



City Research Online

City, University of London Institutional Repository

Citation: Aitken, L. M., Rattray, J., Kenardy, J. A., Hull, A., Ullman, A., Le Brocque, R., Mitchell, M., Davis, C. & Macfarlane, B. (2015). Diaries For Intensive Care Unit Survivors (discuss): Perspectives Of Patients And Family Members Regarding Psychological Support. *American Journal of Respiratory and Critical Care Medicine*, 191, A4503.

This is the accepted version of the paper.

This version of the publication may differ from the final published version.

Permanent repository link: <https://openaccess.city.ac.uk/id/eprint/15135/>

Link to published version:

Copyright: City Research Online aims to make research outputs of City, University of London available to a wider audience. Copyright and Moral Rights remain with the author(s) and/or copyright holders. URLs from City Research Online may be freely distributed and linked to.

Reuse: Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge. Provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.

City Research Online:

<http://openaccess.city.ac.uk/>

publications@city.ac.uk

Diaries for Intensive Care Unit Survivors (DISCUSS): Perspectives of patients and family members regarding psychological support

LM Aitken^{1,2,3}, J Rattray⁴, J Kenardy⁵, AM Hull⁶, A Ullman¹, R Le Brocque⁵, M. Mitchell^{1,2}, C Davis², B Macfarlane^{1,2}

1. Griffith University, Australia
2. Princess Alexandra Hospital, Australia
3. City University London, United Kingdom
4. University of Dundee, United Kingdom
5. University of Queensland, Australia
6. NHS Tayside, United Kingdom

Rationale

Diaries summarising care in the intensive care unit (ICU) have been incorporated into routine practice in some countries, although diary format, content, timing and method of delivery vary. The evidence and underpinning theory to support diary use is limited and uptake by patients and family members is infrequent raising questions of acceptance and generalisability. The purpose of this study was to elicit preferences of ICU survivors and their family members regarding diaries and other psychological support mechanisms, specifically if they wish to receive a diary or alternative psychological support material, what content they would like and preferred process and timing for receiving this information.

Methods

Patients in a general ICU for ≥ 3 days and their family members were invited to participate in this prospective exploratory study. Semi-structured interviews were conducted 3-5 months after ICU discharge via phone or in person. Interviews were transcribed verbatim and thematic analysis was conducted, with codes developed inductively using an iterative process and agreement on themes negotiated by team members.

Results

Forty-one survivors of critical illness and 26 family members consented to participation. Patients were usually male (63%), aged 50 ± 18 years and stayed in ICU for median 8.5 (IQR 5.3-12.6) days.

Patients and family members raised similar themes, although with a diverse range of opinion related to each aspect of ICU diary use. Considerations included: 1) memory and recall with some respondents wanting to know detail while others were either not curious or had no desire to be reminded of their ICU stay; 2) level of detail ranging from a comprehensive summary of clinical activities to a predominantly personal record of the experience; 3) the desire to develop shared memory of ICU and for the patient to understand what the family had been through; 4) timing of provision of diary from soon after the patient woke to months later; 5) concerns regarding the workload of staff to contribute to the diary; 6) potential to

exacerbate or alternatively relieve stress; 7) uncertainty in regard to writing in diary as the patient may not survive; 8) ownership of the diary resting with the patient.

Conclusions

Common themes have been expressed by participants, although views regarding these themes were extremely diverse. Development of future interventions to aid psychological recovery must take into account these variable views to minimise the potential for causing distress to some survivors of critical illness and/or their family members whilst helping others.

Funding: Griffith Health Institute seed funding, Griffith University, Australia