



## Preferred content and usefulness of a photodiary as described by ICU-patients—A mixed method analysis

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### ABSTRACT

Many ICU-patients have memory-gaps which may affect their recovery. A tool in the recovery can be an ICU-diary to explain and clarify thoughts and events from the ICU-period. There are different standards for the content in the ICU-diary. The aim of this study was to identify the preferred content and usefulness of an ICU-diary as described by ICU-patients.

**Method:** A descriptive, exploratory cohort design with a mixed method approach. The patients answered a questionnaire ( $n = 115$ ) and participated in an interview ( $n = 15$ ) six months after the ICU-stay. Data analysis was carried out in three stages; the questionnaire was analysed by descriptive statistics and categorised by content (four open-ended questions) and the interviews were analysed by manifest content analysis.

**Results:** The patients were explained that detailed information about daily activities and medical facts had to be included to understand and give a sense of coherence of what had happened. The content in the ICU-diary had to be chronological in order to follow the process in which photos were an important part. The patients re-read the ICU-diary during the recovery which helped them to fill in the memory gaps and used it as a tool for communication.

**Conclusion:** To construct a coherent story, it was essential that the ICU-diary was complete and were amplified by photos, all appearing in a chronological order. The results of this study could form a basis for further developments of standards and guidelines for ICU-diaries.

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### Introduction

Recent achievements in intensive care have advanced our care for critically ill patients and resulted in more focused and continuously driven treatment.<sup>1</sup> Part of this evolution in care has seen changes in sedation and analgesia management, with patients generally more awake and available for early mobilisation.<sup>2,3</sup> Increased patient awareness and co-operation necessitate changes and increased vigilance in care to stimulate recovery and prevent

physical and psychosocial problems after intensive care. Although the patients are less sedated, most of them have few or no realistic memories from the time in the ICU. On the other hand, they have memories from delusions, hallucinations or nightmares<sup>4–6</sup> which have been associated with an increased risk of developing post traumatic stress disorder (PTSD).<sup>4,7</sup> Experiences of few factual memories increases feelings of vulnerability<sup>8</sup> and loss of factual memories can cause psychological problems.<sup>4,9</sup> Loss of memory is emphasised by a common request to have detailed information about the time in the ICU.<sup>10,11</sup> The fact that the patients have a lack of memory necessitates the need for help in creating a coherent story which is important to avoid psychological recurrences.<sup>12</sup> A constructed story covering the event can help the patients to infuse meaning into it and cope with emotions after traumatic experiences, thus favouring a faster recovery.<sup>13</sup>

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A tool in the psychological recovery could be an ICU-diary written by the staff which has been shown to reduce the level of PTSD.<sup>6</sup> Knowles and Tarrier found that the level of anxiety and depression decreased with the use of an ICU-diary.<sup>14</sup> An ICU-diary explains and clarifies thoughts and events, thus providing understanding of duration to recovery. Although the ICU-diary is not personally written, it helps the patients to fill in the memory-gaps, to clarify chronological coherence and to create meaningfulness.<sup>15,16</sup> The usefulness of ICU-diaries to ICU-patients has previously been described as positive, valuable and helpful. This has been expressed by patients in questionnaires, content analysis of diaries and informal conversations.<sup>9,15,17–19</sup> To our knowledge, the use of a mixed method approach has not previously been applied to this area of research. An ICU-diary can help the patient to discriminate between real experiences and unreal experiences as well as becoming a tool in the communication.<sup>9</sup> To date, the dominating procedure is that the ICU-diary content is selected by the staff. To increase the usefulness, the story has to include different dimensions of coherence to be a narrative construction.<sup>12</sup> However, despite the general impression of “usefulness” expressed by previous studies, the substance or nature of the content included in the ICU-diary preferred by the patient has previously not been extensively explored. A structural incongruence between different ICUs in the keeping of ICU-diaries is obvious.<sup>20</sup> The need to more precisely assess the role of a narrative construction of an ICU-diary has been emphasised by Williams.<sup>12</sup> Guidelines on what content an ICU-diary should have exist to some extent, mostly describing general structure<sup>6</sup> or

relating mainly to what should not be included.<sup>21</sup> The written information in the ICU-diary usually separates medical facts from facts about everyday life.<sup>20,22</sup> How the ICU-diary is actually used by the patient as a tool for physical and psychosocial recovery referring to the ICU-diary content has not been particularly expressed.

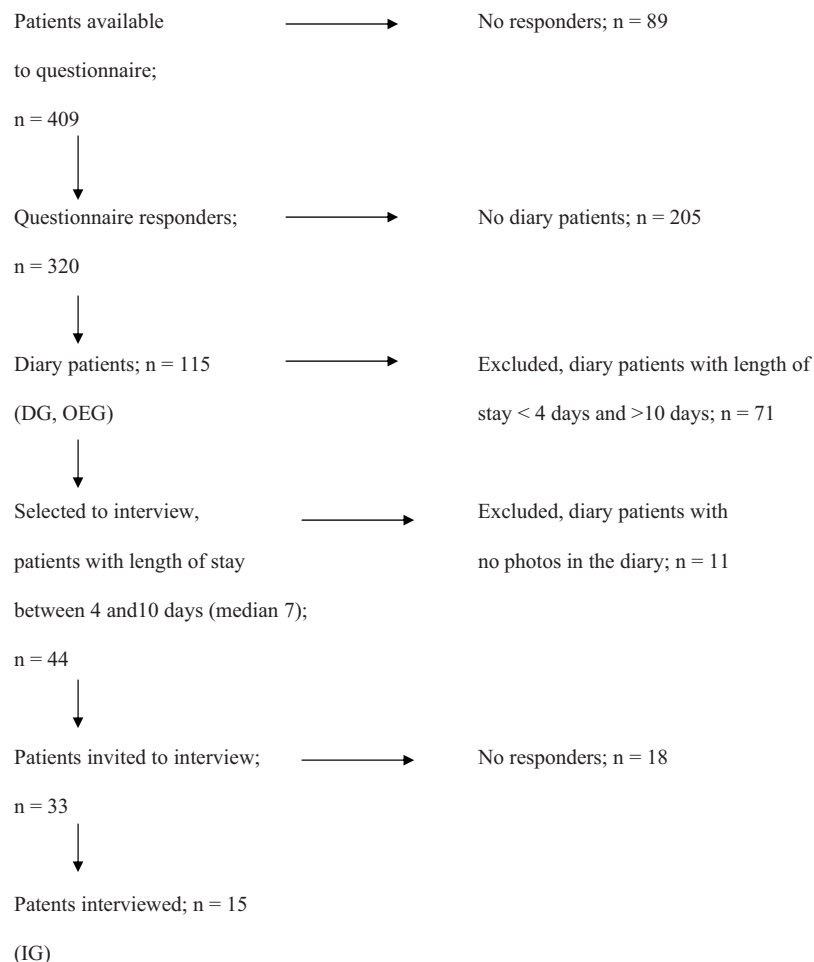
Although, it is believed that daily photos are helpful for appreciation of the ICU-stay, this is not always being practiced.<sup>20</sup> Some ICUs take photos when the patient is critically ill and display wounded bodyparts, etc. while others only include the last days in the ICU when the patient is in the beginning of recovery.<sup>20</sup> The effects of ICU-diaries have been discussed, but to our knowledge little is known about what the patients prefer to read or see in the ICU-diary. Accordingly, the research question was “What content is needed and how should it be presented to enable the patient to construct a useful narrative story helping their recovery?”

The corresponding aim of this concurrent mixed method study was thus to identify the preferred content and usefulness of an ICU-diary as described by ICU-patients.

## Methods

### Design and settings

The study had a descriptive and exploratory cohort design with a mixed method approach.<sup>23</sup> Corroboration between quantitative and qualitative data will promote a higher validity and by using qualitative research to confirm quantitative findings the data



**Fig. 1.** Study flowchart of the data collection procedure among ICU patients. DG=diary group; IG=interview group; OEG=open-ended question group (responders at open-ended questions).

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