Remembering the unforgettable: trialing ICU diaries in North America

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Survivors, and their families, can suffer significant psychological morbidity after intensive care, including the development of anxiety, depression, and posttraumatic stress disorder (1, 2). These conditions can persist after physical recovery, impairing their ability to comprehensively regain function (3). With growing understanding of the significance of post-intensive care unit (ICU) survivorship, clinicians and researchers are seeking tools and strategies to prevent, identify and treat these debilitating disorders (4).

Survivors of critical illness frequently report extensive gaps, or flawed memories, of being in intensive care (5). These distorted memories can be related to medications, sleep-deprivation, ICU therapies, or underlying illness (5). Diaries are emerging in intensive care practice, used by clinicians and families to create a narrative of the patients critical care journey (6, 7). The rationale proposed for the diary is that the availability of a coherent narrative of events will facilitate a more complete understanding of the ICU experience. Despite this rationale, it is unclear whether or how patient and family access to a coherent narrative could impact psychological distress in patients and families after ICU. However, the diaries can be used by families during ICU admission, and by patients during recovery, to provide a chronological, factual description of events. Despite a Cochrane review (8) highlighting the low quality of evidence associated with the efficacy of intensive care diaries to promote psychological recovery, descriptions of their implementation continue to grow (9).

This issue of Critical Care Medicine includes the first randomized controlled trial (RCT) evaluating intensive care diaries to be undertaken in North America (10). Based in a single, tertiary, 10-bed, medical-surgical, adult ICU in Canada, 58 participants were recruited and were randomized to receive one of four arms: (i) usual care; (ii) ICU diary; (iii) psychoeducation (PE); (iv) ICU diary and PE. Designed to test study feasibility (enrolment and

intervention delivery), the secondary outcomes evaluated intervention acceptability, and the efficacy of the interventions to reduce psychological distress, as described as symptoms of anxiety, depression and post-traumatic stress (via self-report survey) at 30 and 90 days after ICU discharge.

With a restrictive eligibility criteria (only 13% patients screened, were eligible) and challenging consent rates (58% of patients approached, consented), recruitment rates were slow (1.9 per month), with recruitment taking 2 ½ years. Of these 58 participants, 64% completed the study (n=37), with attrition due to patient death (n=12), withdrawals (n=6) and lost to follow up (n=2). However, intervention delivery and acceptability was high, with 93% of participants claiming their diary, 96% of participants receiving their PE and frequent ongoing application of the diary (both writing and reviewing the diary). A multi-site efficacy trial of ICU diaries and PE to improve psychological recovery is achievable.

Within this pilot study, only the intervention group that received both the ICU diary and PE had significantly reduced median depression (5.0 [IQR 3-7] vs 2.0 [IQR 1-3]) and post traumatic symptoms (1.0 [IQR 0.5-1.4) vs 0.4 [IQR 0.1-0.7]) between 30 and 90 days. Additional post-hoc analysis revealed that patients who received the diary intervention, with or without PE, had significantly lower median anxiety (3.0 [IQR 2-6.25] vs 8.0 [IQR 7-10]) and depression (3.0 [1.75-5.25 vs 5.0 [4-96]) symptomatology at 90 days, than those that did not.

Small sample sizes, lack of diagnostic interview, reliance on flawed diagnostic tools and post-hoc analysis, limits the generalizability and reliability of the study results. However, there is a growing body of evidence, including RCTs (11, 12) and observational studies (6, 13, 14), to

suggest there is a cohort of patients, families, and ICUs, for which diaries may be helpful. Amongst clinicians, families and patients, who, when invited and elect to use them, their use is associated with improvements towards recovery. Together, this means that ICU diaries are a potentially useful tool, in addition to other forms of psychological support, in this cohort of informed, consenting patients, families and ICU clinicians. However, it is still unclear for whom these diaries are most likely to benefit. Following a post-hoc analysis of their ICU diary intervention, Jones and colleagues (13) suggest that highly distressed individuals might benefit most. If this shown to be a reliable finding, it might be appropriate to focus the ICU diary intervention on high risk patients.

"Diaries were reviewed with each participant by a member of our research team." This statement made within the description of the study interventions fails to define the nature of this review. Was it fact-focussed? Was there any attempt to assist patients to use diaries to promote memory that is more complete? Was there any psychological support provided within this process? In fact, it is not clear what did happen in the intervention, whether there was consistency and fidelity in the intervention?

Is factual memory always comforting? Critical illness and its care in the ICU environment is intimidating, and many survivors may prefer the unknown, to the known experience. How ICU diaries perform in our heterogeneous non-study populations, is yet to be determined. The 'opt-in' nature of the ICU diary trials to date, appears to be key. How this can be replicated and operationalized outside of research studies is important. Additional guidance is needed to ensure pragmatic identification of the appropriate ICU patient and family cohort, and the clinical services that need to provide quality diary development, provision and patient follow up. We have seen harm in previous ICU innovations and psychological interventions (15),

when small clinical trials are over-generalized. This is an innovation yet to be tested in the complex and dynamic, wider ICU environment.

Are ICU diaries the best, or just the best so far? Are there other solutions that are likely to be more effective, but are more expensive? Other models-of-care and health services interventions, such as psychologists on staff and follow-up clinics are also awaiting high quality evidence, and health economic evaluation. Psychological morbidity after ICU admission may be preventable, but by introducing ICU diaries, are we under-treating a potentially significant consequence? Should timing or intensity of an intervention be more tailored, to either individual need or preference?

It could be argued that this study was not really a fair test of a PE intervention. PE is, as the name suggests, an educative intervention. Provision of a brochure could be seen as a remarkably passive model of education in a clinical service context. Individuals appear to have been provided a brochure, however there seems to be no attempt to facilitate its use or comprehension of the information presented, or, in the combined PE and ICU diary condition, to reference and contextualize the information provision to the use of the diary. This seems especially important as the impact of PE appears to be enhanced in combination with the ICU diary. It would be worthwhile exploring how this might be occurring and whether this effect can be facilitated.

So moving forward? A fully- powered RCT (11) of ICU diaries is underway within French ICUs, and this will be an important step towards understanding the power of this intervention. Until then, it may be important to start thinking of diaries as an emerging rather than definitive tool in our toolbox of high quality ICU interdisciplinary care. And, let’s keep transforming.

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