programmes, relying on nurses with a particular interest in follow-up (Egerod et al., 2013; Heindl et al., 2016; Nydahl et al., 2015). Moreover, lack of evidence from clinical trials may inhibit the implementation of follow-up as an integrated part of critical care (Jensen et al., 2016; Ullman et al., 2014).

The target population for having a diary in this study was mainly patients who were expected to survive and patients who had received mechanical ventilation, confirming earlier research showing an association between a need for treatment on a ventilator and the use of ICU diaries (Akerman, Granberg-Axell, Ersson, Fridlund, & Bergbom, 2010; Gjengedal et al., 2010). Similar to the routines followed in other countries (Beg, Scruth, & Liu, 2016), our findings demonstrate that patients who had neurocognitive deficits, severe mental illness or who only spoke foreign languages were less likely to receive a diary. Most ICUs reported that the appropriateness of using an ICU diary was discussed by the multidisciplinary team in particularly vulnerable patients. Thus, the target group for diaries was mostly based on the clinical judgements of the professionals. More research is needed to identify the subsets of patients who benefit most from having a diary (Aitken, Rattray, Kenardy et al., 2017).

Almost all units used photographs. In an earlier study, critical illness survivors reported finding pictures particularly helpful when it came to understanding the severity of what they had gone through, and the majority of patients did not report the photographs as unpleasant to look at (Akerman, Ersson, Fridlund, & Samuelson, 2013).

The ICU diary was placed together with the rest of the confidential patient documentation. The diaries were mainly written by

nurses, rarely by other health professionals, in accordance with earlier findings from Scandinavia (Egerod et al., 2013). We also found that next of kin was given the opportunity to write in the diary in nearly half of the units and formed the second largest group next to nurses giving diary notes. Including relatives in both reading and writing in the diary may support care for the patients by adding information about what happens at home or what the family thinks the patient would like to know (Ednell, Siljegren, & Engstrom, 2017). Moreover, through reading the diary, relatives got access to information about what was happening to the patient. However, while patients often lack memories of their ICU stay, family members may have strong and vivid memories, and their writings may therefore serve more to provide a therapy for themselves than to meet the patient's needs for information and care (Aitken, Rattray, & Hull, 2017). Furthermore, the use of family notes can conflict with the recommended status of the diary in Norway, where it is advised to store the ICU diary as part of the patient's medical records as a professional legal document (Storli et al., 2011). Norwegian nurses have previously been reported to encourage family members to write their own diary or to give them separate sheets that can be added to the diary later (Gjengedal et al., 2010).

The perspective of the diary concept in Norway has been and still seems to be dominantly reported as an act of caring, but also with preventive and therapeutic purposes (Gjengedal et al., 2010). Therapy, empathy and innovation have previously been stated as theoretical understandings held by nurses for the use of patient diaries (Egerod et al., 2013; Heindl et al., 2016). Norwegian ICU nurses predominantly wrote the diary aimed at the patient's needs. The follow-up consultations, on the other hand, were more open to the needs of family members. Acknowledging family wishes for information and support in follow-up consultations is in accordance with a recent review by Jonasdottir et al. (2016). Engstrom, Rogmalm, Marklund, & Walivaara (2015) have described how patients experienced both family members and the diaries as important tools in the

struggle to “create a context and coherence from a missing or unreal time”. Furthermore, earlier studies report that family members often experience traumatic stress and extended periods of sick leave through being the primary caregivers and facilitators of patient recovery (Svenningsen et al., 2015). Thus, the follow-up consultation could be an arena for meeting the families’ needs and for giving information.

This study shows that follow-up in connection to the diary was conducted in 20 units, which is comparable to the previous findings from the Scandinavian interview study (Egerod et al., 2013; Gjengedal et al., 2010). Having a diary was the most frequent criterion for offering a follow-up consultation, beside the need for mechanical ventilation and a long-lasting ICU stay. The combined use of diaries and follow-up consultations in our study is supported by a recent review indicating the value of the diary for improving consultation outcome (Jensen et al., 2015).

In 2010, all ICUs that reported using diaries as part of their nursing care also expressed a need for national recommendations. Thus, Norway was among the first countries to establish national recommendations for the use of diaries (Gjengedal et al., 2010; Storli et al., 2011). Variations in trajectories of illness and recovery among ICU patients also demonstrate the need for an individualised follow-up programme with regard to both content and timing (Aitken, Rattray, & Hull, 2017; Kean et al., 2017) which also may explain variations in follow-up in the present study. Even so, adherence to the national recommendations (Gjengedal et al., 2010; Storli et al., 2011) may reduce unnecessary variation and improve the quality of follow-up activities at ICUs.

In this study, about half of the responding units contacted and offered a consultation with the bereaved family either face-to-face or by telephone between 3 weeks and 2 months after the patient had died. These units aimed at giving a follow-up to all bereaved family members. Admissions to intensive care units are usually unexpected, and the intensity of bereavement after critical care has been shown to be predicted by being unprepared for the death of a loved one and associated with greater use of emotional support, self-blame and denial (Buckley et al., 2015). The ICU diaries were offered to the relatives after patient deaths. This practice is supported by a recent study describing how family members experience diaries to support social interaction, and rational and emotional understanding, and to bridge the gap between the hospitalisation and postbereavement period (Johansson, Wahlin, Magnusson, Runeson, & Hanson, 2017). Complicated grief is experienced by a significant proportion of relatives after intensive care treatment and is associated with being present at the time of death, not having said goodbye, the patient refusing treatment, the patient dying when still intubated and poor communication between relatives and physicians (Kentish-Barnes et al., 2015). Bereavement follow-up services have been reported to be present in about one-third of the Australian and about half of the New Zealand ICUs, and while social workers conducted most of the follow-up in Australia, nurses had this responsibility in New Zealand, which was comparable to our findings from Norway (Mitchell, Coombs, & Wetzig, 2017).

This study is the first to aim at describing the provision of different nurse-led ICU follow-up activities after the implementation of national guidelines. A strength of the study is the comprehensive assessment of follow-up initiatives. Moreover, this study describes different nursing initiatives for both patients and their next of kin that extend critical care to the weeks and months after the discharge from the ICU. On the other hand, the relatively low response rate of 59.1% represents a limitation.

## 6 | CONCLUSIONS

About 80% of the responding Norwegian ICUs offered follow-up to patients or bereaved family members, but the practices were not uniform. Only half of the responding units had follow-up for the bereaved, which is lower than recommended (Davidson et al., 2007). Using diaries was the most common follow-up activity, but the frequency and variations in performance were not satisfactory considering the potential for reducing PTSD in both patients and their relatives (Garrouste-Orgeas et al., 2012; Jones et al., 2010). Only one quarter to one-fifth of the units had organised the follow-up activity by defining positions for aftercare nurses or resource groups, and the follow-up activity was mainly run and led by the bedside nursing staff, perhaps making the implementation more dependent on enthusiasts and time available. Including follow-up in the structure of positions, as an integrated part of the formalised ICU programme, may improve compliance with recommended guidelines. Despite patient and family satisfaction with follow-up (Svenningsen et al., 2015), more research and knowledge are needed to improve follow-up practices at ICUs.

## 7 | RELEVANCE TO CLINICAL PRACTICE

The findings from this study give an overview of nurse-led follow-up for ICU patients and their next of kin and support the development of more standardised programmes and recommendations. The persistence of nurse-led follow-up initiatives over three decades in Norway demonstrates the relevance of follow-up experienced from a nursing perspective. Nursing care extends to a large degree beyond the intensive care unit stay.

## CONTRIBUTIONS

Study design and questionnaire development: all authors; data collection: ALM, SLS, EG, ANH, RL, RK and KH; data analysis: ALM, ANH and AMF; manuscript preparation: ALM, SLS, EG, ANH, RL and KH; revisions and final approval of the article: all authors.

## CONFLICT OF INTEREST

The authors have no conflict of interest to declare.

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