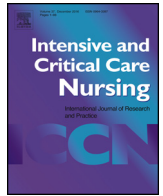




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# Thematic Analysis: How do patient diaries affect survivors' psychological recovery?

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### ABSTRACT

**Aim:** This review aims to use thematic analysis to explore and synthesise evidence of the actual or potential reported effects of diaries on the psychological rehabilitation and recovery of discharged critical care patients.

**Background:** Evidence suggests that whilst admission to critical care may save patient lives, the psychological aftermath can damage a patient's recovery and these needs must be met. Patient diaries are one potential intervention to aid patients understand their critical illness and fill memory gaps caused by sedation, thus reducing psychological distress post-discharge. Prospective patient diaries are increasing in popularity amongst critical care units in the United Kingdom, however there is little evidence base to support their use or understand their effects.

**Method:** A literature review using systematic methods was undertaken of studies relating to the effects of diaries on discharged patients. Thematic analysis enabled the generation and synthesis of themes.

**Results:** Three themes arose from the generated codes: 1) Reclaiming ownership of lost time. 2) Emphasising personhood. 3) Fear and frustration. The diary intervention was shown to have a largely positive impact on survivors' psychological rehabilitation. However, caution should be exercised as recipients could find the contents painful and emotional. Diaries should be embedded within a robust critical care follow-up plan.

**Conclusion:** This review suggests that diaries have the potential to form one aspect of rehabilitation and make a positive impact on patients' recovery. More research is indicated to fully evaluate the effects of diaries on their recipients.

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### Implications for clinical practice

- Diaries can be effective in filling in memory gaps and completing a person's illness narrative.
- Patients experience incomplete diaries as frustrating. They have a special interest in the events surrounding their admission. Nurses should ensure this section is completed as soon as clinically possible.
- Diaries can be read with others and assist in opening up the critical care experience.
- Diaries can be painful and distressing to read, reawakening forgotten trauma. As such, they should form one aspect of a rehabilitative program.
- Some patients may not want to receive a diary or discuss their admission.

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## Background

Many critical care survivors experience disruptive and troubling memories or periods of amnesia which persist for months post-discharge (Svenningsen et al., 2016). False persecutory memories often describe attacks by staff and involvement in bizarre games (Svenningsen et al., 2016). Survivors' psychological needs were highlighted by the National Institute for Clinical Excellence (NICE) in 2009. These can cause distress, preventing a realistic understanding of the admission (Guttormson, 2014).

Diaries were first described in Denmark in the 1980s (Engstrom et al., 2009). Brief notes were made by nurses and relatives about daily events to enable patients to read about the time they spent in critical care, return memories lost through illness and sedation-induced amnesia and promote understanding of the severity of their illness (Egerod et al., 2011; Williams, 2009). More recently, diaries have spread to critical care units in the United Kingdom and their effects have begun to be explored and researched. No national guidelines exist for what nurses should include in diary entries, although some local Trusts have published their guidance online, for example on websites such as ICU-diary.org. Diaries are commonly given out at follow-up clinics or support groups (Guttormson, 2014). Usage is currently patchy and their impact, positive or negative, on survivors' psychological recovery post-discharge requires further research (Ullman et al., 2015).

## Aim

This review aims to use thematic analysis to explore and synthesise evidence of the actual or potential reported effects of diaries on the psychological rehabilitation and recovery of discharged critical care patients. It also aims to explore recipients' preferences regarding diary content.

## Design and methods

### Type of review

A literature review using systematic methods was conducted to identify relevant studies. Deductive thematic analysis was used to identify and synthesise themes (Braun and Clarke, 2006).

### Search strategy

MEDLINE, Embase, CINAHL, and the Cochrane Library were searched (2006–2016) using the key words: Critical care, ICU, intensive care, patient diary, follow-up, psychological, emotional, rehabilitation, post-traumatic stress disorder and memory loss. Reference lists were hand-searched for further relevant studies.

### Inclusion/Exclusion criteria

Primary research studies focussed on adult critical care survivors were included. Studies of non-adult populations, experience of relatives or non-survivors were excluded. Photo-diaries were excluded due to ethical concerns about the use of non-consensual photography. The search began in 2006 to reflect the move towards lighter sedation and daily sedation holds. This has been shown to reduce memory loss (Pattison, 2005).

The search initially yielded 113 citations (Fig. 1), however most were found to be descriptive. The literature was predominately qualitative.

## Appraisal/Data analysis

The quality of the studies selected for inclusion was appraised using the Scottish Intercollegiate Guidelines Network (SIGN) grading system (Baker et al., 2010). This grading system suggests levels of evidence required to enable the researcher to make clinical recommendations. The selected papers were all rated as high quality.

Data abstraction was via the deductive generation of codes relating to the effect of diaries on psychological recovery. Papers were read and re-read iteratively to ensure all codes were included. Tensions and inconsistencies from the initial codes were embraced to provide a rich variety of codes from which to draw themes (Braun and Clarke, 2006). The codes were grouped into common themes, then re-read to ensure they had not become decontextualised.

## Results

Ten primary studies were selected to be included in the thematic analysis, four quantitative and five qualitative (Table 1). The studies originated from England, France, Scandinavia and the United States. Interviews (n=4) and focus groups (n=1) were used to explore patient experience of reading the diary. The diary itself was explored through content analysis (n=2). Sample sizes were typically small in the qualitative studies, ranging from four to thirty-six participants. The four quantitative studies offered larger sample sizes. Patients were interviewed at differing points, from one month up to three years post-discharge. Three over-arching themes emerged from analysis:

- Reclaiming ownership of lost time
- Emphasising personhood
- Fear and frustration

### a Reclaiming ownership of lost time

Four sub-themes evidenced how the diary could enable patients to regain control of their admission memories.

#### i) Evidence, understanding and memory gaps

Discovering the severity of their illness can be complicated for patients, and is often difficult to fully comprehend, leading to feelings of frustration (Storli and Lind, 2009; O'gara and Pattison, 2016). The diary assisted survivors in the setting of realistic rehabilitation goals through allowing recipients to read about their illness and understand why physical recovery was slow (Storli and Lind, 2009). In contrast, participants interviewed by Williams (2009) found that reading the diary emphasised their ultimate survival over illness. In this way, the diary can help survivors 'move on' (O'gara and Pattison, 2016).

Memory loss is common following critical illness, and light sedation can induce fragmentary memories, dreams and misunderstandings (Engstrom et al., 2009). Patients expressed a 'need to know' about the forgotten details of their admission (Williams, 2009). The diary can become a source of information and method of validation of memories (Egerod and Bagger, 2010; O'gara and Pattison, 2016). One participant in Williams' (2009) study claimed that her lack of memory of her critical care admission left her feeling like a stranger in her own body. She was aware of her illness, but her limited recall prevented full processing the trauma, delaying her recovery. The diary aims to assist patients in completing their story and memories (Egerod and Bagger, 2010).

#### ii) Delusions and post-traumatic stress disorder (PTSD)

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