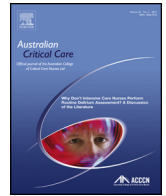




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## ICU survivors' utilisation of diaries post discharge: A qualitative descriptive study



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### ABSTRACT

**Background:** A growing body of evidence has confirmed that intensive care unit survivors encounter myriad of physical and psychological complications during their recovery. The incidence of psychological morbidity in intensive care survivors is increasingly being recognised. The causes of psychological morbidity are multi-factorial but may be associated with a complete lack of, or delusional recall of events in intensive care. Intensive care unit diaries are an initiative designed to enable survivors to help restore factual memories and differentiate those from delusional.

**Purpose:** To explore survivors' and family members' perceptions and utilisation of diaries following discharge from hospital.

**Method:** A single centre qualitative descriptive study was undertaken in a general intensive care unit in Western Australia. Participants were surveyed 3, 6 and 12 months following discharge from hospital. Eighteen participants completed one or more surveys.

**Findings:** Many of the participants who completed the surveys read their diaries but few made entries in them following discharge. Reading the diaries evoked mixed emotions for these participants; however they still viewed the diaries as a positive initiative in their recovery. Diaries enabled survivors to fill the memory gaps, make sense of their experience and reinforced the human connection when they were immersed in a technological environment.

**Conclusion:** Use of patient diaries was received positively by the participants in this study. Diaries are a simple, cost effective initiative which enabled survivors to piece together the time they had lost, concreted their experience in reality and enabled them to retain a connection with their loved ones whilst immersed in a technological environment.

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### Introduction

The impact of a critical illness and consequent intensive care unit (ICU) stay upon patients and their families cannot be underestimated. The ICU experience and its aftermath are described by some survivors as traumatic and life changing; and is associated with a significant risk to short and long term physical and psychological morbidity, reduced quality of life (QoL) and delays in optimal functional recovery for a significant percentage of survivors.<sup>1–19</sup>

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Complications reported include sleep disturbance, anxiety, depression and Post Traumatic Stress Disorder (PTSD).<sup>4–7,14,15,20</sup> However, the prevalence of psychological complications reported is variable but is postulated to range from 24 to 44% of survivors with some evidence to support that up to 64% of survivors report symptoms of PTSD. This variance has been attributed to endogenous patient characteristics as well as the ICU experience itself. A pessimistic outlook, a pre-ICU history of mental health disorders, intrusive memories, memories of pain and longer duration of sedation have all been recognised as independent risk factors for the development of PTSD.<sup>4,5,21–23</sup> The wider implications of the trauma of an ICU experience and associated complications is a higher burden of ill-health and an associated increase in the use of healthcare resources.<sup>8,24–29</sup> The concept of trauma is defined in the literature as any unexpected and unfamiliar experience, during which

unusual and extreme stress is experienced.<sup>30</sup> Exposure to a trauma may generate feelings of intense fear, horror and/or helplessness caused by subjection to the threat of actual or potential death or serious injury, or bearing witness in others.<sup>30</sup> Traumatic events, which have been identified and which may precipitate psychological distress in some individuals, include exposure to military conflict, torture and physical and sexual violation.<sup>31</sup> The effects of such trauma, can be so powerful as being recognised as capable of tearing the protective fabric of one's self apart.<sup>32</sup> There are many similarities between the psychological distress associated with "conventional" trauma exposure and that experienced by survivors of a critical illness and an ICU experience.<sup>4–6,10,13,14,16,33</sup> This could be because the reports of a critical illness and ICU experience are similar to that of other trauma survivors and, therefore, similar sequelae could be anticipated. Similar to other trauma exposures, it may be asserted that a critical illness is often unexpected, patients are rendered helpless in an unfamiliar environment, confronted by extreme stress and frequently report recollections of persecution and impending death, despite their apparent subconscious state.<sup>34–39</sup>

The realisation of short and long term physical and psychological morbidity associated with ICU survivorship, has led to an exploration and identification of both the precipitating factors and interventions which could reduce the incidence and severity of complications.<sup>8,15,24,28,40–46</sup> An association between psychological morbidity in ICU survivors and absent or delusional recall of the ICU experience or the presence of delirium has been postulated.<sup>14,16,39</sup> Rates of delirium in Australia have been estimated to be 45%<sup>47</sup> compared to higher rates reported in the rest of the world.<sup>48</sup> Delirium is characterised by a fluctuating mental state, inattention, disorganised thinking and altered level of consciousness.<sup>49–52</sup> The process of re-defining and clarifying the experience and filling the memory gap or re-defining true memory from delusional, may impact upon the incidence of psychological morbidity and recovery.<sup>53,54</sup> Despite the realisation of the scale of complications which ICU survivors face, a lack of consensus regarding the most appropriate focus and structure of programmes to assist survivors to regain their pre-morbid functionality and QoL persists.<sup>16,55</sup>

Survivors of a critical illness display a unique assortment of atypical and complex problems which often require specialised and individualised support to enable recovery. As the recovery trajectory is not homogenous, the duration and extent of recovery are difficult to predict, with many survivors never regaining their pre-morbid physical or psychological state.<sup>41,55</sup> The explanation for these inconsistencies in recovery trajectories is probably multi-factorial but may, in part, be attributed to the paucity of rigorous research to inform the provision of physical and psychological rehabilitation frameworks.<sup>55</sup>

Early interventions to improve the quality of life of ICU survivors focussed upon the implementation of ICU follow-up clinics. These clinics were pioneered in a UK centre in the 1990s as a treatment and support modality for ICU survivors.<sup>56</sup> Evaluation of these clinics demonstrated high levels of user satisfaction and associated health service endorsement in the UK.<sup>57</sup> Unfortunately, the model was plagued by sporadic implementation, disparate composition and inadequate methodological evaluation.<sup>44,58,59</sup>

Another strategy which has attracted significant interest and associated investigation in Europe has been the implementation of patient diaries in ICU. Patient diaries have been used in follow up clinics as a springboard to promote discussion about the ICU experience and resulting recovery. Recent studies have demonstrated the potential of ICU diaries in assisting physical and psychological recovery in this population.<sup>54,40,60</sup>

Patient diaries are based on the premise that ICU survivors have difficulty in constructing a narrative of their experience because of enforced pharmacological amnesia and severity of illness which

may have detrimental effects upon their recovery.<sup>61,62</sup> It has been suggested that providing a narrative of events of which the survivor has no recollection, may be beneficial to recovery.<sup>45,63</sup>

Patient diaries are usually commenced in ICU after the patient is ventilated and entries are completed by relatives and ICU staff to serve as a factual record, in words and photographs of the survivors' ICU experience. ICU patient diaries emerged in Scandinavia in the 1980s, with their implementation sporadically disseminating to the UK and Switzerland but not as yet further afield.<sup>64–68</sup> Early examination of the benefit of diaries focused upon survivors' descriptive feedback, however recently, empirical methodologies have been employed exploring the benefit of diaries on QoL and the potential reduction of PTSD.<sup>60,69</sup> A non-randomised study was conducted in Sweden to investigate if the use of diaries in ICU would improve patients' QoL.<sup>69</sup> Diaries were commenced for 38 patients and anyone involved in patient care was encouraged to contribute. Questionnaires were sent to the patients post-discharge to measure survivors QoL at 6-, 12-, 24- and 36-month intervals. In addition to the diaries, as standard ICU practice, patients also received follow-up visits from staff. The findings of the study demonstrated that the use of diaries and the follow-up visits were associated with improved health-related QoL. However, it is not apparent if the non-diary group received a follow-up visit too. It is therefore not possible to attribute the improved quality of life in the diary group to the diaries alone. The single site, small sample size, the inability to compare pre-morbid quality of life and mental health status to post-morbid state and lack of information pertaining to how often the diaries were read by the participants, are further limitations of this study.

A UK randomised controlled trial (RCT) evaluated the effectiveness of patient diaries in ICU on levels of patient anxiety and depression.<sup>54</sup> Nursing staff kept diaries for ICU patients using a series of standardised headings and 36 patients were recruited into the study. The findings demonstrated a reduction in anxiety and depression scores in the diary group survivors at 2 months post-hospital discharge.<sup>54</sup> Although the results of the study showed that the use of diaries in ICU may have a beneficial impact to reduce survivors' anxiety and depression, the authors highlighted limitations including the small number of participants and the time available to complete the study, making the findings less generalisable.

An RCT conducted across six European sites, evaluated the use of patient diaries following ICU discharge and the reduction of new onset PTSD. Nursing staff and family members were encouraged to make written and photographic entries in the diaries, which were constructed in a standard format across all sites. There were 352 participants recruited to the study who completed a validated screening tool at 1 and 3 months post ICU discharge. The statistically significant results from the study indicated that the prevalence of new onset PTSD was reduced in the diary group (5%) compared to the control group (13%). The researchers concluded that reading the diaries may yield a similar effect as Cognitive Behavioural Therapy, in that diaries help survivors change the way they think about their illness and enable the recreation of an autobiographical memory.

Overall, the use of diaries has been positively evaluated by European survivors and their families and the diaries have also been acknowledged as giving nursing staff insight into the patients' experiences when utilised as a follow-up tool. Diaries have also been attributed to contributing to the reduction in survivors' memory gaps, concreting their experiences in reality and enabling them to comprehend the severity of their illness and set realistic goals to achieve meaningful recovery.<sup>53,54,70–72</sup> Maintaining a diary for ICU patients and their families has been shown to provide a coherent narrative of the patient's ICU experience and nursing performance.<sup>73,74</sup>

In a qualitative study<sup>53</sup> several emergent themes were identified from patient diaries including; the sharing of daily events,

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