

The extent and application of patient diaries in German intensive care units



Peter Nydahl, RN, Coach and instructor for Basic Stimulation in nursing care, Mentor in nursing, Neurological Department, Intensive Care and Stroke Unit, University Hospital Schleswig-Holstein, Campus Kiel, Germany

Dirk Knüick, RN; BSN, ICU Nurse, Intensive Care Unit, Hirslanden Clinic, Zurich, Switzerland

Ingrid Egerod RN; MSN, PhD, Associate Professor, The University Hospitals Centre for Nursing and Care Research, Copenhagen University Hospital, Rigshospitalet, Copenhagen, Denmark

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E-mail: peter@nydahl.de

ESPAÑOL

Extensión y aplicación de diarios de pacientes en unidades de cuidado intensivo Alemanas

Palabras clave

Barrera del lenguaje, diario del paciente, enfermería, memorias, unidad de cuidado intensivo

Resumen

- El uso de diarios de pacientes en cuidado intensivo se ha vuelto más común en el Reino Unido y los países Escandinavos. Estos diarios son herramientas simples y efectivas para dar a los pacientes y sus familias la oportunidad de recolectar experiencias durante los períodos de sedación y ventilación.
- El objetivo de este estudio fue examinar la extensión de la aplicación de los diarios en las unidades de cuidado intensivo de adultos en hospitales Alemanes. En 2008, todas las unidades de cuidado intensivo de dos estados federales de Alemania (n = 120) fueron contactados ya sea por teléfono y/o por correo. El reclutamiento fue apoyado por invitaciones publicadas en tres revistas de enfermería, cuatro discusiones por internet, una invitación postal a 23 universidades, y el uso de contactos personales por los investigadores; todo en Alemania.
- Utilizando el método anterior, no se identificaron unidades de cuidado intensivo de adultos que usaran diario de pacientes.
- Las razones posibles incluyen limitaciones en la educación del plantel de enfermería Alemán, la barrera del idioma y la falta de involucramiento en el cuidado de enfermería con un abordaje científico. Sin embargo, los diarios de cuidado intensivo podrían adecuarse a la estructura del cuidado de enfermería en Alemania, parece posible y efectivamente deseable introducir los diarios en las unidades Alemanas. Por lo tanto proponemos posteriores publicaciones del concepto y la creación de una red de usuarios.

SUMMARY

- The use of patient diaries in intensive care has become increasingly common in the UK and Scandinavian countries. These diaries are simple and effective tools to give patients and their relatives an opportunity to recollect their experiences during periods of sedation and ventilation.
- The aim of this study was to examine the extent of the application of intensive care unit diaries in German hospitals for adult patients. In 2008, all intensive care units in two federal states of Germany (n = 120) were contacted either by phone and/or mail. The recruitment was supported by invitations published in three nursing journals, four internet discussion boards, a postal invitation to 23 universities, and the use of personal contacts by the investigators; all in Germany.
- Using the above methods, it was found that no adult intensive care units were using patient diaries.
- Possible reasons include limitations in the education of German nursing staff, language barrier and lack of involvement with scientific approach to nursing care. However, intensive care unit diaries may well fit into the structure of nursing care in Germany and it appears possible and indeed desirable to introduce the diary to German intensive care units. We therefore propose further publication of the concept and to create a user network.

INTRODUCTION

Patients who have been sedated and mechanically ventilated often need to reflect retrospectively on their experience of critical illness (Griffiths & Jones, 2007). In recent years it has become increasingly clear that many patients suffer from nightmares and stress related to their time in the intensive care unit (ICU) (Jones et al., 2001). ICU survivors describe memories and dreams, which they are unable to comprehend, and which often lead to a reduction in their quality of life (Ulvik et al., 2008). Patients have also described symptoms of post-traumatic stress disorder (PTSD) similar to those experienced by casualties of war, natural disasters and serious accidents (Kvale et al., 2003). Symptoms of PTSD include otherwise unexplained and recurrent panic attacks, depression, fear, sadness, pain, or mental/physical flashbacks in which unreal memories are re-experienced (Pattison, 2005; Schelling, 2008). It has been demonstrated that as many as half of the relatives of surviving intensive care patients also

express symptoms of PTSD (Jones et al., 2004).

In the UK, Scandinavia, and other European countries, patient diaries are being explored as a low cost technology to improve the quality of life after critical illness and mechanical ventilation (Combe, 2005; Egerod et al., 2007). Entries into the intensive care diary are made by nurses and relatives during the patient's stay. The diary is written in everyday language and contains daily entries on the current patient status and new developments. It is written directly to the patient, using an empathetic and reflective style and therapeutic communication (Roulin et al., 2007).

BACKGROUND

The practice of writing a diary for intensive care patients was first noted in Denmark in the 1980s and was soon followed up in Sweden and Norway (Bergbom et al., 1999; Egerod et al., 2007). In the 1990s, intensive care patient diaries were reported in the UK (Combe, 2005; Robson, 2008), and have since emerged in Switzerland, Italy and Portugal (Jones et al., 2006; Roulin et al., 2007).

Qualitative studies show that patients and relatives generally welcome the diary (Storli et al., 2003; Combe, 2005). The diary enables patients to evaluate their recovery and improves communication with their families about their experiences, thus sustaining family centred care (Roulin et al., 2007; Bergbom, 2008). By reading the diary, patients are able to understand their perceptions of their dreams and to connect these to diary entries and photographs during their period of critical illness (Backman & Walther, 2001; Robson, 2008). Patients may even be able to distinguish between reality and imagination, and determine whether some memories are misinterpretations of what actually happened. This may lead to a better understanding of their fears and the changes they have gone through. Diaries enable patients to make sense of their intensive care experiences, which they previously failed to understand (Storli et al., 2003; Storli & Lind, 2008).

A survey using telephone interviews was conducted in Denmark in 2006 on the prevalence and application of diaries (Egerod et al., 2007). A network of intensive care nurses at each of the 48 ICUs in Denmark was used to identify the 19 units (40%) that used patient diaries (Egerod, 2006). The study showed that patient diaries had evolved as a "grass-roots movement" without a standardised method of application. As a result, variations were seen among the units on cardinal issues such as authorship, ownership, and the practice of photographing critically ill patients. Danish patient protection laws were not always followed (Egerod, 2008).

It was decided by the Nordic Association for Intensive Care Nursing Research (NOFI) (Bergbom et al., 2005) to replicate the Danish survey by Egerod et al. (2007) in Sweden and Norway. In 2008 the effort was expanded to Germany. In order to sustain international collaboration, a workshop on 'Patient Diaries in ICU' was conducted in Copenhagen, which included the following presentations:

- The patient perspective of using ICU patient notebooks, by David Rier from Israel
- Analysis of patient diaries, by Marie-José Roulin from Switzerland
- Preliminary findings on a Norwegian survey of patient diaries, by Sissel Storli
- Preliminary findings on a Swedish survey of patient diaries, by Eva Åkerman
- Preliminary findings on a German survey of patient diaries, by Peter Nydahl and Dirk Knüick

It was demonstrated that diaries were used in 32 out of 70 (46%) ICUs in Norway, and at 65 out of 85 (76%) ICUs in Sweden.

This article presents the German replication study, where it was hypothesised that patient diaries had been implemented in German ICUs. The aim of the study was to examine the extent and application of intensive care patient diaries in Germany in 2008.

METHODOLOGY

The study had a qualitative exploratory multi-centre design, and the method of research was key informant telephone interviews. As the volume of ICUs in Germany is much greater than that of the Scandinavian countries, it was decided to limit this study to two federal states of Germany. The original Danish interview guide was translated into German. For pragmatic reasons, the interview guide was first translated into English, and then into German. The study was limited to diaries written for sedated and ventilated adult intensive care patients. Other types of diaries, such as biographies, memoirs, or diaries written for children in the intensive care unit were not included.

Sample and method

Approximately 1100 ICUs for adult patients existed in Germany in 2006 (German Bureau of Statistics). As the high volume of units exceeded the resources of the researchers, the design was modified to represent two of the 16 federal states of Germany; Schleswig-Holstein in the north and Baden-Wuerttemberg in the south.

The recruitment strategy was to implement a broad search including hospitals, professional journals, websites, universities, and educators. The search for participants included head nurses at 120 intensive care units, who were approached by e-mail or telephone to help identify potential informants. A call for participation was published in three German-language nursing journals with wide circulation. The same call was placed at four internet discussion boards known by nurses:

- <http://www.basale-stimulation.de>
- <http://www.zwai.net>
- <http://www.krankenschwester.de>
- <http://www.pflegedialog.de>

A call was also sent to 23 universities with nursing attendance, and finally a call for participation was mailed to 19 nurses involved in teaching anesthesia or intensive care.

The plan for data collection was to select a convenience sample of volunteers, who wished to participate in 30-minute telephone interviews. E-mail information on the study would then be sent to informants and an appointment set up for the interview. Note-taking was to occur during the interview and these would then be mailed to the informants for member checking and additional information (Stake, 1995). The interview guide for the study was that developed by Egerod et al. (2007). The questions were as follows:

- How long have patient diaries been used at your unit?
- What is the purpose of patient diaries at your unit (for example, care, therapy, research)?
- What was your source of inspiration for introducing patient diaries?
- Are patient diaries used systematically (for example, for all patients, particular patients)?
- Are patient diaries structured (for example, format of the diary, pre-printed introduction, pictures)?
- Who authors patient diaries (for example, staff, family, patient)?
- Who is responsible for the application of patient diaries (for example, qualifications, ethics, photos)?



- Is there a theoretical framework for patient diaries (for example, literature)?
- Are patient diaries used in conjunction with follow-up visits?
- How have patient diaries been received?
- Do you have suggestions for improvement of patient diaries?
- Have you experienced negative effects of patient diaries?

Data analysis

The strategy of analysis was thematic, using the terms in the interview guide. The process of analysis consisted of (1) familiarisation with the data by reading all transcripts, (2) thematic condensation, and (3) synthesis.

Preconceptions of the researchers

Previous personal and professional experience and beliefs, motivation and qualifications for exploration of the field, and perspectives and theoretical foundations were accounted for in order to increase reflexivity and gain trustworthiness (Malterud, 2001). The primary investigators, the first two authors of this article, are nurses with more than fifteen years of experience in intensive care. They are familiar with the language and culture of intensive nursing, the team and organisational structure of intensive care units. The lead researchers expressed a strong positive interest in patient diaries, which could potentially present a bias to the study. The awareness of these convictions and collaboration with a nurse researcher without local involvement would hopefully sustain objectivity.

Ethical Considerations

No personal data were collected based on the study. Participation in the investigation was voluntary and there were no disadvantages for non-participation or withdrawal of participation statement. Data were handled confidentially and the informants and anonymity was ensured. The study was approved by the ethics committee of the University of Schleswig-Holstein.

FINDINGS

To our surprise, the survey showed that none of the participating ICUs used patient diaries nor made provision for their introduction. This meant that no informants volunteered to participate in the study. The responses from our survey, however, were diverse and it appeared that many ICU nurses, teachers, and ward managers showed interest in a potential use of the ICU diary.

Intensive care units in Schleswig-Holstein and Baden-Wuerttemberg

Patient diaries in ICU were not used, but due to the e-mail and telephone contact, several nurses showed interest in introducing diaries. Some responses were:

- What? Patient diaries? (laughing) No, we don't use them ...
- Patient diaries ... that sounds interesting! No, we do not have them, but can you tell me more about it?
- Although no informants could be identified that had experience with patient diaries, several nurses wished to introduce diaries on the basis of nursing journal descriptions. The responses included:
- I have read your article about the 'respiratory diary'. We are respiratory therapists who work at various units; we are interested in different types of respiratory diaries.
- At our hospital we do not use diaries. But the topic seems to be very interesting, have you got a hint, where we get more information?

No informants came forth, who had experience with patient diaries, but the calls in the discussion boards were frequently used. In board no. 2 (www.zwai.net) the diary was discussed. In discussing its definition, a participant pointed out some links to online diaries in the board. The discussions brought about some relevant concerns:

- The concept of patient diaries includes the question of how to deal with the diary. How does the patient respond? What if the patient loses control? I would like to hear what trauma-therapists have to say about diaries.

No 'expert' informants were identified, but the primary investigators received invitations to participate in three different conferences in Germany to introduce patient diaries. One of the e-mail contacts was a member of the German Society for specialist nurses, who offered to disseminate the information to senior members. These members teach ICU nurses in central institutions during their training in a rotation system at various ICUs in the region. This way other members may discover what is happening in the surrounding hospitals or intensive care units. Some remarks were:

- I think the concept needs to be published. It is an innovation that may help patients to cope.
- Thank you for informing us of this study. Unfortunately, diaries are not used at our ICUs, but I have forwarded your mail to others.
- We are planning a symposium in Hamburg. Actually, I am putting together the program, and have heard from a colleague that you are involved in ICU diaries. It sounds interesting and would fit into our program.

DISCUSSION

Our hypothesis was not supported by the study; patient diaries have not spread to the two sample federal states in Germany. The internal validity of the study was increased by the many ways of contacting potential informants. The study design is assumed to be valid because similar studies in Germany have demonstrated positive results in surveys and interviews (Dobke et al., 2001; Görres et al., 2002; Schneider et al., 2006; Köberich, 2007). As conditions in hospitals and the educational system in Germany are similar across the federal states, it may be assumed that the results may be transferrable to the rest of the country at this time.

The mode of recruitment of potential informants may have affected participation, because nurses were confused about the concept of patient diaries. The call for the study was published in three nursing journals. From the time the call was published, requests for further information about the topic were frequent, which demonstrates that the calls were read. But the presentation of the concept may have been misleading. An attempt was made to find a term in German that would be intuitively understandable for the nurses. The chosen term was *Beatmungstagebuch* (respirator diary), because it is a diary for mechanically ventilated patients. But this could also be construed as a kind of protocol for mechanical ventilation, which was not intended. Mechanical ventilation falls within the scope of intensive care nursing. When ICU nurses hear the term "respirator" they categorise it among their responsibilities. But the term does not speak to nurses' caring practices. The study has demonstrated how important it is to get terms right and to explain the content sufficiently.

Although the study failed to produce positive results, it is emphasised that negative results are also results. A Danish survey of the extent and application of 'Basic Stimulation' has shown that a German nursing technology has spread via word of mouth through Denmark and Norway, despite the fact that literature on the subject is predominantly in German (Egerod et al., 2008). By the same token, patient diaries could have migrated south from Denmark to Germany.

Despite the close proximity of Denmark and Germany, only a few nurses transfer from one country to the other, due to the language barrier. The nursing journal *Die Schwester Der Pfleger*, a well known German nursing journal, exports about 400 journals per month to Switzerland, 35 to the Scandinavian countries, and a mere 7 journals to Denmark (information by personal mail of the publisher). Hence, the information flow stops with the language barrier (and geographically at Flensburg).

The language barrier presents a challenge for German nurses, who are unable to read English nursing articles. Most papers on patient diaries are published in English, which may explain why the technology has reached other European countries that rely on this language for research publications. Another factor that may be detrimental to the introduction of patient diaries is the educational system. Germany is among the last countries in the European Union to provide a bachelor degree in nursing. This means that nurses may lack the knowledge and leadership to introduce new methods. Finally, the idea of a systematic follow-up or Intensive Care Aftercare, which is well known in the UK and Scandinavia is non-existent in Germany (Griffiths & Jones, 2002; Storli & Lind, 2008). Nevertheless, there is a rotation system for nurses from Germany and Scandinavia while they are in intensive care training (exchange of different intensive care units during the training).

A number of qualitative studies have demonstrated the importance of patient diaries (Combe, 2005; Jones et al., 2006; Roulin et al., 2007; Storli et al., 2008). Quantitative studies into the effect of patient diaries across Europe are on their way. If more qualitative and quantitative evidence is produced, showing how patient diaries may help intensive care survivors and their family, it should pave the way for the introduction of the technology into German intensive care units. Patient diaries are a method to empower the patients and promote family centered care.

IMPLICATIONS

We are working on the systematic introduction of diaries in German intensive care units - on a voluntary basis. Our approach is to implement intensive care diaries and systematically coordinate and evaluate the approach. We are developing guidelines and a method for implementation in German intensive care units. Two papers have been published in German already (Knück & Nydahl, 2008; Bagger et al., 2009) and a German website has been set up that provides information to health care workers (<http://www.intensivtagebuch.de>).

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