



Research paper

The extent and application of patient diaries in Australian intensive care units: A national survey



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ABSTRACT

Background: Critical illness can be a psychological stressor for patients and family members. Scandinavian studies have portrayed patient diaries as a supporting catalyst for patients and their families through a process of reflection and fact presentation. However, the small number of randomisation trials exhibits theoretical and methodological limitations. Given the increased interest amongst Australian Critical Care Nurses, further understanding of nurses' perceptions and use of patient diaries was warranted.

Objectives: To identify nurses' perceptions of patient diary use and to describe their application within Australian ICUs.

Method: A descriptive, exploratory study design using an online survey of the Australian College of Critical Care Nurses was used. Descriptive statistics illustrated participant responses and textual data were subjected to content analysis for emergent themes.

Results: Out of the 194 participants, 19% ($n = 37$) reported patient diary use in their unit, with nine indicating some form of evaluation. Fifty (70%) of the non-diary users, who responded, indicated hesitancy to introduce them. Respondents noted a lack of guiding policies and potential medico-legal ambiguity. Content analysis revealed three themes, considering diaries as: communication tool, patient recovery tool and a family centred care strategy.

Conclusion: Patient diary use appears to be in its infancy in Australia with a lack of guiding policy for format and processes including evaluation. Nurses using diaries were enthusiastic about the initiative, holding optimistic perceptions about the potential positive impact of diaries on patient and family outcomes. Further research on their efficacy is required.

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1. Introduction

Over the past decade the psychological outcome of patients following admission to intensive care has attracted the interest of clinicians and researchers alike. During an admission to an intensive care unit (ICU), patients experience multiple, acute, often overwhelming physical and psychological stressors due to

the nature of their illness or injury, which extends beyond their discharge.^{1,2} These problems may be related to the ICU environment, sleep deprivation, or health related issues like, illness, pain and an inability to express needs.^{2–4}

Patients' can be affected by limited recall and/or inaccurate or hallucinogenic memories. These may lead to poor psychological recovery post-ICU admission.^{5,6} Conversely, the presence of accurate ICU memories, that may be distressing to patients have been associated with a positive emotional outcome.^{5,7,8} Studies have suggested that as many as 20–25% of ICU patients may go on to develop Post-Traumatic Stress Disorder (PTSD), posing limitations on their return to an optimum functioning level.^{9,10} The prevalence

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of poor psychological outcome for ICU patients has led to many ICU clinicians acknowledging the need for patient psychological assessment and support during and beyond the ICU admission.^{11,12}

A novel strategy using 'patient diaries' has emerged and developed from Scandinavian countries' academics in the past decade. The initiative was originally designed to provide factual accounts of the patient's ICU stay through cataloguing key events through texts and photographs by staff, family and friends.⁷

2. Literature review

A search for published research in CINAHL, Embase, Medline and PsychInfo databases using MeSH and textual terms related to 'intensive care' and 'patient diaries' was conducted. Two hundred and twenty-one articles were identified. Duplicate articles were excluded and remaining article abstracts were examined. Those articles that did not pertain to an intensive or critical care context were excluded. Eleven original research articles were reviewed in detail and their reference lists were checked for relevant articles.

Early research in this area was largely limited to small descriptive, qualitative studies exploring patient and staff experience of diaries as well as their content and format. Initial evaluations and reports on patient diary use with ICU patients suggested that they assisted patients in accepting the severity of their illness and helped relatives cope with feelings of grief and loss, with subsequent studies reporting that diaries improved communication channels.^{6,13,14} These descriptive studies served to explore patients' and families' views of diary use, their content and processes, which generally indicated a positive reception, and laid the foundation for subsequent studies.^{6,13,14}

There have only been three trials that have examined the impact of diaries on patient and family psychological outcomes.^{7,15,16} A small Randomized Controlled Trial (RCT) conducted in 2009 examined the effect of diaries on the levels of anxiety and depression in 36 ICU patients, using the Hospital Anxiety and Depression scoring System (HADS).⁷ Participants were assessed at two time points: Time 1 had a median of 30 days post-ICU discharge and Time 2 was three weeks after the first assessment. The control group received their diary after the Time 2 test whereas the experimental group received the week following the Time 1 assessment. Analysis revealed that the experimental group displayed a statistically significant decrease in anxiety ($t(1, 17) = 2.65, p < 0.05$) and depression scores ($t(1, 17) = 3.33, p < 0.005$) at Time 2. There were significantly fewer anxious patients in the experimental group at the Time 2 assessment ($p < 0.05$) but with no significant difference in the number of those with depression when compared to the control group ($p = 0.07$). The wide variation in when participants were first tested, (range from 21 days to 8 months) and therefore when they received their diary, may have impacted upon the results, which suggested that diaries may assist in decreasing anxiety, but there is no evidence that there is a significant effect on depression.⁷

A larger RCT with 352 ICU patients across six European countries was performed to test whether the provision of an ICU diary reduced the occurrence of new cases of Post-Traumatic Stress Disorder (PTSD) in patients.¹⁵ The ICU Memory Tool (ICUMT) was completed by all participants one to two weeks post-ICU discharge and again three months later. The intervention group could elect when they received their diary, whilst the control group received theirs after the three-month follow-up questionnaires were completed. Participants were generally given their diaries with explanations by the research nurse or doctor during an out-patients visit but some received theirs via post with discussion occurring via telephone. Baseline assessment was conducted at randomisation using the Post-Traumatic Stress Syndrome 14 (PTSS-14) screening tool. At the three-month post-ICU testing time the PTSS-14

was repeated and the Post-Traumatic Stress Disorder diagnostic scale (PDS) was administered.

Over 85% of the intervention group elected to receive their diary at randomisation. At three months there was no significant difference in PTSS-14 scores between the two groups but in post hoc analysis when the researchers tested the PTSS scores above a cut-off of 45, there was a significant reduction for the intervention group ($p = 0.04$). When the PDS results were analysed, there were fewer probable cases of PTSD in the intervention group (5% versus 13%, $p = 0.02$).¹⁵ More importantly, the PDS was not used at baseline and the use of the PTSS-14 as a surrogate measure for PTSD was not adequately rationalised. Aitken and colleagues highlighted that the use of the PDS, which is designed to be a self-reported tool, was not validated for administration by interview as occurred in Jones et al.'s study.¹⁷ In addition there is the potential for unequal treatment of study groups relating to the interviews with limited descriptions provided on the specifics of how and where they were conducted within the six European countries.

Jones and colleagues also studied the impact of patient diaries with a pilot study of close relatives ($n = 30$) of ICU patients in two of the 12 sites in the study above.^{15,16} The authors hypothesised that families of ICU patients may benefit psychologically from the delivery of the diary. The theoretical concepts underpinning this study are not clearly defined and would benefit from further exploration.

In the family member study, the aim was to test whether a patient diary delivered to the patient at one month reduced the levels of PTSD symptoms for close relatives who had read the diary after the patient returned home.¹⁶ Relatives' baseline PTSD-related symptoms were assessed one month after ICU discharge using the PTSS-14 screening tool and again at three months. Families of patients who received the diary during the treatment period (less than two months post-ICU discharge) had lower PTSS-14 scores at the three-month follow-up in comparison to the control group (median PTSS-14 score change -5 for intervention group versus $+5$ change for control group, $p = 0.03$), indicating that at three months family members of patients in the intervention group had fewer psychological symptoms. This is the first study of its kind and larger studies are required to both understand conceptually and further evaluate the impact patient diaries may have on their family members' psychological well-being following patient discharge from ICU.

A number of other studies aimed to quantify the extent of patient diary use. These studies were conducted by researchers in Scandinavia and Northern Europe, where overall diary use ranged from zero use in Germany to 76% in Sweden.^{18–21} Studies performed in Denmark highlighted the legal and ethical ambiguity of the diaries, whereas the Swedish and Norwegian researchers emphasised the need for a systematic follow-up programme.^{12,19,20,22} The predominance of diaries in Scandinavian countries has been attributed to efficient networking amongst nurses in the region.²³

In summary, diary use appears to be limited to selective countries in Scandinavia and Northern Europe, with isolated reports in the UK. Reports of patient diary use in Australian ICUs are currently limited to conference presentations and anecdotal reports.^{24–26} The authors' review of the literature highlights the need for further studies that explore diary format, use and delivery in Australia, as well as trials that evaluate its benefits or potential harm to patients or families. The emerging interest and use of patient diaries in ICUs are the impetus for this study, that aimed to identify Australian ICU nurses' perceptions of the application of patient diaries in their ICU.

3. Methodology

This study used a descriptive, exploratory design, with the aim to:

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