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Feature

Intensive care patient diaries in Scandinavia: a comparative study of emergence and evolution

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Critical illness and intensive care therapy are often followed by psychological problems such as nightmares, hallucinations, delusions, anxiety, depression, and symptoms of posttraumatic stress. Intensive care patient diaries have been kept by nurses and the patients' family since the early 1990s in the Scandinavian countries to help critically ill patients come to terms with their illness after hospital discharge. The aim of the study was to describe and compare the emergence and evolution of intensive care patient diaries in Denmark, Norway, and Sweden. The study had a comparative international design using secondary analysis of qualitative data generated by key-informant telephone interviews with intensive care nurses (n = 114). The study showed that diaries were introduced concurrently in the three Scandinavian countries as a grass-roots initiative by mutual cross-national inspiration. The concept has evolved from a pragmatic practice to an evidence-based domain of inquiry propelled by academically prepared nurses. Several schools of thought were identified in our study: diaries as (i) a therapeutic instrument, (ii) an act of caring, (iii) an expression of empathy, and (iv) a hybrid of the above. Diaries have the potential to fulfill the existential needs of patients who struggle to make sense of their experiences and construct their own illness narrative.

Key words: diary, intensive care nursing, interview, qualitative research, rehabilitation, secondary analysis.

As more patients are surviving critical illness, studies are showing that patients recovering from intensive care frequently suffer psychological problems such as memory loss, nightmares, and delusions (Jones et al. 2001; Ringdal et al. 2006; Bench and Day 2009). Some patients develop symptoms of anxiety, depression, and posttraumatic stress after discharge (Griffiths and Jones 2007; Knowles and Tarrier 2009). These issues require attention in relation to intensive care rehabilitation. After hospital discharge patients need information about what happened and how they reacted during critical illness (Storli and Lind 2009), and diaries kept in the intensive care unit (ICU) by nurses and family provide this kind of information. A personal account of the ICU stay enables patients to construct or reconstruct their illness trajectory and come to terms with their experiences (Egerod and Christensen 2009). Patient diaries have been an integrated part of intensive care nursing in the Scandinavian countries Denmark, Sweden, and Norway for several decades and the intervention has gradually extended to other European countries including the United Kingdom, Switzerland, Italy, and Portugal (Jones et al. 2007; Roulin, Hurst, and Spirig 2007; Jones 2010).

BACKGROUND

Intensive care diaries, also known as patient diaries or prospective patient diaries, have been kept for critically ill patients in the Scandinavian countries since the early 1990s

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(Bergbom et al. 1999; Storli, Lind, and Viotti 2003). According to Nortvedt (1987), patient diaries were inspired by the concept of 'dialogue in nursing' introduced in 1984 at a Danish hospital. The project was to promote patient emancipation and involvement in care. In the new regime, nurses' progress notes were shared with the patients as the closed charting system was transformed to a vehicle of communication between nurse and patient. The 'open charting system', however, threatened to violate patient privacy and patient protection laws soon put an end to the practice (Olsson 1985). Nonetheless, the initiative inspired Norwegian nurses to reengineer the concept to target intensive care patients, who were unable to write their own story (Schou et al. 1993). The patient diary was considered a therapeutic nursing intervention with the goal of helping patients remember after critical illness, and facilitating contact between patient and hospital after discharge. The diary was described as a source of information for patients, who needed to piece together their story at a later time.

In 1997, Gjerland, Wærstad, and Furuheim described patient diaries and follow-up as a systematic approach at a Norwegian ICU. Guidelines were written and goals were defined. The purpose of the diary was to fill in the patient's memory gaps, and follow-up was introduced to help patients come to terms with their ICU experiences and to develop intensive care nursing. At a Swedish ICU, Backman and Walther (2005) described a similar initiative as a 'photo-diary' with follow-up. The diary included photographs of the actual patients to promote an understanding of the severity of their illness and to prepare the patients for a lengthy convalescence. Also, to help patients accept the limitations imposed by their illness; the overall purpose was to orient the patients toward reality. In Norway and Sweden diaries have become an adjunct to post-ICU follow-up, whereas Danish nurses have introduced either diaries or follow-up, but not both.

Through the years, intensive care diaries have been adapted by nurses in an increasing number of ICUs. Studies on diaries have emerged, but the diary itself has rarely been the subject of analysis. A Danish single-center study described the structure and content of 25 patient diaries and demonstrated the dual perspectives of nurse and patient in the texts (Egerod and Christensen 2009). A Swiss study of eight diaries identified a main category of meaning: sharing throughout the ICU time, where patient, family, and health professionals collaborate on creating a story and 'sharing the presence' (Roulin, Hurst, and Spirig 2007). A Danish study comparing patient diaries and hospital charts showed that the diary is coherent, personal, and supportive, whereas the hospital chart is fragmented, impersonal, and technical (Egerod and Christensen 2010). Although studies are emerging that describe the meaning and effect of patient diaries, we still need to know more about the history and theoretical underpinnings of diary practice in ICU. The aim of the study was to describe and compare the emergence and evolution of intensive care patient diaries in Denmark, Norway, and Sweden. Our research questions were: What are the differences and commonalities in using patient diaries in the three Scandinavian countries? How did it start and where are we now?

METHODOLOGY

The study had a comparative international multicenter design, applying qualitative secondary analysis of data from individual studies performed in Denmark, Norway, and Sweden. According to Polit and Beck (2008, 325): 'Secondary analysis involves the use of data gathered in a previous study to test new hypotheses or explore new relationships'. In the present study we reexamine three datasets that were previously used to describe the practice of keeping patient diaries in each of the three Scandinavian countries. Thorne (1994, 266) described five variations of qualitative secondary analysis: Analytic expansion, retrospective interpretation, armchair induction, amplified sampling, and cross-validation. The present study falls in the category of analytic expansion, where we have made use of our original dataset to answer questions at the next level of analysis and ask new questions as the available theory base expands. Our study is also a kind of retrospective interpretation, where we considered new questions that were raised, but not thoroughly examined in the context of the original studies. The focus of our primary analysis was on the extent and application of patient diaries, that is, how widely were ICU diaries used and how were diaries kept. In the present study we focused on emergence and evolution of intensive care diaries, that is, what was the impetus for starting diaries and how has the concept developed over time and across national boundaries. We have pooled our data from the three countries and attempt to piece together the history of intensive care diaries, and discuss the theoretical assumptions behind the practice to expand our knowledge base and encourage generation of theory.

International collaboration study

Our study was a collaborative effort initiated and conducted by the Nordic Association for Intensive Care Nursing

Table 1 The interview guide

1. How long have patient diaries been used at your unit?
2. What is the purpose of patient diaries at your unit (e.g., care, therapy, research)?
3. What was your source of inspiration for introducing patient diaries?
4. Are patient diaries used systematically (e.g., for all patients, particular patients)?
5. Are patient diaries structured (e.g., format of the diary, preprinted introduction, pictures)?
6. Who authors patient diaries (e.g., staff, family, patient)?
7. Who is responsible for the application of patient diaries (e.g., qualifications, ethics, photos)?
8. Is there a theoretical framework for patient diaries (e.g., literature)?
9. Are patient diaries used in conjunction with follow-up visits?
10. How have patient diaries been received?
11. Do you have suggestions for improvement of patient diaries?
12. Have you experienced negative effects of patient diaries?

Research (NOFI) (Bergbom et al. 2005). The original data were generated in Denmark in 2006, in Norway in 2008, and in Sweden in 2008, and the three datasets constitute data in the present comparative study (Egerod et al. 2007; Akerman et al. 2010; Gjengedal et al. 2010). The original interview guide was translated methodically from Danish to Norwegian and Swedish (table 1).

Data generation

Data were generated by key-informant telephone interviews with critical care nurses (n = 114). In each country we identified the ICUs that used patient diaries. The head nurse at each participating ICU was asked to help select an informant with experience in patient diaries, who would volunteer for a telephone interview. A time was set up to contact the key informant, and the semi-structured interview was conducted in the course of 30–60 minutes. The interviews were digitally recorded and transcribed verbatim by ourselves or a professional typist. Data were verified by key-informant member checking (Gilchrist and Williams 1999, 81). In Denmark and Sweden the interview notes or transcripts were e-mailed to the informants who had a chance to verify their statements or add comments. The Norwegian investigators validated the responses during the interview.

Strategy of analysis

Qualitative content analysis was performed according to a priori themes, and emerging themes and concepts (Polit and Beck (2008, 750). The steps in our analytic process were:

1. Overview: Getting a sense of the whole by reading the transcripts.
2. Selection: Sorting data according to themes: each investigator selected data from their own dataset. Themes of interest for the present study were selected by choosing themes that focus on the emergence and evolution of diaries and omitting themes such as legal and practical issues.
3. Cross-case and cross-dataset analysis: Data within each theme were integrated across cases in each dataset (national level) and across the three datasets (international level). Data are presented according to Danish, Norwegian, and Swedish data, in that order, throughout analysis.
4. Condensation: Themes were compared, contrasted, and condensed.
5. Documentation: Quotes were selected for illustration and documentation.

According to Malterud (2001, 484), 'Multiple researchers might strengthen the design of a study – not for the purpose of consensus or identical readings, but to supplement and contest each others' statements'. During the stage of analysis we maintained communication, mostly by e-mail, but also by phone conferences and actual meetings. We were aware of variances in nursing culture in the three countries and tried to obtain equal representation of our views and values. We reflected on other issues that might threaten our objectivity such as personal interests in promoting patient diaries and latent competition among our nationalities. A particular challenge was analyzing the datasets in three different languages: Danish, Norwegian, and Swedish. Each investigator analyzed their own data and we negotiated linguistic issues by translating meaning units into English, to ensure common ground throughout the process. The three languages are similar, which means that we were able to understand each other and read each others' original texts in cases of doubt. Many years of inter-Scandinavian collaboration has prepared us for this task.

Secondary analysis is a way of making use of large datasets, where information was not exhausted in the original study. There are some hazards within this method (Thorne 1994, 267). We acknowledge the potential for researcher bias, but the fact that we have pooled our data

Table 2 Use of patient diaries in Denmark, Norway, and Sweden

Country	Inhabitants in millions	Number of ICUs in each country*	ICUs using diaries, *n* (%)	Years diaries in use, median (range)	Units with a diary purpose statement, *n* (%)
Denmark	5.4	48	19 (40)	5 (1–18)	14 (74)
Norway	4.8	70	31 (44)†	7 (1–18)	26 (87)
Sweden	8.9	86	65 (76)	7 (1–18)	54 (83)

*ICUs were included if they had ≥2 mechanical ventilator beds not used for surgical recovery (Egerod et al. 2007; Akerman et al. 2010; Gjengedal et al. 2010).
†In Norway, 31 ICUs used diaries. Only 30 ICUs participated in our study (Gjengedal et al. 2010).
ICU: intensive care unit.

minimizes this risk. We primarily view our study as an opportunity to examine an emergent practice across national boundaries. If practice has developed in different directions in each country, this kind of analysis will enable us to discuss the various approaches to the practice. This secondary analysis was planned from the onset of the original studies, so it was not what Thorne (1994, 268) has described as 'lazy' research, where data are reused for convenience. As such, our study was not a subset of the primary analysis, but rather, the secondary analysis of two planned sequential investigations.

Ethical considerations

The informants in each country were made aware of the voluntary nature of the study before they consented to participate and again prior to the interview. They were informed that data would be handled confidentially and that they would maintain anonymity. Some quotes have been altered slightly to prevent recognition. National and ethical approval is not required for interviewing staff in Scandinavian countries, but the Norwegian Social Science Data Services approved the Norwegian study. We did not obtain additional consent for the secondary analysis.

RESULTS

Intensive care diaries have been used for 1–18 years in the Scandinavian countries (table 2). Many units have introduced diaries within the past few years, suggesting that the number of units using diaries is increasing in all three countries. Figure 1 shows the distribution of ICUs according to years of keeping diaries, for example, nurses at 63% of the Danish ICUs using diaries have kept diaries for 0–5 years, whereas nurses at 40% of Norwegian ICUs have kept diaries for 6–10 years.

Emergence of intensive care diaries – how did it all start?

DENMARK

According to the informants, patient diaries were introduced in Danish ICUs by bedside nurses as a bottom–up initiative. The nurses introduced the concept intuitively as a tool to help critically ill patients deal with their ICU experience after hospital discharge. One informant explained that patient diaries started as early as the 1970s or 1980s. The idea gradually evolved from non-critical patients to critically ill children, and then to adult patients requiring intensive care. Several of the informants stated that patient diaries had been introduced to their unit at their own initiative after they had come across the idea by chance: 'I experienced that my brother was very sick and my mother wrote a diary' [D07]. Much of the inspiration was the result of national or inter-Scandinavian networking among ICU nurses. The intensive care specialization program requires the nurse to work at

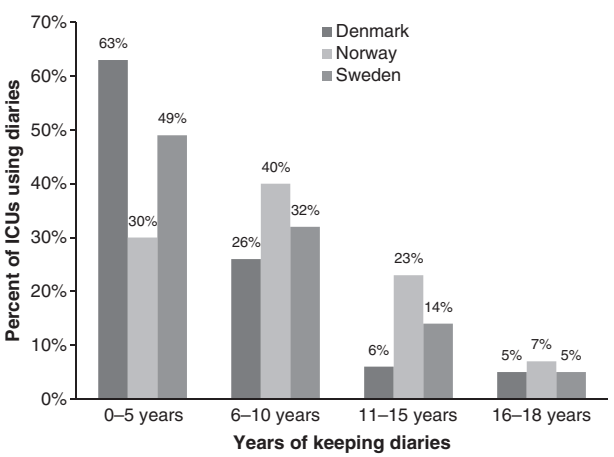

Figure 1 Distribution of intensive care units according to years of keeping diaries in Denmark, Norway, and Sweden.

different units on an exchange basis, which promotes networking among ICU nurses. According to the informants, patient diaries were not introduced by local management, professional journals, or conferences. One informant described the evolution of intensive care diaries:

> Well, I worked with diaries … 25 years ago … I kept diaries in the late 1970s. It was before we did it in ICU. In the mid 1980s I kept the first, or we did, for the first adult patient … It was not at all systematic, and it still isn't. It was, and it still is, random when we start a diary, but we do it mostly for patients we expect will stay in ICU for a while. [D09]

NORWAY

Much of the inspiration for the practice of keeping diaries derived not only from 'pioneers', but also from conferences, publications, and professional visits to units using diaries. Nurses at the pioneering unit in Oslo were inspired by the Danish movement of 'dialogue in nursing' in the early 1990s. In the mid-1990s an additional two 'pioneering units' became the main inspirational beacons. The first guidelines for patient diaries were developed by nurses at these units, who also introduced follow-up care and disseminated practice through journals and conferences. Patient diaries were inspired by the academic work of Norwegian nurses: Gjengedal (1994) and Storli (1999), who explored the experiences of patients in ICU, and by Schou (1997), who described the patients' perceptions of diaries. The concept of diaries was included in the nursing curriculum for ICU specialization, and students who had chosen to write about patient diaries in their final paper went on to introduce diaries at their home units. A proliferation of ICUs using diaries was seen in the early 2000s, when publications started to emerge from the United Kingdom (Jones et al. 2001) and Sweden (Backman 2002). While nurses' passion for diaries was important, the strongest motivational factor was positive feedback from patients and their families.

SWEDEN

The first Swedish diaries were kept in 1991. Initially these did not include photographs of the patients, but now most Swedish ICUs provide diaries and most diaries include photographs. In ICUs with more than 10 years of diary experience, the inspiration to introduce diaries came from bedside nurses, conferences, colleagues, and patient or family feedback. Nurses who introduced diaries within the past five years have reported conferences and baccalaureate preparation as their main sources of inspiration. The academic work of Swedish nurses Bergbom et al. (1999) was inspirational as well as the pioneering work of Backman (2002), who introduced patient diaries, and published and lectured on the concept.

SUMMARY

Intensive care diaries emerged as a bottom–up initiative; local nurses and pioneers inspired each other and the practice spread at the grass-roots level. Inter-Scandinavian networking has been important, and inspiration has been propelled in Sweden and Norway by academic nurses.

The purpose of patient diaries – why do nurses keep diaries?

Most of the informants in the three countries stated that their ICU had a declared purpose for patient diaries, but the purposes varied for lack of national guidelines. Table 3 shows the many purposes of patient diaries provided by the informants.

DENMARK

Each informant in Denmark provided different rationales for keeping diaries; the most common were related to therapy and patient support. Some informants gave more pragmatic reasons for keeping diaries, such as preventing misunderstandings and providing evidence: 'I am sure that little misunderstandings are cleared up when the family reads the diary' [D14].

NORWAY

When diaries were first introduced in Norway, the nurses assumed that patients had very little recall of their ICU stay. As Scandinavian nursing research on the patient perspective increased through the 1990s, more ICU memories and unreal experiences were reported. The practice of keeping diaries went in several directions. Initially nurses aimed to provide information and fill the memory gaps, but later nurses tried to capture the patients' experiences to help them find meaning in their suffering. Most informants expressed the dual purposes of diaries as a hybrid of therapy and caring.

SWEDEN

The Swedish informants provided a number of purposes for diaries that aimed at helping the patient remember and understand what happened. One informant explained that knowledge of the ICU stay could be important even if it was only a short stay:

> Generally [diaries] are for patients where we expect a long stay; more than three or four days. But if we feel – this is a bit subjective – that it is very important [we start a diary] even if it is only for one day'. [S30]

Table 3 Purpose of patient diaries in Denmark, Norway, and Sweden

Denmark	Norway	Sweden
To fill the patient's memory gaps	To help the patient find meaning in chaotic experiences and fragmented memories	To give back lost time
To help the patients deal with their ICU experience after discharge	To help the patients deal with their ICU experience after discharge	To provide information
To prevent posttraumatic stress disorder (PTSD)	To prevent complaints/PTSD	To fill memory gaps
To explain unreal experiences	To reorient the patient toward reality	To explain what has happened
To demonstrate patient progress	To explain strange experiences	To process events and memories
To increase patient satisfaction	To fill the patient's memory gaps	To help the patient understand
To prevent misunderstandings between patient and family	To do 'good' for the patient	To help the patient feel better
To help the family understand the patient's experience	To express care	To facilitate rehabilitation
To aid follow-up care	To aid follow-up care	
To inform bereaved families of non-survivors	To promote professional development	

SUMMARY

Local guidelines for keeping diaries existed at many ICUs. Explicit goals or purpose statements narrowed down the scope of diaries to include therapeutic, caring, and pragmatic reasons for the practice. A main objective was to enable the patients to view their ICU experiences in context, which might facilitate coping and prevent long-term complications.

Patient selection – when to start a diary?

DENMARK

The initiation of a diary was contingent upon the availability and personal interest of the nurses. Diaries were generally started on sedated and ventilated patients, who were expected to have a lengthy ICU stay. Most diaries were started three days after ICU admission. One informant said: 'We start a diary when we feel it's the right thing to do' [D04].

NORWAY

The Norwegian criteria for starting a diary varied; most of the informants stated that diaries were for ventilator patients only, while some included non-intubated patients, for example, non-invasive ventilation. In most cases, the estimated chances of survival and potential benefits for the patients were considered before a diary was initiated. If mechanical ventilation was assumed to continue for three days or more, a diary was started. Diaries were generally not provided for patients who were either awake and oriented or had severe cerebral damage, dementia, or developmental delay. More patients were included by experienced nurses, and the limits of inclusion are still expanding:

> Lately, we have also kept [diaries] for non-invasively ventilated patients that seemed to be awake. But you know, we are often fooled … Later [the patients] told us about really chaotic experiences, and we realized that it is not being on a ventilator itself that gives these experiences. It's their whole situation … So now we encourage also keeping diaries for patients on mask-ventilation. [N24]

SWEDEN

At most Swedish ICUs diaries were started on a predefined patient group, including all ventilator patients and patients with a predicted ICU stay of three days or more. In some cases, a patient was selected even if the ICU stay was short, because a nurse sensed that it was important. Patient selection was more systematic at ICUs that provided follow-up care. Regarding patient selection, one informant said: 'All patients that are ventilated or sedated for more than two days; perhaps we start earlier if it looks like it will be a long stay' [S27].

SUMMARY

Diaries were initially kept for long-term, ventilated and sedated patients. The practice has evolved as the collective experiences of nurses have demonstrated that diaries might help shorter-term, non-invasively ventilated and non-sedated patients. The nurses are still learning.

Structure and content of patient diaries – what to write?

DENMARK

Most diaries had a standard layout, including a cover and a preprinted introduction for the patient. Some diaries included generic pictures of the most common ICU equipment with explanations. The cover included pictures, for example, of the hospital, a nurse, a patient, or even a flower. Pictures were chosen with care to encourage the patient, and one informant described the writing style as empathetic: 'We try to put ourselves into the patient's place and describe what is happening and how we think the patient is experiencing it …' [D07].

NORWAY

Most units used guidelines or general principles for patient diaries including purpose, patient selection, appearance, content, storage, and hand-over. Each entry started with a short summary of events and ended with some conclusive remarks. All notes were dated and signed. The informants agreed that the style should be personal and professional, but not private. Nurses were discouraged from using the term 'Dear'. The language should be non-medical and easy to understand. The informants agreed that the appearance of the diary was important and many diaries included a picture or a poem with symbolic value for encouragement:

> We have put a lot of thought into the design. On the cover there is a picture of a tree with roots; green leaves symbolizing hope and the strong roots perhaps saying something about inner strength or belonging … [N29]

Some Norwegian informants described the 'art of wondering' as an essential way of writing to the patient:

> We can never know their experiences of living through intensive care! So we try to take the posture of wondering what the patient's experience in the situation might be, and we use many question marks in the text to allow the patient to reflect while reading the diary. [N19]

A different strategy was a more factual description of the ICU environment, equipment, and procedures, aimed at orienting the patient toward reality. But most of the informants employed both fact and wonder, such as wondering what certain events might mean to the patient:

> When, for instance, a mother sings to her child in the next bed, we write … that someone is singing a lullaby. We know this is a kind of sensory impression that can become part of a patient's strange experiences from intensive care. [N22]

SWEDEN

Most Swedish ICUs had diary guidelines that typically included an introduction and a glossary explaining the most common equipment, some with pictures. Each diary started with a summary followed by daily notes written by ICU staff and the patient's family focusing on the patient. Nurses avoided description of medical progress, but concentrated on general themes and contextual events. Everyday language was encouraged to the exclusion of medical terms and abbreviations:

> We don't write medical things any more, such as 'you are going to surgery'. We write what is happening in the unit and whether the patient is better or worse … we write short notes that are clear and easy to understand, not medical terms from the patient chart. [S64]

SUMMARY

Diaries have evolved in a similar fashion in the three countries. The external format was much the same with a loose-leaf notebook system including preprinted information. The writing styles were comparable with a preference for easy everyday language and avoidance of medical jargon. The nurses in each country, however, were inspired by different theories and thinkers. Danish nurses leaned toward an empathetic style; Norwegian nurses had refined the 'art of wondering', while Swedish nurses promoted a more factual style of writing.

Photographing the patient – why do diaries include pictures?

DENMARK

Photographs of the individual patients were used as a type of contextual clue or evidence that might help the patients remember or understand the severity of their illness. Some informants were concerned that photographing without prior consent would potentially impinge on patient privacy. The issue was negotiated at some units by using generic pictures of patients in ICU, whereas nurses at other units stored the pictures securely until the patient was able to give retrospective consent to their use in the diary. Most of the informants supported photography, because pictures could provide evidence and prevent misunderstandings. One informant described how a picture had helped a patient who was uneasy whenever the nurses left the room. After seeing his picture he realized that the nurses stayed just outside the door. The informant explained:

> [We take pictures] because we had a patient who told us what it actually felt like to be in ICU. He didn't understand

> that when we left the room to let him rest, we were just on the other side of the glass window. We disappeared from his world. It has given us something to think about – this was when he was most afraid. [D11]

NORWAY

Most ICUs used patient photos, which were inserted in the diary text or kept in an envelope in the back of diary until the patient gave consent to use it. The nurses avoided potentially harmful pictures and tried to balance openness and censure. When the diary was handed over, the patient was given the choice to accept or reject his pictures. This kind of retrospective consent was considered ethically justifiable by the informants. In most units, family members were informed when pictures were taken:

> We tell [the family] that most patients appreciate the pictures, and that they may become very important later when the patient searches for meaning. But if they say 'No, my husband would not like that!' we have to reconsider. It's about exercising discretion. [N22]

SWEDEN

The reason for photographing patients varied. Although it was considered beneficial to take daily photographs to follow progress, it was not always feasible. If the patient had been badly injured or marred, some nurses believed that photographs could help the patient deal with the situation. But other nurses discouraged photography, that is, if the patient had temporary facial swelling. Pictures of unusual situations such as cooling outfits or prone position were encouraged to help patients grasp what had happened. Pictures were inserted into the diary along with an explanation. 'We take some photos, usually two or three, when the patient is very ill with all the equipment and tubes' [S41].

SUMMARY

Photographing patients was widely practiced, but all informants were aware of potential problems, such as legal issues, ethics, patient privacy, esthetics, and dignity. The main reason for sustaining the practice was the overwhelmingly positive patient feedback.

Systematic follow-up – what happens after discharge?

DENMARK

Danish ICUs did not offer systematic follow-up. Diaries were handed over without follow-up and little was known about how diaries were used and how the patients reacted.

NORWAY

More than half of the participating units in Norway offered systematic follow-up after ICU discharge, whereas other units provided more erratic follow-up. During follow-up the nurse and patient discussed the patient's ICU experience and used the diary as a reference. The nurse read from the diary and the patient asked questions related to text and pictures. Follow-up was not only beneficial to the patients, but also to the nurses: 'When I meet a patient who says that the diary is worth its weight in gold, I write with even more enthusiasm next time' [N25].

SWEDEN

Follow-up was common in Sweden, but timing and frequency varied. Most often there was follow-up while the patient was still hospitalized and by telephone two months after hospital discharge.

SUMMARY

Follow-up was not offered in Denmark, but many ICUs in Norway and Sweden offered follow-up and regarded it as an integral part of diary practice.

DISCUSSION

The aim of the study was to describe and compare the emergence and evolution of intensive care patient diaries in Denmark, Norway, and Sweden. The three countries are geographically, historically, culturally, and linguistically close. Hofstede (1980) has demonstrated that the Danish, Norwegian, and Swedish people, compared with 40 nationalities, are characterized by high individualism and small power distance. These cultural traits have enabled Scandinavian nurses to act autonomously and introduce patient diaries as a bottom–up initiative. The proximity of the Scandinavian countries helps explain how nurses have inspired each other to introduce and develop the concept of intensive care diaries. Just as the cultural similarity of the Scandinavian countries might explain the proliferation of practice, the lack of common language, culture, and educational possibilities, as well as a larger power distance, might explain why the practice has not immediately extended to Germany, which borders Denmark to the south (Nydahl, Knück, and Egerod 2010). In addition to cultural issues, implementation of diaries appears to be associated with the academic level of nurses.

Our main results: Diaries were introduced concurrently in the three Scandinavian countries as a grass-roots initiative by mutual cross-national inspiration. The practice has evolved from a pragmatic practice to an evidence-based

domain of inquiry propelled by academically prepared nurses. Diary-keeping started as a spontaneous, compassionate, and unsystematic initiative and has become increasingly regulated with guidelines, quality control, and purpose statements. Diaries are kept to inform patients, support and complete their ICU memories, and help patients find meaning in their illness. The target population for patient diaries has expanded from sedated long-term mechanically ventilated patients to include awake, short-term, non-invasively ventilated patients. The style of prose has evolved in various directions from factual writing, to empathetic writing, to the art of wondering. The text is accompanied by pictures of the patient during the stages of progress to reinforce the story and provide context. Finally, the diary has become an adjunct to post-ICU follow-up.

Several schools of thought that influenced patient diaries were identified in this study: The diary as (i) a therapeutic instrument, (ii) an act of caring, (iii) an expression of empathy, or (iv) a hybrid of the above. The first diaries in the early 1990s were regarded as therapeutic tools. Norwegian nurses Gjerland, Wærstad, and Furuheim (1997) described the diary as an instrument to help patients work through their crisis. The background theories were Lazarus and Folkman's (1984) coping theory (coping as a process) and Cullberg's (1976) crisis theory (crisis, reaction, resolution, new-orientation). The authors stated that, according to Lazarus, the psychological defence mechanisms of denial, repression, regression, and rationalization might help the patients cope with their memories, based on the assumption that factual description of the ICU trajectory would facilitate coping and promote crisis recovery.

Swedish authors Backman and Walther (2001) described the diary as a debriefing instrument, and Backman (2002) encouraged 'realistic description' of the ICU stay. Later Backman and Walther (2005, 75) presented the photo-diary as tool for the rehabilitation process: 'By giving the patient and relatives logical and chronological information based on fact as early as possible, they are better equipped to deal with their trauma'. In the same vein, international studies have demonstrated that diaries help reduce depression, anxiety, and new onset of symptoms of posttraumatic stress (Knowles and Tarrier 2009; Jones et al. 2010). Recently, Backman et al. (2010) demonstrated that ICU diaries show promise in relation to quality of life after critical illness.

The second direction was described by Norwegian pioneering nurses, who viewed the patient diary as an expression of caring (Lind and Storli 1998). In this perspective, the patient is the interpreter of meaning in his own experience. The method of 'wonder', which was initially inspired by Martinsen (1993), and later by van Manen (2002), has been cultivated by Norwegian nurses. van Manen (2002, 249) regards his phenomenological thinking as a 'way toward human understanding' and describes wonder as a vocative phenomenon; 'one cannot ''will'' oneself to wonder'. According to van Manen (2002, 250), Wittgenstein regarded wonder as a form of questioning for which there is no answer. Once the question has been answered; the wonder stops. The opposite of wonder is matter-of-factness. In our analysis we construe wonder as an activity that cannot be willed, but which might be inspired by quiet contemplation. Wonder has been described by Martinsen (2006, 2008), as a sudden notion or insight that helps unfold possible meaning for the patient. While writing in the diary, nurses attempt to induce wonder to help the patient to retrospectively understand what transpired, for example, 'I wonder what you see out the window' (Storli, Lind, and Viotti 2003). Wonder provides contextual clues that might be meaningful to the patient. The goal is not necessarily reorienting the patient, but accepting that 'being somewhere else' might also be important to the patient (Storli, Lindseth, and Asplund 2007). This mode of writing integrates caring and healing.

The third direction was expressed by Danish nurses, who suggested that diaries were a method of 'empathetic writing'. Bagger (2006) described how the mode of address in diaries might be inspired by the teachings of Martin Buber (1878–1965), who distinguished between 'I–You' and 'I–It' relationships. The I–You relationship stresses the mutual, holistic existence of two beings as a concrete encounter, whereas the I–It relationship regards the being as an object. Bagger suggested that the I–You relationship should be present in the diaries, where a relation to the patient was sustained, even when the patient was sedated. She used the term 'empathetic writing' to describe the I–You relationship between nurse and patient, for example, 'You are in a deep sleep, but when we bathe you we can see that you react. You try to open your eyes … It is hard to tell if you will later be able to recall any of this, but we talk to you and explain what we are doing, even if you cannot respond' (Bagger 2006, 65). Empathy has been defined as 'the ability to identify with the emotions, feelings and reactions that another person is experiencing, and to communicate that understanding effectively to the individual' (Freshwater and Maslin-Prothero 2005, 205). The nurse cannot (and should not) guess what the patient is thinking, but the aforegiven example suggests that empathetic writing might actually combine factual writing of the therapeutic direction and the act of wondering in the caring direction.

Diaries are kept 'for' the patient, who is unable to write or recall his own story. This is in keeping with the Hendersonian view of nursing: 'assisting the individual in the performance of activities that he would perform unaided if he had

the necessary strength, will or knowledge' (George 2002, 87). The nurse serves as a substitute for patient deficits. Henderson used the metaphor of 'getting under the patient's skin' to illustrate the nurse–patient relationship (Schettle 1998). But the nurse is unable to know what the patient is going through, as Lorentsen et al. (1983) stated: 'It is important that we are aware that dialogue loses its purpose when the nurse takes over the thoughts of the patient'. Conversely, nurses have chosen to write 'to' the patient, as a kind of ongoing conversation, or rather, monologues. By writing to the patient, however, the nurses inadvertently become part of the story. This is an inescapable, but not necessarily negative, feature of patient diaries (Creswell 2007, 57). Care must be taken to maintain the focus on the patient. An earlier study has demonstrated how nurses instinctively emphasize their own tasks rather than the patient response, that is, stating that the nurse reduced sedation, rather than describing how the patient was waking up (Egerod and Christensen 2009). At the same time care should be taken to maintain the nurse as a natural part of the story. Patient diaries provide a platform for nurses' performance that might increase our knowledge of the essence of intensive care nursing. Cultivating just the right 'pitch' in the diary text requires practice and an understanding of the underlying theories.

Timeless memories, also called half memories, have been described by people who have experienced trauma and consequently experience dissociated memories (White 2006, 79). These memories exclude an account of the person's response to what they were being subject to. Patients need to know how they reacted during the time they have lost. This means that it is important to include the patient's reactions in the narrative account in the diary. It does not suffice to state that the patient was confused or delirious; the patient needs to know what he said and how he reacted. This requires the factual and realistic writing of the therapeutic school of thought, but may also be facilitated by wonder and empathy. An important feature of the patient diary is the immediacy, not unlike a personal letter from the nurse to the patient (Hallett 2007).

Our study had several limitations. The three original studies were not conducted simultaneously, resulting in a minor time lag among the three datasets. The Swedish study relied more on quantitative data, whereas the Norwegian study was predominantly qualitative, thus producing different types of data in some situations and resulting in fewer Swedish quotes. Only the Danish study included information on the preconceptions of the researchers (Egerod et al. 2007). We acknowledge the importance of reflexivity and attending systematically to the context of knowledge construction (Malterud 2001). The strength of the study was the fact that the secondary analysis was planned from the beginning, and that the same investigators were involved in the first and the second analyses in each country. We have striven to avoid redundancy between the primary and secondary analyses. Another strength was the multiple researcher design giving us a chance to discuss our findings across national boundaries. A multicenter study is a strong design, if the informants are representative. We selected informants who were highly involved in patient diaries, but we neglected to address nurses who were less enthusiastic about patient diaries. As an international study we benefitted from a larger volume of participants. The internal validity was increased by similar results within each country, while the external validity was expressed by the cross-national understanding of what diaries are about and by the findings in the literature. The qualitative data gained trustworthiness as the interview guides were translated and back-translated and the meaning was validated by the primary investigator.

CONCLUSION

Our study has explored the emergence and evolution of patient diaries in Denmark, Norway, and Sweden. Several schools of thought were identified: Diaries as (i) a therapeutic instrument, (ii) an act of caring, (iii) an expression of empathy, and (iv) a hybrid of the above. Diaries kept for intensive care patients are viable therapeutic instruments for ICU rehabilitation and an important adjunct to ICU follow-up. Furthermore, diaries have the potential to fulfill existential needs of patients as they struggle to make sense of their intensive care experience and construct their own illness narrative. Future studies are needed to provide insights into the patient-family experience of using diaries kept in ICU. We recommend national guidelines for patient diaries to inform clinical practice and to promote nursing education.

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REFERENCES

Akerman E, A Granberg-Axell, A Ersson, B Fridlund and I Bergbom. 2010. Use and practice of patient diaries in

Swedish intensive care units: A national survey. *Nursing in Critical Care* 15: 26–33.

Backman CG. 2002. Patient diaries in ICU. In *Intensive care aftercare*, eds RD Griffiths and C Jones, 125–9. Oxford: Butterworth Heinemann.

Backman CG and SM Walther. 2001. Use of a personal diary written on the ICU during critical illness. *Intensive Care Medicine* 27: 426–9.

Backman C and SM Walther. 2005. The photo-diary and follow-up appointment on ICU: Giving back time to patients and relatives. In *Critical care focus 12. The psychological challenges of intensive care*, ed. SA Ridley, 72–9. Oxford: Blackwell Publishing Ltd.

Backman CG, L Orwelius, F Sjöberg, M Fredrikson and SM Walther. 2010. Long-term effect of the ICU-diary concept on quality of life after critical illness. *Acta Anaesthesiologia Scandinavica* 54: 736–43.

Bagger C. 2006. Dagbog til kritisk syge patienter [Diary for critically ill patients]. *Sygeplejersken* 106: 62–5.

Bench S and T Day. 2009. The user experience of critical care discharge: A meta-synthesis of qualitative research. *International Journal of Nursing Studies* 47: 487–99.

Bergbom I, C Svensson, E Berggren and M Kamsula. 1999. Patients' and relatives' opinions and feelings about diaries kept by nurses in an intensive care unit: Pilot study. *Intensive and Critical Care Nursing* 15: 185–91.

Bergbom I, I Egerod, SL Storli and AG Axéll. 2005. Research platforms in the Nordic Association for Intensive Care Nursing Research (NOFI). *Connect: The World of Critical Care Nursing* 4: 91.

Creswell JW. 2007. Qualitative inquiry & research design. In *Choosing among five approaches*, 2nd edn, ed. JW Creswell, 53–84. Thousand Oaks, CA: Sage Publications.

Cullberg J. 1976. *Krise og udvikling* [Crisis and development]. Copenhagen: Hans Reitzels Forlag.

Egerod I and D Christensen. 2009. Analysis of patient diaries in Danish ICUs: A narrative approach. *Intensive and Critical Care Nursing* 25: 268–77.

Egerod I and D Christensen. 2010. A comparative study of ICU-patient diaries vs. hospital charts. *Qualitative Health Research* 22: 1446–56.

Egerod I, KH Schwartz-Nielsen, GM Hansen and E Laerkner. 2007. The extent and application of patient diaries in Danish ICUs in 2006. *Nursing in Critical Care* 12: 159–67.

Freshwater D and SE Maslin-Prothero. 2005. *Blackwell's nursing dictionary*, 2nd edn. Oxford: Blackwell Publishing.

George JB. 2002. *Nursing theories. The base for professional nursing practice*. Englewood Cliffs, NJ: Prentice Hall.

Gilchrist VJ and RL Williams. 1999. Key informant interviews. In *Doing qualitative research*, 2nd edn, eds BF Crabtree and WL Miller, 71–88. Thousand Oaks, CA: Sage Publications.

Gjengedal E. 1994. Understanding a world of critical illness: A phenomenological study of the experiences of respirator patients and their care givers. PhD thesis, Department of Public Health and Primary Health Care, Division of Nursing Science, University of Bergen.

Gjengedal E, SL Storli, A Holme and R Eskerud. 2010. An act of caring – Patient diaries in Norwegian intensive care units. *Nursing in Critical Care* 15: 176–84.

Gjerland A, T Wærstad and V Furuheim. 1997. Respiratorpatienterne er våre samarbeidspartnere [The ventilator patients are our collaborators]. *Sykepleien* 85: 55–8.

Griffiths RD and C Jones. 2007. Delirium, cognitive dysfunction and posttraumatic stress disorder. *Current Opinion in Anaesthesiology* 20: 124–9.

Hallett CE. 2007. The personal writings of First World War nurses: A study of the interplay of authorial intention and scholarly interpretation. *Nursing Inquiry* 14: 320–9.

Hofstede G. 1980. *Culture's consequences: International differences in work related values*, 2nd edn. Beverly Hills, CA: Sage.

Jones C. 2010. Practical problems of doing research across different cultures: Experiences from the RACHEL study. *Intensive and Critical Care Nursing* 26: 125–7.

Jones C, RD Griffiths, G Humphris and PM Skirrow. 2001. Memory, delusions, and the development of acute posttraumatic stress disorder-related symptoms after intensive care. *Critical Care Medicine* 29: 573–80.

Jones C, C Backman, M Capuzzo, H Flaatten, C Rylander and RD Griffiths. 2007. Precipitants of post-traumatic stress disorder following intensive care: A hypothesis generating study of diversity in care. *Intensive Care Medicine* 33: 978–85.

Jones C, C Backman, M Capuzzo, I Egerod, H Flaatten, C Granja, C Rylander, RD Griffiths and RACHEL Group. 2010. Intensive care diaries reduce new onset PTSD following critical illness: A randomised, controlled trial. *Critical Care*, 14: R168.

Knowles RE and N Tarrier. 2009. Evaluation of the effect of prospective patient diaries on emotional well-being in intensive care unit survivors: A randomized controlled trial. *Critical Care Medicine* 37: 184–91.

Lazarus RS and S Folkman. 1984. *Stress, appraisal, and coping*. New York: Springer.

Lind R and SL Storli. 1998. Kommentar: Filosofien får følger [Commentary: The philosophy has consequences]. *Tidsskriftet Sykepleien* 86: 59.

Lorentsen B, B Pedersen, I Sonne, L Thomsen and U Windfeld. 1983. Dialog i sygeplejen [Dialogue in nursing]. *Fokus på sygeplejen* 83: 123–36.

Malterud K. 2001. Qualitative research: Standards, challenges, and guidelines. *Lancet* 358: 483–8.

van Manen M. 2002. Writing in the dark. In *Writing in the dark*, ed. M van Manen, 237–52. London; Ontario, Canada: The Althouse Press.

Martinsen K. 1993. *Fra Marx til Løgstrup [From Marx to Løgstrup]*. Otta: Tano.

Martinsen K. 2006. *Care and vulnerability*. Oslo: Akribe.

Martinsen K. 2008. Innfallet og dets betydning i liv og arbeid [Sudden insight and its meaning for life and work]. *Klinisk sygepleje* 22: 20–32.

Nortvedt L. 1987. Dialog i Sykepleie [Dialogue in nursing]. *Sykepleien* 74: 6–11.

Nydahl P, D Knück and I Egerod. 2010. The extent and application of patient diaries in German intensive care units. *Connect: The World of Critical Care Nursing* 7: 122–6.

Olsson E. 1985. Dialogen for de udvalgte [Dialogue for the chosen]. In *Fokus på sygeplejen 86 [Focus on nursing 86]*, eds B Persson, K Ravn and R Truelsen, 70–83. Copenhagen: Munksgaard.

Polit DF and CT Beck. 2008. *Nursing research. Generating and assessing evidence for nursing practice*, 8th edn. Philadelphia, PA: Wolters Kluwer, Lippincott Williams & Wilkins.

Ringdal M, L Johansson, D Lundberg and I Bergbom. 2006. Delusional memories from the intensive care unit: Experienced by patients with physical trauma. *Intensive and Critical Care Nursing* 22: 346–54.

Roulin MJ, S Hurst and R Spirig. 2007. Diaries written for ICU patients. *Qualitative Health Research* 17: 893–901.

Schettle S. 1998. A nurse's reflection: Nursing in the'90s: Old hats, new ways. *American Journal of Nursing* 98: 16J.

Schou I. 1997. Dagbok til intensivpasienter: E middel for å hjelpe pasienten til å huske oppholdet på intensivavdelingen [Diary for intensive care patients: A means to help the patient remember the ICU stay]. Master's thesis, University of Oslo, Institute of Nursing and Health Sciences.

Schou I, M Nordvik, AM Tørseth, U Fet, I Thon and M Møkkelgard. 1993. Dagbok til intensive patienter [Diary for intensive care patients]. *Nye Fagoscopet* 4: 7–10.

Storli S. 1999. Den forunderlige reisen: Pasienterfaringer fra intensivavdelingen [The astonishing journey: Patients' experiences of ICU]. Masters thesis, The Faculty of Medicine, University of Tromsø.

Storli SL and R Lind. 2009. The meaning of follow-up in intensive care: Patients' perspective. *Scandinavian Journal of Caring Sciences* 23: 45–56.

Storli S, R Lind and IL Viotti. 2003. Using diaries in intensive care: A method for following up patients. *Connect: The World of Critical Care Nursing* 2: 103–8.

Storli SL, A Lindseth and K Asplund. 2007. ''Being somewhere else'' delusion or relevant experience? A phenomenological investigation into the meaning of lived experience from being in intensive care. *International Journal of Qualitative Studies on Health and Well-being* 2: 144–59.

Thorne S. 1994. Secondary analysis in qualitative research. Issues and implications. In *Critical issues in qualitative research methods*, ed. JM Morse, 263–79. Thousand Oaks, CA: Sage Publications.

White M. 2006. Working with people who are suffering the consequences of multiple trauma: A narrative perspective. In *Trauma. Narrative responses to traumatic experience*, ed. D Denborough, 25–85. Adelaide, South Australia: Dulwich Centre Publications.