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# An audit assessment of the use of diaries as a therapeutic rehabilitation tool within an Intensive Care unit

## Abstract

Intensive care (ICU) diaries are on the increase in UK hospitals as a therapeutic means to address any psychological impact on the ICU patient. The National Institute of Health and Clinical Excellence (NICE) recommend the development of services to address the psychological needs of patients following critical illness. This article discuss ICU diaries as a service that would aim to meet these needs. There is a greater demand for evidence-based research to support the positive effects of the diaries. Equally, there is a necessity to highlight the negative impact on those patients that oppose their diaries due to traumatic bearing of their critical illness. To gain an insight into the use of patient diaries, an audit was conducted in a single ICU. The article provides an overview of the available literature. Recommendations are made to enhance the use of ICU diaries for clinical practice in the future.

## Introduction

The purpose of this paper is to discuss the results of an audit, which has been undertaken in order to assess compliance of an Intensive care diary as a therapeutic rehabilitation tool in one local Intensive Care Unit (ICU). The objective will aim to promote the use of ICU diaries as a resource to facilitate patient recovery following admission to ICU. A rationale will be justified in conjunction with local and national guidelines. The methodology will be explored and a critical analysis of the underpinning literature will be evaluated. The data collection will be interpreted, analysed and the findings will be provided. Recommendations for future practice will be proposed with regard to improving compliance and delivery of diaries as a strategy to maximise patient recovery.

## Background

A review of the literature was conducted using an online database, Discover More, in order to facilitate the search. Identifying search terms such as 'ICU diaries' and 'patient diaries' influence the scope and quality of the results. Articles published in the preceding ten years were favoured as the literature would assess current ICU diary material.

The Intensive Care National Audit and Research Centre (ICNARC) estimate an approximate 155,239 admissions to 232 adult critical care units in England, Wales and Northern Ireland per year (Ferrando-Vivas et al, 2017). ICNARC Statistics for 2013-2014 show that hospital mortality risk of death is less than 20%. Until relatively recently, there was little understanding of the long-term impact of an ICU stay on patient's physical and psychological wellbeing. Aitken et al (2017) emphasise the complexity of physical and emotional recovery from critical illness. Survivors of critical illness and their families are reported to experience significant psychological distress, including anxiety, depression and posttraumatic stress disorder (PTSD). Rattray (2013) supports these findings and classifies psychological problems as anxiety, depression, post-traumatic stress and cognitive dysfunction, negatively influencing perceptions of subsequent health status. The North of England Critical Care Network (NoECCN, 2016) suggests that patients were often discharged home from intensive care units with no psychological follow-up or counselling. The psychological problems which patients experienced were often undiagnosed and patients were left to cope at home without support.

National Institute for Clinical Excellence Clinical Guideline 83, acknowledge the grave necessity for rehabilitation after critical illness (NICE, 2009). The report outlines the need for follow up and support of patients who have been critically ill. The "optimisation of recovery" as a therapeutic objective rather than mere "survival" is a key point in

these guidelines. The publication recommends that patients are reviewed at follow up clinic two to three months after discharge from critical care to assess individual need for support. The guidelines propose that rehabilitation should be commenced as early as clinically possible to address psychological and physical symptoms such as muscle wastage, requirement for physiotherapy and altered sleep patterns following an encounter in critical care. Turton et al (2016) support these guidelines, demonstrating that critically ill patients acquire muscle weakness due to prolonged stay in the Intensive care setting. As a result, survivors of intensive care admission have difficulty with mobility and require complex rehabilitation. The study emphasises the importance for early rehabilitation in critical care.

The Critical Care Follow-up clinic was established both nationally and locally to review the progress of patients who have been in critical care. Where extended ICU follow up exists, patients report great satisfaction with the service (Griffiths et al, 2006). The service aims to provide much needed psychological support to patient who may have been affected by their inpatient stay. In addition to the long term recovery from the definitive cause of their ITU admission, a combination of disrupted circadian rhythms, use of hallucinogenic or amnesiac medications and altered body image may contribute to the multitude of after effects experience (Moody and Griffiths, 2014). Earlier research conducted by Bergbom et al (1999) suggest that equipping patients with a better understanding of what has happened to them during critical illness aids to set realistic recovery goals and reduce the risk of long term problems, it was essential to consider earlier seminal research that had been conducted prior to the literature review dates as many of the reviewed articles discussed this key paper. Most recently, the results of a multicentre UK randomised control trial suggested that written information

may help lower patient's level of depression and symptoms of PTSD when provided as part of a broader rehabilitation strategy (Bench et al, 2015).

Lifesaving intervention in an intensive care unit (ICU) is said to increase patient risk of PTSD. Warlan, Howland and Connelly (2016) describe PTSD as a 'cluster of symptoms', including nightmares and flashbacks, depressed mood, lack of concentration and irritability. Ratzler, Romano and Elklit (2014) identified the disorder characterised by three symptom groups: 1) re-experience symptoms (flashbacks, nightmares and intrusive memories related to the traumatic event); 2) avoidance symptoms (the person is making efforts to avoid stimuli reminding of the trauma) and 3) symptoms of increased arousal (irritability, hyper vigilance, diminished concentration) The report highlights that psychopathology prior to ICU admission is an important risk factor for PTSD.

The prevalence of patients with PTSD following an ICU encounter are reported between 9-27%, based on a statistic between 2008-2012 (Wade et al, 2013). This report highlights the clinical risk factors identified with the use of benzodiazepines, duration of sedation and mechanical ventilation consistent with development of PTSD. Jones, Backman and Griffiths (2012) propose that the families of the recovering ICU patient may also experience psychological effects including PTSD, anxiety and depression. The evidence suggests that PTSD-associated symptoms identify similarly with the recovering ICU patient as well as their families, indicative that support should be available to both patients and their relatives.

In view of the above discussions, the focus is to improve the long-term holistic health outcome of the ICU survivor. Given the impact on poor quality rehabilitation and impaired recovery from severe illness, the NICE guideline 83 initiated the development of patient diaries as a therapeutic aid to recovery. Clinicians have developed patient

diaries with the aim to provide ICU survivors with an accurate account of their stay in ICU. Whilst the nurse is typically the primary author of the diaries, there is often an expectation or suggestion that relatives will also actively contribute. This can pose a challenge for nurses, who may feel uncertain as to the nature of their input. Nurses are expected and required to provide clear, professional documentation to support their nursing care (NMC, 2015). The use of the diaries is more complex as they do not hold the same legal standing as the documentation related to patient care. There is recognition that language must be appropriate to the level of the patient's understanding. It must be factual whilst avoiding the use of overly complicated terminology. Whilst relatives may use colloquial language and create a less formal narrative, the use of this style of language could arguably misrepresent the professional role of the nurse from what has been imparted from training. Nurses are advised to write in their professional capacity in everyday language as a narrative (Ewens et al, 2014).

Storli and Lind (2009) found that the diary was received well by patients, viewed as a caring gesture from hospital staff. Nielsen and Angel (2015) agree that patients expressed gratitude and treasured the diary post ICU discharge, despite the pain caused on reading it. The evidence suggests that reading the diaries enables the survivor to gain coherence and understanding of their experience. A randomised study carried out by Knowles and Tarrier (2009) has shown reduced levels of depression and anxiety in patients who received a diary. Phillips (2016) explores one theory that stipulates the diary fills a void in patient's memory by providing objective information and orientates the patient back to reality. In contrast, Phillips (2017) argues that the diaries need to be part of a supportive process and allow patients the opportunity to read their diary and return to explore any questions. Litz, (2008) and Toien et al, (2010)

relate to this information and express that one off debriefs are known to be potentially harmful to the patient. Phillips (2017) highlights the process of empowering the patient to accept or reject their diary and make choices that best suit how they feel and cope. She recognises the need for support in ICU, highlighting eleven UK ICUs only to have access to a designated Clinical Psychologist.

Despite the advantages of ICU diaries, Perier et al (2013) challenge the issues regarding their implementation of the diaries. Perier et al (2013) states that nurses expressed difficulties in unwanted closeness to patient or relatives which impacted their writing of the diaries. Nydahl et al (2013) suggest that implementation of the diaries appears to have common issues from nurses such as lack of time, resulting as the ultimate barrier to using a diary. This is supported by Kneuck and Nydahl (2010) who reached the same conclusion.

Collaborative writing of both relatives and professionals is felt beneficial locally to illustrate mutual patient support. Families need to comprehend information given to them and are often exposed to medical terminology, increasing stress to an already difficult experience. Warrilow, Farley and Jones (2015) uphold that family members consistently report call for change in communication with the interdisciplinary team during admission to ICU. In authoring the diaries, it is suggested the feelings expressed by relatives were both positive and negative, whereby feelings expressed by healthcare professionals were always positive (Roulin, Hurst and Spirig, 2007). The nurses' writing would seek to demonstrate a positive tone, irrespective of the gravity of the patient's condition. It would also aim to appear non-judgemental and perhaps representative of wider nursing values. The relatives' input may be more 'honest' and utilise less formal language. Given the nature of nurse's professional boundaries, compared to the personal relationships of the relatives with the patient, it is expected

that the diary entries would differ in tone. The nurses' additional knowledge and expertise may account for the content being different between nurse and relatives. Relatives are encouraged to express their feelings to loved ones whilst in ICU, enabling survivors to gain an understanding of how difficult the time had been for their families (Ullman et al, 2015).

ICU patients are diverse and vulnerable in population and it is said that psychological intervention may not always have a positive impact on patient recovery. It is understood that in offering the ICU diary as a recovery tool, there is an assumption that the patient's wishes to have an enhanced awareness of their ICU experience. Rattray et al (2010) propose that the research, although limited, suggests that only 50% would prefer to know additional details about their ICU experience. Hull (2012) concurs that large quantities of information given to a patient already experiencing a level of physical or psychological distress, may inhibit rather than optimise recovery. Aitken, Rattray and Hull (2017) assert that those who are most likely to benefit from an ICU diary should be targeted. This implies that the subjective opinion of the bedside clinician would determine who should obtain a diary. This may impact the long-term recovery of that patient. Aitken, Rattray and Hull (2017) also highlights the inadequate data to determine the characteristics of patients for whom the ICU diaries are appropriate.

Sedation and analgesia are often used to manage comfort and pain whilst in ICU and to help reduce anxiety. Sessler and Varney (2008) argue that such substances may contribute to psychological problems after critical care admission. It is determined that longer length of stay in critical care increased delusional memories, implicating the ripple effect on increase in cost. Jones et al (2010) acknowledge the effects of the diary in reducing PTSD, anxiety and depression and on ICU patients and their

relatives. It is reported that patients often have a distorted perception of what has happened to them. This is challenged by Ullman et al (2015) who emphasize the lack of evidence of the diary in reducing PTSD and fundamental concern regarding the effectiveness in improving psychological recovery after critical illness.

Nationally, it has become apparent that there are no quality standards regarding ICU diaries. In view of the above literature discussed, it is recognised there is widespread disparity on how diaries are utilised on a local level. It is clear that the reviewed literature identifies the need for improved quality rehabilitation in relation to the diaries. Impaired recovery from severe illness is a substantial problem, therefore ICU diaries should be commenced as a rehabilitation tool as early as clinically possible. This justifies the rationale for performing this audit on a local level in set some local standards.

### Method and Study Design

The audit received approval from the Intensive care unit clinical audit lead for a 'snapshot' clinical audit to be carried out to monitor compliance of ICU diaries within one local trust. Medical consent was also received by the audit lead to utilise anonymous data for analysis.

Clinical and Healthcare Audit involves comparing current practice to evidence based Best practice in the form of standards, identifying areas for quality improvement in implementing changes to practice to meet the standards. Healthcare professionals have a duty to provide the highest possible standards of care to their patients (NMC, 2015). Biradar, Reddy and Vishnu (2015) suggest that in order to guarantee the achievement of standards, nurses audit their work accordingly.

Whilst there is no known target to be achieved, due to the guidelines produced rather than standards, there was no record of compliance to compare to. For the purpose of this study, it was decided, based upon the literature and the importance of the diaries decided that no less than 100% target could be aimed.

A retrospective review of patients with ICU diaries was carried out. The study included a total of thirteen ICU patients and measured compliance to local ICU guidelines from day of admission for a period of three days. Rationale for the small number was due to the number of patients within the ICU at the time, and three days was chosen to provide a snapshot of current practices. Patient's age, sex, diagnosis or length of stay was not measured. Patients who had been admitted less than three days were excluded from the study.

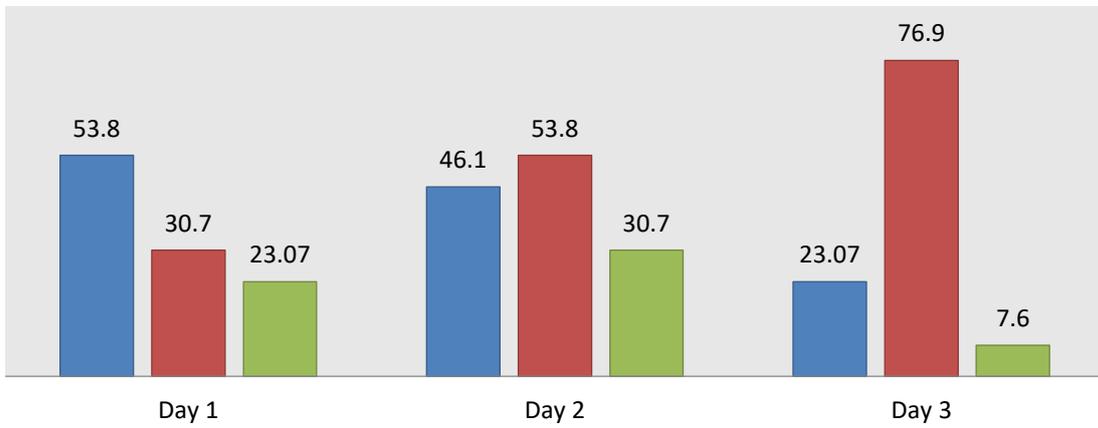
ICU diaries within the Intensive care unit were generally circulated to a bed space by the admitting nurse. A hand written entry in the diary logbook must be completed, stating that as the admitting nurse, a diary has been commenced for that patient.

Compliance to ensure diary completion for each day was via tick box on nurses' paper chart as per trust guideline to prompt staff to complete their diaries. This is part of nurses' safety checks. Also, the author assessed whether the diary was in fact completed for that day following ticking the box. Non-compliance was measured by whether the diary entry had been completed for that day. Completion of diary entry can be written by either nurse or relative at least once daily as per ICU trust guidelines.

### Data collection

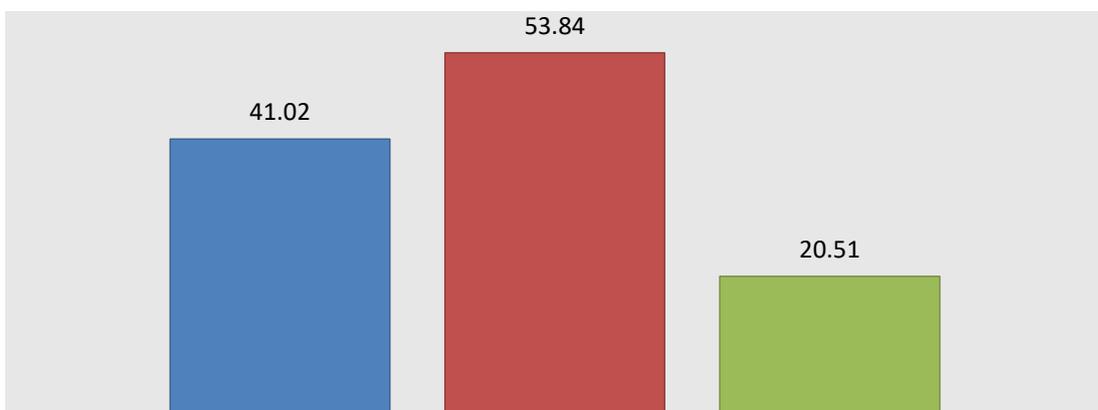
### Cumulative data from 13 patient over three days - all figures are presented as a %

■ Compliance ■ Non-Compliance ■ Box ticked but not recorded



### Cumulative data from all three days- all figures are presented as a %

■ Compliance ■ Non-Compliance ■ Box ticked but not recorded



## Results

The results highlighted poor over compliance to adhere to trust guidelines with only 41.02% of documentation that was audited, demonstrated best practice. Therefore, a total 53.84% established non-compliance to diary writing. Another 20% of the data analysed demonstrated evidence that diaries completed on the main nursing documentation chart (by documenting a tick in the appropriate box), had an absent diary entry therefore suggested that the nurse responsible was not aware of current trust guidance.

### Findings and Discussion

The audit highlighted areas for service improvement. Acknowledgement of the compliance of ICU diaries relied on the communication of the bedside nurse to handover diary continuity to their colleague and equally to the relatives. There was no evidence why a multi-disciplinary approach could not be taken towards diary writing, such as doctors or physiotherapy input; however, there was no evidence of this within the diaries (Phillips, 2017).

The diaries occurred in ad-hoc fashion, being commenced on day one or being commenced on day four, five or six, which would later potentially impact patient rehabilitation. Consensus is needed to ensure approach to diaries is consistent with structure (Rooney, 2013). It was observed during a patients account of their stay on ICU at a follow-up clinic, how the patient had expressed their pain of the 'not knowing' about the time spent in ICU. Regrettably, this patient did not have a completed diary.

Local guidelines for ICU diaries suggested best practice of completion of diaries on day one admission to Intensive Care for all patients. Aitken, Ratray and Kenardy

(2017) oppose this guidance, proposing a process of selection for those most likely to benefit from ICU diaries, further demonstrating disparity in implementation in practice.

Family inclusion in the diary writing appeared to be minimal in most of the thirteen patients with just five patients having contributions, a total of 38% over the three-day period.

### Recommendations for future practice

Effective communication between Patient relatives and nursing staff can be crucial to the coping mechanism of the families. Breen and Houghton (2017) suggest that when nurses witness the impact of their patients' inability to share concerns, needs, and emotions, they may feel helpless and ineffective in their ability to understand their patient's needs to provide appropriate support.

Nursing staff to have awareness raising sessions to understand the issues that patients experience when they have left ICU such as the issue of 'not knowing' what had happened to them.

### Conclusion

The ICU diaries have the potential to be a therapeutic tool to improve the recovery of patients and their families in ICU. Auditing is an indicator for benchmarking performance in the UK critical care units and provide a solid framework for annual public reporting of critical care unit outcomes to improve practice. Based upon the findings, it is evident that on a local level, much more education and input is required

to improve compliance of ICU diaries. Although diary handover is the role of the follow-up clinic, the author is also mindful of those who do not want to be exposed to information that they are not ready to confront. It is clear that having a diary aids to regain control in terms of self-identity and confidence during recovery.

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