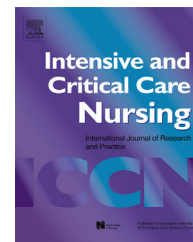




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ORIGINAL ARTICLE

A qualitative exploration into the long-term perspectives of patients receiving critical care diaries across the United Kingdom



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KEYWORDS

Adults;
Critical care;
Diaries;
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Summary

Background: Increasing evidence suggests the use of a diary with entries by nurses, doctors, AHPs and the patient’s family can potentially help by “filling in the gaps” and help the patient make sense of a time that they have forgotten or feel confused and have fears about.

Aims: A qualitative exploration of the impact of diaries on critical care patients around the United Kingdom in order to describe the long-term effects of patient diaries.

Methods: In-depth qualitative interviews, using principles of grounded theory, via telephone and email were undertaken. The sample included former patients who responded via adverts on critical care charity/support websites. People who had diaries in the previous 1–3 years were asked about their experiences.

Findings: Eight people who had been patients in various critical care units across the United Kingdom and who had a critical care diary were interviewed. All reported value in having diaries, however, participants reported needing support when first receiving the diary to understand events that took place in critical care.

Conclusion: Diaries can offer a means of filling the gaps for patients who struggle with coming to terms with their critical care recovery, but should be given to patients with forethought and subsequent support.

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Implications for Clinical Practice

- Diaries may be helpful for some people to aid psychological recovery, however it is not always clear who will benefit.
- Diaries should be given back to patients with the support of critical care follow-up services, and at an appropriate time point after discharge.
- The impact of families of having a relative in critical care is highlighted and can be an added burden for the patient when reading diaries retrospectively.
- A question emerges about how diaries should be formatted and administered.

Introduction

There is evidence that patients’ who have been critically ill may experience severe psychological effects such as anxiety and depression, and that at least one in five patients may develop post-traumatic stress disorder (PTSD). Such effects can impact on long-term recovery (Combe, 2005; Pattison et al., 2007; Wade et al., 2013). Some patients experience delusions and hallucinations (Combe, 2005; Jones et al., 2001; Pattison et al., 2007). Many critically ill patients “lose” time in the critical care unit (CCU) when they are unconscious, sometimes for several days (Myhren et al., 2009). Patients and families recount that the patient who has recovered spends a lot of time trying to recall this “lost” time and piecing together what has happened to them (Pattison et al., 2007). Patients have also reported delusional memories which are oftentimes persecutory in nature and can be recalled in vivid detail (Kiekkas et al., 2010), and patients’ descriptions of their critical illness experience are often associated with subsequent distress (Roulin et al., 2007).

Background

Several researchers have demonstrated in small studies that patients and their families have benefited from the use of a diary in the CCU, using it afterwards to fill in the gaps and as a debriefing aid in the CCU follow up clinic (Egerod and Bagger, 2010; Jones et al., 2010; Knowles and Tarrier, 2009). CCU diaries are recognised as PTSD symptoms in CCU patients (Parker et al., 2015). However, the longitudinal effects of diaries are relatively unknown (Elliot and Ratray, 2011), specifically in relation to harm, and have not been explored in any of the existing studies published on diaries. A potential increase in PTSD symptoms for some patients has been suggested (Aitken et al., 2013). A recent Cochrane review found minimal evidence for benefit or harm associated with CCU diaries (Ullman et al., 2014), suggesting a lack of evidence. Longitudinal research beyond six months has been recommended by Ramsay (2011), in order to adequately capture recovery time from critical illness, which can take up to a year (Pattison et al., 2007; Ramsay, 2011).

This article reports on phase one of a two phase study. In phase one, we proposed to explore the issue of effect of CCU diaries on patients who have already been given diaries between one and three years ago in units around the United Kingdom (UK) in order to inform our main evaluation study (phase 2). The rationale for the qualitative interviews with the participants was to gain their in-depth experience of using the diary to aid in their recovery from a critical

illness and to explore any potential harm. Harm was defined as participants describe it.

Method

Recruitment was undertaken with the assistance of three third parties (ICU charities: *ICU steps*, the *Patients and Relatives Committee of the Intensive Care Society* and *I-CanUK*). Adverts were placed on the websites, and through their networks, for ex-ICU patients to take part in the research. The research team had no access to email addresses or contacts unsolicited from the people recruited via the charities. The Chairs of each passed on details to interested parties and professional contact details were on the website. Former patients were offered phone or email interviews. Email interviews followed information governance requirements (Health & Social Care Information Centre, 2015) with contact first being made by participant and only nhs.net email addresses being used for security. In-depth interviews were conducted using a grounded theory approach via these telephone or email interviews (participants’ choice). The interview was a focused qualitative interview allowing some standard cues to be used by the researcher but also allowing for the participant to have the freedom to choose and develop their thoughts, in keeping with grounded theory (Charmaz, 2006; Glaser, 1992; Strauss and Corbin, 1998). Telephone interviews were audio-recorded and transcribed. Participants were consented prior to and following each interview for their tape and subsequent transcript to be used in the study. Each tape was then transcribed, with each transcript being anonymised using a coded number for identification. Data were collected from December 2013 to December 2014.

Ethical approval

A favourable ethical opinion was provided by an NHS Research Ethics Committee (REC). All charity partners were given information about this approval and the REC number was advertised online. Each participant provided informed consent and retained a copy of the participant information sheet and a copy of their consent.

Analysis

Eight interviews were carried out ranging from 29 to 50 minutes. The analysis process involved coding, which is a process for both categorising qualitative data and for describing the implications and details of these categories.

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