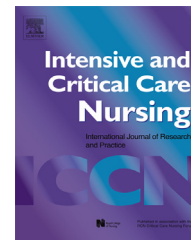




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ORIGINAL ARTICLE

# Family members' experiences of keeping a diary during a sick relative's stay in the intensive care unit: A hermeneutic interview study



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## KEYWORDS

Diaries;  
Experiences;  
Gadamer;  
Hermeneutics;  
ICU;  
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## Summary

**Objective:** The aim of the study was to explore family members' experiences with keeping a diary during a sick relative's stay in the ICU.

**Design:** A qualitative method with a hermeneutic approach was used. Eleven participants, who recorded nine diaries in total, were interviewed. The collected data were analysed using a hermeneutic approach inspired by Gadamer.

**Results:** The analysis revealed a meta-theme: 'it [writing in the diary] felt like contact' which was created by a feeling of togetherness and the opportunity to communicate with the patient. Keeping a diary likely meets the needs of family members in several ways because it becomes a way to be present at the patient's bedside, to provide caregiving, to maintain hope and to relay cogent information. However, concerns regarding negative aspects of diary keeping were also raised; for example, the diary created feelings of stress, guilt and failure and exposed intimate details.

**Conclusion:** The diary symbolised the maintenance of relationships with the patients and was a substitute for the usual opportunities for communication. Furthermore, it was instrumental

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in meeting the needs of the majority of family members in several ways. Nevertheless, the diary did have negative effects for certain individuals, which highlights the importance of an individualised approach.

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### Implications for Clinical Practice

- Diaries may act as a useful source of information for both patients and family members thereby facilitating communication between them when the patient recovers consciousness.
- Involving family members in diary writing may be therapeutic.
- However, diary writing may have negative effects for some family members, highlighting the need for a more individualised approach to the use of a diary with family members of patients in the ICU.
- There is a need for practice guidelines about how best to promote appropriate use of diaries in everyday practice in the ICU setting, including families' role and involvement in diary writing. Such guidelines would emphasise the importance of adopting an individual approach and explore with key family members who and how many should be involved in keeping a diary. Should the diary include photographs? How should the integrity of the patient be upheld?

### Introduction

Admission to the intensive care unit (ICU) is a source of physical and mental stress for patients and their family members, and this experience might have long-lasting psychological consequences. The literature emphasises that high levels of posttraumatic stress disorder (PTSD) symptoms amongst recovering ICU patients are associated with similar symptoms amongst their family members (Jones and Griffiths, 2007; Jones et al., 2004). A diary offers a way to explain and clarify stressful thoughts and events in the ICU; moreover, it "fills the memory gap" by constructing a narrative of patients' stays in the ICU, which can help them make sense of their situations (Griffiths and Jones, 2001). An ICU diary is a notebook in which nurses and family members write using everyday language. The diary begins with a summary that includes the reason for admission. The summary is followed by other entries that describe the course of events and are supported by photographs (Backman and Walther, 2001).

Keeping diaries for ICU patients is a common practice in Scandinavia, Switzerland and the United Kingdom (Egerod et al., 2011). In Sweden, 75% ( $n=65$ ) of all ICUs ( $n=85$ ) use diaries (Akerman et al., 2010). Diaries are now often part of nurse-led intensive care after-care programmes, with follow-up visits to identify the needs of patients and counsel them with regard to how their needs should be met (Storli et al., 2003; Samuelson and Corrigan, 2009). Engstrom et al. (2009) and Ewens et al. (2014) noted that patients experience the diary as a long-term support by (for example) helping them set realistic goals. ICU diaries have been described as a low-cost intervention to reduce the post-discharge symptoms of PTSD, anxiety and depression amongst patients (Jones et al., 2010) and relatives (Garrouste-Orgeas et al., 2012). An increasing body of knowledge about ICU diaries exists within nursing but only a few findings within the empirical literature concern the effect that these diaries on family members.

An early exploration of the benefit of diaries by Bergbom et al. (1999) comprised 10 patients and four relatives of

eight non-survivors. They answered a questionnaire consisting of five close-ended and two open-ended questions. The main interest was to investigate if keeping a diary for the patient was of value for patients and their family members. All the family members except one stated that the diary helped them to return and adjust to everyday life and the diary also made it easier to accept what had happened. In addition, the diary was considered as a source of information about the entire care episode and offered consolation.

In line with Bergbom et al., Backman and Walther (2001) explored if the diary was of importance to patients and their family members, as an aide to debriefing patients and family members following a critical illness. The study revealed that all diaries had been read by survivors ( $n=41$ ) or family members ( $n=10$  to non-survivors). 67% of participants were either very positive or positive about the diary and no negative responses were reported. Moreover, the researchers found that the diary helped the family members to cope with their bereavement.

Ewens et al.'s questionnaire study (2014) ( $n=18$ ) included three multiple choice items (out of a total of nine items) that focused on participant families' views of the diaries, the frequency with which patients and their family members had read their diaries and what thoughts and feelings this practice generated. Participants were surveyed at three, six and 12 months following discharge from hospital. They found that all family members welcomed the idea of writing a diary and they saw the diary as a means to express their feelings and it provided a quick reference of information. In addition, family members felt appreciative of and supported by the nurses' entries, and these entries provided a focal point to open up discussion with other family members. However, some family members stated that they had never read the diary.

Gaps in the literature, *prima facie*, seem to be that (a) the studies are predominantly quantitative and there appear to be no qualitative investigations specifically involving family members; (b) most of the findings are related to

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