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

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Implications for 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.

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 & Clarke, 2006).

Search Strategy

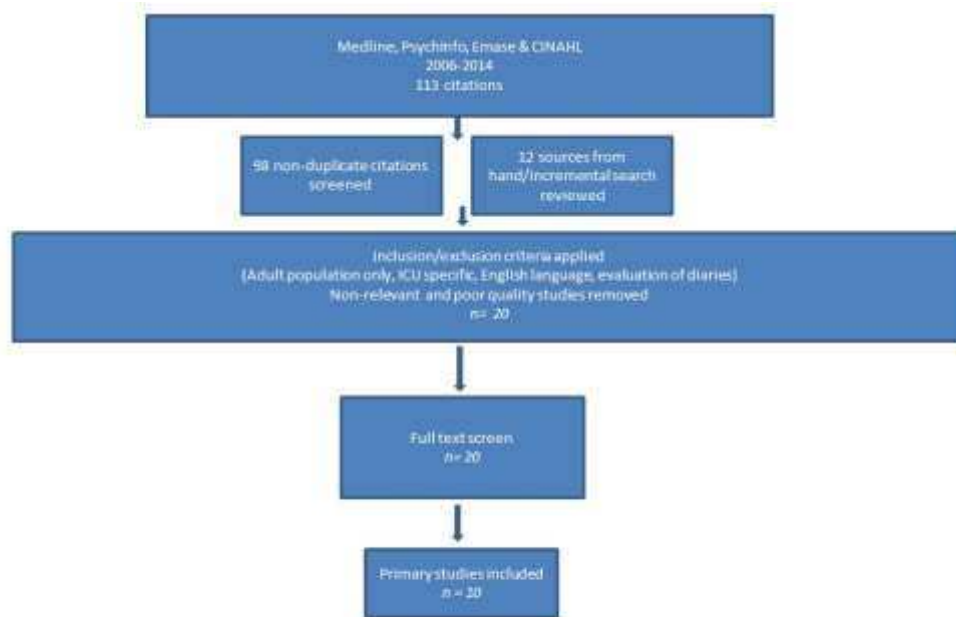
MEDLINE, Embase, CINAHL, and the Cochrane Library were searched (2006-2016) using the key words: Critical care, ICU, intensive care, patient diary, follow-up, psychological, emotional, rehabilitation, post-traumatic stress disorder and memory loss. Reference lists were hand-searched for further relevant 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 (Figure 1), however most were found to be descriptive. The literature was predominately qualitative.

Figure 1: PRISMA diagram



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 & Clarke, 2006). The codes were grouped into common themes, and then re-read to ensure they had not become decontextualized.

Results

Ten primary studies were selected to be included in the thematic analysis, four quantitative and five qualitative (table two). 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**

Author	Title	Design	Sample Size	Summary
Backman et al (2010)	Long-term effects of the ICU diary on quality of life after critical illness	Non-randomized prospective study	38 patients	The diary is associated with improved health-related quality of life.
Egerod & Bagger (2010)	Patients' experiences of intensive care diaries – A focus group study	Focus group	4 patients	The participants were frustrated by the incompleteness of their diaries. The diary could enable the construction of an illness narrative in conjunction with hospital charts. The diary did not stimulate recall, but helped patients fill in memory blanks.
Engstrom et al (2009)	Experiences of intensive care unit diaries – Touching a tender wound	Interviews Content analysis	9 patients	Reading the diary was a strongly emotive experience, with a degree of re-experiencing. The diary adds coherence, but reading it can be painful. Appreciation of entries made by relatives.
O'Gara & Pattison (2016)	A qualitative exploration into the long-term perspectives of patients receiving critical care diaries across the United Kingdom	Interviews	8 participants	All respondents valued their diary. Feelings of loss of control and vulnerability can persist years post-discharge. Survivors had unrealistic post-discharge goals. The diary assisted with validating the critical care experience and could help them 'move on'. It was difficult to read the diary for the first time.
Garrouste-Orgeas et al (2013)	Impact of an intensive care diary on psychological distress in patients and relatives	Prospective study. Intervention period between two control periods.	143 patients (48 pre-diary, 49 diary and 46 post-diary)	Minimal effect observed at 3 months post-discharge. The provision of the diary had a significant positive effect on post-traumatic stress-related symptoms in patients at 12 months post-discharge.
Jones et al (2010)	Intensive care diaries reduce new-onset post-traumatic stress disorder following critical illness: a randomized, controlled trial	RCT	352 patients	The incidence of new-onset PTSD was reduced in the diary group at 3 months post-discharge.
Knowles & Tarrier (2009)	Evaluation of the effect of prospective patient diaries on emotional well-being in intensive care unit survivors: A randomized controlled trial	RCT	36 patients	The diary intervention had a positive impact on anxiety and depression two months post-discharge from critical care.
Roulin et al (2007)	Diaries written for ICU patients	Content analysis	8 diaries	Four themes were found in the diaries: 1) Sharing the story, 2) Sharing the presence, 3) Sharing feelings, and 4) Sharing through support.
Storli & Lind (2009)	The meaning of follow-up in intensive care: Patients' perspective	Interviews	10 patients (4 lost to second follow up)	Patients seek to discover the events of their illness. The diary acts as a signposting tool to guide discussion. Diary was seen as a 'gift', emphasis on individualistic, patient-centered care. Confirmation of the presence of relatives.
Williams (2009)	Recovering from the psychological impact of intensive care: How constructing a story helps	Unstructured interviews	5 patients	Psychological recovery can be aided by the construction of a coherent illness narrative.

Table 2 Search Results

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 & Lind, 2009; O’Gara & 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 & 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 & 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 & Bagger, 2010; O’Gara & 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 & Bagger, 2010).

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

PTSD is common amongst critical care survivors, affecting up to one in ten who have an admission greater than 48 hours (Jones et al, 2010). The condition is thought to be precipitated by vivid delusional memories and is exacerbated by the contrast between these and fragmented factual recollections (Jones et al, 2010). There seemed to be emerging evidence that the diary could assist survivors to make sense and reinterpret memories through reading about their behaviour (Williams, 2009). Additionally, the diary provides a written testament to the care and close attention the patient received (Storli & Lind, 2009), reducing feelings of vulnerability (O’Gara & Pattison, 2016). Survivors tend to have vivid memories of unpleasant aspects of their admission period (Roulin et al, 2007). Reading descriptions of care and encouragement may help survivors move beyond their nightmares.

The four quantitative studies provide evidence that the provision of a diary has a positive impact on reducing the incidence of PTSD and anxiety post-discharge (Jones et al,

2010; Knowles & Tarrier, 2009; Backman et al, 2010). Jones et al (2010) found that diaries given to patients one month post-discharge significantly ($p=0.02$) reduced the incidence of new-onset PTSD, by filling gaps in memories and placing recipients' delusional memories into context, robbing them of much of their frightening power (Jones et al, 2010). Similarly, Garroute-Orgeas et al (2012) found that the provision of a diary was associated with significantly reduced symptoms of PTSD at 12 months post-discharge. Backman et al (2010) found improved health-related quality of life amongst diary recipients. Knowles and Tarrier (2009) found anxiety and depression significantly reduced ($p<0.005$) in the diary intervention group, and attributed this to an increased understanding of their illness (Knowles & Tarrier, 2009).

iii) Narrative construction and regaining control

Storytelling enables us to make sense of the world around us (Williams, 2009). Critical illness interrupts the construction of narrative, leaving the survivor unable to respond to the trauma (Williams, 2009). The provision of a diary aims to assist survivors' in recreating their illness narrative through augmenting their memories and offering a chronology. This helps order survivors' memories and lend them coherence (Engstrom et al, 2009; O'Gara & Pattison, 2016). Through the construction and ownership of an illness narrative, the traumatic event is rendered manageable and integrated into the survivor's internal and external world (Williams, 2009). Garroute-Orgeas et al (2012) analysed the content of the diary, finding that only 2% of the diary was given to descriptions of places, whilst 26.3% focussed on building a chronology of events, aiming to re-establish the continuity of the patient's life.

iv) Sharing the experience

Critical care is a traumatic and stressful experience for the patient and their relatives. Entries written by relatives offered survivors an insight into their family's experience (O'Gara & Pattison, 2016). Jones et al (2010) found that 84% of their participants had allowed others to read their diary. This sharing of experience and empathy of a traumatic event was experienced as therapeutic (Williams, 2009). Knowles & Tarrier (2009) found that reading the diary with another person enabled the reappraisal of traumatic memories and was effective in improving emotional recovery.

b) Emphasising personhood

Three sub-themes focussed on how the diary affects survivors' emotions and emphasises their personhood.

i) The human touch, care and empathy

The act of writing a diary demonstrates nurses' ability to see the impact of critical illness on the person (Egerod & Bagger, 2010). Critical care can be a dehumanizing experience and it is difficult to meet, or even discover, personal preferences during the acute stages of admission. Post-discharge, patients describe feeling invisible to staff (Phillips, 2011). The diary helps staff re-focus on the patient as a person (Storli & Lind, 2009; Roulin et al, 2007) and regular entries suggest the constant presence of a nurse, which may not be remembered by the patient and can act as a comfort (Roulin et al, 2007).

ii) The contribution of relatives

Diary contributions from relatives were rated as highly significant by patients (Engstrom et al, 2009) and formed the bulk of the entries in the diaries studied by Garrouste-Orgeas et al (2012). Entries from relatives confirm to the patient that they were visited by friends and loved ones and held to be of great value (Engstrom et al, 2009). The entries made by relatives were full of love, care and encouragement (Storli & Lind, 2009; Roulin et al, 2007). The messages form a bond between the unconscious patient and their relatives which can be built upon post-discharge (Storli & Lind, 2009).

iii) Gratitude

Survivors describe their surprise and pleasure at receiving a diary (Storli & Lind, 2009). The diary is evidence that the patient received care beyond what they would ordinarily expect (Storli & Lind, 2009). Patients were grateful that nurses had taken time to complete diary entries (Storli & Lind, 2009). Backman et al (2010) cite gratitude as a possible reason for the high response rate in their study. The diary also provides an account of the life-saving treatment given to the survivor. Participants in the O'Gara and Pattison (2016) study describe their appreciation and desire to thank those who cared for them.

c) Fear and frustration

Two sub-themes emerged where the diary failed to impact positively on survivors, rather causing fear and frustration.

i) Fear

Participants described a range of emotions being awoken on reading the diary, from joy to sadness, and wonder at the severity of their illness (Engstrom et al, 2009). Reading the diary for the first time can be challenging and frightening, as it describes the reader's fight for survival (Storli & Lind, 2009), providing evidence of their mortality. Interviews conducted one year post-discharge evidence that psychological recovery from the trauma of admission to critical care is slow, and that experiences and emotions can easily be re-awoken (Engstrom et al, 2009). Participants report that reading the diary felt like being made to relive their experience (Engstrom et al, 2009; O'Gara & Pattison, 2016). Recipients also reported feelings of discomfort and embarrassment when reading about confused or delirious behaviour (Roulin et al, 2007). Reading the diary can also be physically difficult. A participant in the focus group held by Egerod and Bagger (2010) three months post-discharge was reluctant to read the diary as his inability to turn the pages left him feeling defeated, and reminded him of his helplessness during hospitalisation.

Participants in the interviews held by O'Gara and Pattison (2016) felt that the diary could hinder recovery by becoming a focus which the survivor repeatedly returned to. They describe a potential over-reliance on the diary, showing how it might inhibit recovery for some survivors.

ii) Insignificant and incomplete

The participants in Egerod and Bagger's (2010) focus group found the diary have little impact on their recovery. One saw his diary as frivolous, whilst another felt it was written as a coping mechanism for nurses (Egerod & Bagger, 2010). Writing entries in diaries may help nurses express empathy for their patients, however the intent is that the diary should be read by the survivor. The focus group was held one to three months post-discharge, early when compared to other studies and the patients' admission periods were relatively short. It is possible that, due to these factors, these patients may not fully appreciate the diary. The participants also wanted to read entries by medical staff (Eggerod & Bagger, 2010). These were only noted as being present in the diaries issued in the Garrouste-Orgean et al (2012) study. Infrequent diary entries were experienced as frustrating by recipients (Engstrom et al, 2009) as the diary failed to fill in memory gaps. The crisis of the admission was of particular interest, and patients were disappointed to find this frequently omitted (Egerod & Bagger, 2010).

Discussion

The review adds to others in identifying a paucity of primary research relating to the impact of diaries on psychological recovery post-critical care discharge (Ullman et al, 2015; Aitken et al, 2013). The implementation of diaries remains inconsistent, with only local guidance available. This is reflected in the review, with diaries being given at different times post-discharge and variations in who contributes to the diary. This review builds upon previous work by synthesising evidence of how survivors perceive the effectiveness of the diary together with objective quantitative data.

Critical care interventions, especially those experienced by long-stay ventilated patients, can produce post-discharge emotional distress that outweighs the severity of the illness (Rattray & Hull, 2008). This has an adverse effect on the socio-economic functioning of survivors and their families (Griffiths et al, 2013). The need for continued multi-disciplinary post-discharge support was emphasised by NICE in 2009. However, for many units, this is complicated by the lack of availability of staff (Cuthbertson et al, 2009). However, this review suggests that simply issuing a diary is not enough to alleviate this distress, and could even cause harm. The survivor population is not homogenous, as shown by the variety of responses elicited from recipients in this review. It is important to note that not all survivors will want to read about their critical illness.

Patients with poor factual recall often remember hallucinations and dreams vividly (Svenningsen et al, 2016) and experience difficulty in differentiating between the real and the imagined (Jones et al, 2010). This is thought to increase the likelihood of developing PTSD (Jones et al, 2010), with factual memories offering some protection (Jones et al, 2001). However, Myhern et al (2010) found that factual memories of pain were independent predictors for the development of PTSD. No systematic review has shown a link between delusional memories of critical care and the development of PTSD. However, it is known that many critical care survivors experience significant psychological distress (Svenningsen et al, 2016; Guttormson, 2014).

The emotional impact of the diary on recipients emerged as a central theme. This could be positive, as evidenced by subjects who spoke about their pleasure in receiving the gift of a diary. However, reading the diary could also potentially reawaken feelings of fear (Storli & Lind, 2009), evidencing the importance of providing continued support for diary recipients. This could be facilitated by the provision of a follow-up clinic or support group. Such a group would also enable the sharing of delusional memories and negative memories can be a release for survivors (Guttormson, 2014). This has been shown to reduce symptoms of depression (Ringdal et al, 2009).

The act of writing in the diary, and addressing the patient directly by name, re-focuses nursing care on the individual rather than the disease (Engstrom et al, 2009; Storli & Lind, 2009). Studies have shown that patients can feel invisible to critical care nurses (Stayt et al, 2015). Through writing entries, nurses demonstrate consideration for their patients beyond discharge. The review showed that diaries should include entries made by both healthcare professionals and relatives. Nurses' entries provide a skeleton to the diary, a chronology of the events of the admission, together with words of empathy and encouragement. However, the entries made by relatives were experienced by participants in the studies reviewed as being the most emotionally significant (Engstrom et al, 2009). They indicated the relatives' presence and their words of love and encouragement were treasured. The individuality of the survivor is emphasised.

Limitations

The review is limited by the paucity of studies eligible for inclusion and small cohort sizes. The majority were qualitative, reflecting the human experience of receiving and reading a diary. However, the quantitative studies produced robust evidence indicating that receiving a diary impacts positively on health-related quality of life (Backman et al, 2010), reduces anxiety and depression (Knowles & Tarrier, 2009) and reduces new-onset PTSD (Jones et al, 2010; Garrouste-Orgeas, 2012).

Implications and Recommendations for Practice

The review shows that, if used in isolation, the diary could have a negative impact on recipients, particularly if issued without offering the opportunity to address the questions and fears which may surface from reading the entries (Engstrom et al, 2009; Storli & Lind, 2009). It might be useful to suggest that patients read the diary in reverse order, to emphasise their recovery rather than the crisis of their admission. Physical weakness can make it difficult to hold a diary, reawakening feelings of helplessness (Engstrom et al, 2009). The format of the diary should therefore be considered. The review showed the diary being used effectively as one aspect of post-discharge psychological care, for example, a support group (Storli & Lind, 2009). Units wishing to introduce patient diaries should consider their resources for appropriate follow-up.

Incomplete diaries, especially ones which failed to fully describe admission were experienced as frustrating (Egerod & Bagger, 2009). It is very difficult for a diary to be written concurrently with the admission of a patient due to the clinical pressures on staff. However, this period is clearly of interest to patients, so should be completed as soon as possible.

Staff might consider alternative methods of recording the diary, for example using audio or photographic methods. However, the use of photographs of sedated patients is controversial as they are unable to give consent. Akerman et al (2013) found that the use of chronological photographs facilitated patient understanding of the severity of their illness and gave a visual representation of their recovery. However, some patients may find the photographs distressing.

It was also remarked upon that serious or life-threatening episodes were 'glossed over' (Egerod & Bagger, 2010) by diarists. This could be due to discomfort about relating such events in a non-confidential document, or concern that the patient may experience distress. Staff education, continued support and survivor feedback are vital for the successful introduction of the diary intervention.

Conclusions

In conclusion, this review offers a synthesis of existing research relating to the effect of prospective patient diaries on the psychological rehabilitation and recovery of critical care survivors. The results suggest that the use of patient diaries, as one aspect of critical care follow-up, can assist some patients in making a meaningful psychological recovery and are generally greeted positively. The diary acts as a therapeutic tool and debriefing aid, but also to demonstrate the human act of caring and refocus nurses on the person inside the patient.

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