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

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### **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  $\geq 3$  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  $50 \pm 18$  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.

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