Clinical

Lost Days - Diaries for Military Intensive Care Patients

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Abstract

There is a real possibility of critically injured service personnel suffering from psychological disturbance as a result of not being able to recall traumatic events. Many patients report symptoms of depression, anxiety and other psychological disturbances such as hallucinations, delusional memories and nightmares after discharge from an Intensive Care Unit (ICU). Patients who have memories of ICU, sometimes unpleasant ones, as opposed to those who have no memories of their stay in ICU, suffer less anxiety, panic attacks and other PTSD-related symptoms. The impact for clinical practice is that, whilst health care professionals cannot remove all of the stressors of treatment in ICU for service personnel, we must try to minimise their impact by providing continued patient information and reassurance. The introduction of patient diaries has helped this vulnerable group of patients and the feedback from patients and their relatives validates this. Patient diaries have been developed and introduced for use by military patients and further exploration of their impact expected.

Introduction

It is becoming increasingly acknowledged that a patient’s psychological state and the adverse effects of being critically ill within an Intensive Care Unit (ICU) are important factors in their long term recovery and rehabilitation. Many patients report symptoms of depression, anxiety and other psychological disturbances such as hallucinations, delusional memories and nightmares after discharge from an ICU, which can continue for up to 12 months, and in some cases, much longer, after discharge(1,2). Furthermore, it has also been suggested that the presence of delusional memories can, in some cases, contribute more widely to the long-term psychological well-being of a patient(3). Jones et al, examined the link between memory of ICU, delusional thoughts and the development of Post-Traumatic Stress Disorder (PTSD)(4). Their findings revealed that, patients who had memories of ICU, even unpleasant ones, suffered less anxiety, panic attacks and other PTSD-related symptoms compared to those who had no memories of their stay in ICU. It follows then, that appropriate intervention is needed to alleviate these symptoms, to promote personal, social and vocational well-being in the long term.

Care following discharge from ICU

Not that long ago, a patient’s treatment episode within ICU was deemed successful once they were discharged to a ward or other less intensive area for further treatment(5). This was based mostly on their physical well-being, with little regard to their subsequent quality of life. Over time, it has been realised that there needs to be some way of measuring the therapeutic interventions that we give as healthcare practitioners, taking into account a person’s psychological well-being, to ensure optimum quality of care is given. More recently, ‘Critical to Success’(6), a national review of Critical Care Services within the UK, and ‘Comprehensive Critical Care’(7), recommended a) the provision of aftercare following a stay in ICU, and b) that all hospitals in the UK should provide a rehabilitation
service for the critically ill. These two major pieces of work have helped to set the national perspective and it is useful to bear in mind how the political conscience of government and the progression with the various healthcare professions have influenced the improvement of clinical services, in order to maintain public confidence, and provide the best available clinical expertise. However, it should also be remembered that although the recommendations that have been suggested are considered best practice guidelines, they are not mandatory requirements for National Health Service (NHS) Trusts.

Patient and Carer Perceptions
Several studies have been conducted looking at patients and carers perceptions of their stay in ICU. Roberts et al, undertook a multi-centre study in Australian ICU's, and concluded that most patients were able to recall factual memories of their stay in ICU 2 years after discharge from the ICU (8). However, they also concluded that those patients who were identified as having a degree of delirium at the 2 year stage post discharge, had significantly less factual recall. This finding is consistent with other studies that have been conducted looking at the physical and psychological sequelae post discharge from ICU (9,10). The implication being that the ability to cope with stressful events is reduced when the subject has little or no control over them, a view put forward nearly 30 years ago (11). The impact for clinical practice is that, whilst health care professionals cannot remove all of the stressors of treatment in ICU, we must try to minimise their impact by providing continued patient information and reassurance.

Patient Diaries
Bergbom et al, undertook a small study involving 10 patients in a general ICU, who were given retrospective diaries (12). Her findings suggest that the use of diaries helped patients in coming to terms with the seriousness their illness and stay in ICU. This is supported by Lind & Storli, who found that by giving patients diaries of their stay in ICU, patients were able to separate ‘fact from fiction’, and that in many cases, episodes where they thought they were ‘going mad’, could be easily explained as clinical procedures being undertaken (13).

Based on this existing evidence, retrospective diaries were commenced in an ICU in East Anglia (10). These diaries were constructed by the ICU follow-up sister, and involved trawling through large volumes of medical and nursing notes and reconstructing events into a chronological timeline. They were given to patients at follow-up clinic and the patient was invited to re-attend clinic to discuss further. Her findings showed that whilst many patients and their carers found the information useful in terms of ‘piecing together a jigsaw’, patients stated that they found the information impersonal and had difficulty relating to it. Changes were made to the diaries so that they would be written prospectively by the staff involved in the patients’ care, with the aim of making them more meaningful.

Also a senior critical care nurse in Sweden has led a project offering prospective diaries to ICU patients (14). The study involved the use of diaries over a 3 year period, detailing their condition, events during their stay and all relative and visitor involvement. He stated that patients reported that the diaries were a useful debriefing tool, and helpful in setting more realistic goals for their recovery. Storli et al, further expands on the use of prospective patients diaries and what she feels they have to offer the patient (15). They are very clear about the type of language that care-givers should use, in that it should be unambiguous. To that end, they encourage the nursing staff to write in normal, everyday language, limiting the use of medical jargon to where necessary, for example, where a patient has been positioned prone, a nurse writes “You have been lying on your stomach for several hours today. This is to help your body’s uptake of oxygen. I wonder if you usually lie in this position, as you seem very comfortable?” What gives this narrative a real sense of tangibility is that the patient responded 3 months later saying “Just imagine that you took the time to do this... you have no idea what this means to
me... that someone cared about my thoughts – not just my organs”. Storli further stipulates that by using everyday language, it enables the writer to go back and forth, thus giving room for conjecture rather than definitive answers. It follows then, that by using this type of approach, possibilities, as opposed to limiting answers, are offered to the patient in which they can help fill missing gaps in their memories of ICU.

In a reflective piece of work, the participants talk candidly about their experiences and examine lessons learnt from 20 years of following up ICU survivors(16). Based on personal narrative, they show an understanding of the legacies of the physical, psychological and cognitive problems associated with critical illness.

In our host NHS Trust, there is a follow-up clinic run by a sister, who also compiles retrospective diaries for all patients that have been in ICU for more than 3 days. Discussion took place with the sister about the advantages and disadvantages of compiling retrospective diaries, whose over-riding concern about prospective diaries being compiled at the bedside was the issue of maintaining patient confidentiality. Curiously, this important issue was not mentioned by Combes’(14); all that was stated was that the diaries were kept at the patients’ bedside. It was not mentioned in any of the other studies cited, although it is recognised that because these studies were from countries outside the UK, different regulations might apply to the holding and handling of such information. Whilst no information could be derived from the local Critical Care Network with regards to the use of patient diaries, a neighbouring Critical Care Network has issued guidance for all ICU’s within the Sussex region(17). In this region, patient diaries are kept in a locked cupboard, with a register of which patients have had a diary compiled. The diary does not follow the patient to a ward area, unless the patient has accepted to take it; an acceptance/refusal form is signed by the patient and a photocopy of the diary is put into the patients’ critical care notes to stop additional entries being made after the diary has left the ICU. This network has provided clear guidance for the use of a patient diary and has met its obligations with regards to the handling and storage of patient information(18,19).

Introduction of Patient Diaries for military personnel

The idea for implementing a Patient Diary for military personnel sprung to mind whilst serving in Afghanistan in 2006 when looking at current issues in Critical Care. One example of the potential benefits of these diaries was a patient who complained that she had been subjected to ‘torture’, specifically, that she had “been put into a tunnel and gassed several times”; “that she had been forced to lie flat for days on end by the ‘gaoler’ who kept a big bunch of keys attached to her uniform.” It was clear that these instances of ‘torture’ could be easily explained as undergoing certain radiological procedures, and the Sister holding the ward keys. This does highlight how patients may perceive the care that they receive, particularly those with a degree of memory or cognitive impairment. With this in mind, consideration was given to the use of a military Patient Diary and the added value it could give to the care that injured service personnel received.

There was no specific science or methodology to developing the template, except a ‘keep it simple’ format to be written prospectively. Guidelines for the use of the Diary were also developed, taking into account the relevant statutory and governance regulations concerning the handling and storage of patient information, with an over-arching caveat of “do not write anything in the diary that you would not be prepared to discuss face-to-face with either the patient and/or their relative”. The Defence Specialist Nurse Advisor and her team at the Royal Centre for Defence Medicine at Birmingham took the lead in evaluating the project – and already have had significant positive feedback from both patients and relatives. This concept has been developed over the last 24 months, with a wider subject matter expert involvement, and has allowed a more coherent approach to recording significant events and milestones for patients.
who have suffered very complex and traumatic, and often life-changing, injuries.

The French Philosopher, Merleau-Ponty, compares our bodies to a work of art, stating that our body ‘is a focal point of living meanings’[20]. The introduction of a patient diary for critically injured servicemen and women has the potential to give personnel working within the Defence Medical Services a chance to bring back some meaning to the lives of those injured and in our care.

Conclusion
The evidence concerning the psychological effects of being ill within a critical care environment is compelling and conclusive. Undoubtedly, the introduction of patient diaries has helped this vulnerable group of patients and the feedback from patients and their relatives validates this. Patient diaries have been successfully implemented in many ICU’s around the world, albeit with slight nuances in their protocols. The evidence for retrospective versus prospective diaries is not totally clear cut, although it is felt that prospective diaries offer a more meaningful approach.

There is a myth that patients do not remember, but many do. However, in many cases, what they remember is often disjointed, and can feel like a chaotic mixture of dreams and unreal perceptions. We have much to gain from understanding a patients’ struggle to make sense of their ICU experiences and it could be argued that we have a moral obligation to take action to reduce any feelings of loss or confusion.

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References


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