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Article:

Teece, A orcid.org/0000-0001-9001-2619 (2020) An ICU diary written by relatives: Who is it really written for? *Intensive and Critical Care Nursing*, 57. 102815. ISSN 0964-3397

<https://doi.org/10.1016/j.iccn.2020.102815>

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An ICU diary written by relatives: Who is it really written for?

Dear Editor,

I read with interest the paper by Hojager Nielsen et al. (2019) regarding patients' perceptions of a diary written for them by their relatives.

I was struck by one of the patient responses in particular: 'Yes, it's my fault and I don't want to dwell on it' This patient refused to read his diary as he found the account of trauma that his illness had caused his relatives too distressing to read.

My clinical experience with diaries is primarily that they are written by nurses for the patient and family to read together. The diary forms an account of the critical care stay, with the intention of 'filling in gaps' for the patient and providing a 'way in' for the patient and relative to share experiences of the illness (Engström et al., 2009).

A diary written solely by relatives could risk the emphasis shifting from the patient's experience to the experience of the relatives. In this way, the diary becomes a repository for their trauma rather than a method through which the patient might reconstruct their illness narrative and move forwards towards recovery. Evidence suggests that many patients require formal or informal care post-discharge and may not be able to return to their previous jobs (Griffiths et al., 2013). They may already feel like a burden on their families. To receive a document containing the grief and distress their illness caused their loved ones may add to feelings of guilt, frustration, and distress.

I believe relatives have a place in the completion of the diary. Their words of love and encouragement are valued by patients and evidence that the patient was not alone (Storli and Lind, 2009). However, I feel they should be guided by clinical staff when completing the diary to keep the purpose of the document in mind, and support should be offered to enable them to access help in expressing and processing their own trauma.

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