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Editorial: The creation of patient diaries as a therapeutic intervention – for whom?

There is now widespread evidence of the potential adverse psychological impact of critical illness (Parker et al., 2015, Nikayin et al., 2016, Rabiee et al., 2016). While many patients will show great resilience, others may develop post-traumatic stress disorder (PTSD) that endures for several years (Bryant et al., 2015) or anxiety or depressive symptoms, often co-morbidly (Parker et al., 2015, Nikayin et al., 2016, Rabiee et al., 2016). One intervention that is thought to reduce these negative psychological outcomes is the use of patient diaries. These tend to be completed by nurses and on many occasions, relatives. Their putative use is to fill any ‘memory gaps’ and provide a ‘sense of coherence’ for patients after critical care (Engstrom et al., 2009). However for the relative, a diary may function more as a ‘journal’ that includes information not just about the patient, and the patient’s experience but also the relatives’ feelings, hopes and emotions. There are a number of important issues to be considered in relation to the use of diaries (Aitken et al., 2013), five of which will be discussed in this editorial: the wish to help; early interventions; journals for relatives; whether journals for relatives are separate to diaries for patients, and reframing interventions to include the relatives.

The wish to help

The wish from many critical care clinicians is to do something to help, and to do so as early as possible during the course of recovery. This is confirmed by a quick browse of relevant literature; the choice to do nothing has been rejected. There are no replicated studies of specific interventions for any psychological distress or disorder after critical illness (Mehlhorn et al., 2014); in its absence the vacuum has been filled by the increasingly widespread, though not universal, adoption of patient diaries. The desire to help has outstripped the supporting evidence.

Early interventions

The complexities of generalising between populations who have experienced different types of trauma needs to be recognised but the potential advantages should also be embraced. Re-inventing the wheel is likely unnecessary, and empirically supported interventions in other populations should be examined – they may need modifications but they may be effective. Although the potential for collaboration between clinicians and researchers from critical care and mental health is clear, it is often yet to be established, and in that void some of what has been learned elsewhere has likely been lost. Inverting this argument other psychological trauma fields would likely learn from treatment of survivors of critical illness. Some features of the critical care experience as a “potentially traumatic event” are unique but there are many commonalities suggesting evidence based treatments for potentially traumatic events are likely fit for purpose for most individuals after critical illness. The use of early interventions of proven efficacy for acute PTSD have not been studied in critical care. A rationale and preferably evidence as to why they may, or may not, work for critical care patients should guide the design of other interventions. Innovative critical care specific approaches may be necessary but the decision is not yet supported by empirical testing. We would argue that in this context any widespread adoption of patient diaries is premature.

Journals for relatives?

In a previous edition of *Nursing in Critical Care* Nielsen and Angel (Nielsen and Angel, 2016) described a timely, helpful and reflective interpretive study on the impact for relatives of writing a journal about their feelings and experience during their relatives critical care stay. The exploration of the perceptions of seven relatives writing journal entries in a “patient diary” was a much needed step forward in

development of this body of evidence. However, as with many such studies, the premise of using a diary is presented relatively uncritically with no discussion of possible alternative approaches. Crucially, the findings assist the understanding of the role of diaries not for the critically ill patient during recovery, but specifically for relatives after having a family member in critical care.

Noteworthy amongst the findings are the relatives describing their involvement as a “meaningful activity” and that writing “allowed them to create a personal space for reflection in the ICU” (Intensive Care Unit). Themes of affiliation are prominent, with the patient and with the nurses, but Nielsen and Angel also mention the affect laden entries of relatives (Nielsen and Angel, 2016). This clearly echoes a previous content analysis (Garrouste-Orgeas et al., 2012) comparing entries from nurses and relatives, with the latter expressing stronger feelings. Indeed in that latter study unlike the positive, hopeful feelings expressed by staff, relatives’ diary entries expressed a mix of both negative and positive feelings. So, when presented with the diary the patient would be exposed to emotional material that is in effect someone else’s distressing recollection or content precipitated by their experience of visiting a critically ill relative. One relative astutely described this as “...writing for my own sake”, and this may be the crucial response from the study. Indirectly Nielsen & Angel touch upon the crux of the matter “...relatives’ narrative in a diary might influence patients in ways not yet known...” (Nielsen and Angel, 2016). In a non-critical care psychological trauma setting criticism of debriefing centred around the timing of the intervention - in the immediate aftermath of trauma – with concern that there was considerable risk of retraumatisation during that period as well as the potential to limit the individual’s ability to naturally process the potentially traumatic events (Bledsoe, 2003).

Diaries for patients and/or for relatives?

There are stark and fundamental differences between helping compose a diary as a family member for your benefit and viewing a diary of your time in critical care, prepared by others. Patients view the diary during their recovery, usually away from critical care; relatives wrote their journal entries whilst still exposed to the critical care environment – the contemporaneous aspect should not be underestimated in any potential therapeutic impact. It would seem unlikely that the same “diary” would provide meaningful activity, catharsis, assistance as a memory prompt, and a shared understanding for relatives while also presenting the coherent narrative of their illness period for patients alongside the other putative impacts (Egerod and Christensen, 2009, Egerod et al., 2011). Crucially, should entries from relatives denoting a farewell or a much needed emotional catharsis be shared with a patient during recovery from the myriad challenges of critical illness? Perhaps as the cover of many personal diaries have warned, some diary entries (by relatives) really should be for the eyes of diarist alone.

Neilsen & Angel (Nielsen and Angel, 2016) rightly state further exploration is needed but their statement that “...asking the relatives to author a diary *for the patient* can be an important nursing intervention...” is not supported by the evidence presented to date.

Reframing the focus of intervention to include relatives

One of the most consistent predictors of PTSD is the relative lack of social support after psychological trauma (Brewin et al., 2000). As many relatives will suffer psychological distress themselves during the critical care admission of their relative (Davidson et al., 2012) this highlights the need to extend the frame of who needs intervention; the relative will be the main source of social support for the patient and if impaired and less able to care, the social situation will be less than ideal. The expansion of the

traditional focus of psychological interventions to include the relative is necessary to maximise the environment the patient encounters after discharge.

The use of some variant of a journal is worth further exploration. However, completing journal entries does not guarantee a benefit, or even the absence of harm - or worse - for either the relative or patient. Indeed, echoing the needs of the gamut of patients, not all relatives will have needed the “intervention”. It is also very possible that the relatives who benefit and the patients who benefit would not be those related to each other, further complicating the intervention strategy.

Conclusion

The introduction and implementation of diaries for critical care patients has tended to be piecemeal and driven by motivated individuals rather than a co-ordinated approach. The Cochrane review process demonstrated that currently there is no evidence of an effect on post-traumatic stress symptoms for patients after receipt of a diary, though there was a significant reduction in post-traumatic stress symptoms for family members (Ullman et al., 2014). The study by Nielsen and Angel (Nielsen and Angel, 2016) is certainly consistent with the latter, with relatives’ experiencing the contribution to a diary as positive.

More research on early interventions for psychological disorder after critical illness is needed, and this clearly includes patient diaries. It is crucial that harsh lessons learned elsewhere in various populations after psychological trauma are applied; the effectiveness of any intervention needs to be demonstrated, and the intervention targeted at those with an identified need for help. Sleeping dogs should be allowed to lie.

Conflict of Interest

The authors all contributed to the Cochrane collaboration review “Diaries for recovery from critical illness”

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