EDITORIAL

Psychological Consequences of Admission to the ICU Helping Patients and Families

Louise Rose, RN, MN, PhD; Fiona Muttalib, MDCM; Neill K. J. Adhikari, MDCM, MSc

For most patients and their families, admission to the intensive care unit (ICU) is an unanticipated event that causes substantial psychological distress. For patients, short- and long-term consequences include delirium, anxiety, depression,

 \leftarrow

Related articles pages 216 and 229

and acute and posttraumatic stress disorder (PTSD).¹ Psychological consequences may be exacerbated by delusions

experienced during delirium, which is common among critically ill patients and has adverse effects on physical and cognitive function and leads to increased health care use and costs. For families, anxiety and acute stress arise from concern and uncertainty regarding the prognosis of their family member. Long-term psychological effects in family members appear similar to those experienced by patients. Mitigating these effects is increasingly recognized as a core objective of critical care, along with managing and preventing organ failure and providing timely prognostic information and compassionate end-of-life care when appropriate.

In preceding decades, clinicians conceptualized the ICU as psychologically disturbing and stressful. Limiting exposure of family members (via restricted visiting hours) and patients (via heavy sedation) to this environment was thought to be beneficial for both, and clinicians likely perceived benefits to uninterrupted workflow. This concept led to actions, now viewed as paternalistic, of locked doors, limitations on visiting hours and on the number and type of bedside visitors (eg, 2 at any time and only immediate family), and removal of visitors from the bedside during medical procedures, nursing care, and rounds.

Alternative approaches that may improve psychological outcomes for patients and families in the ICU are unrestricted family visits to the patient's bedside and recording details of the patient's ICU admission using plain language and images in a diary format. Visiting family members may provide patients with psychological and cognitive support by grounding them in their life before critical illness and participate in care activities to relieve pain and mobilize the patient. In doing so, visitors may also benefit from decreased separation anxiety and less uncertainty and distress relating to prognosis and the treatment plan, and may engage more with the ICU team, facilitating a trusting relationship. Similarly, ICU diaries allow family members to document the patient's experience of the ICU admission and serve as a real-time record of events that can be reviewed during admission and after discharge. These functions may decrease anxiety and PTSD symptoms associated with poor

or absent recall of the ICU admission in both patients and family members.⁵

In this issue of JAMA, 2 reports focus on the psychological well-being of patients in the ICU and their families. Rosa and colleagues⁶ report findings from a cluster crossover randomized clinical trial in 36 Brazilian ICUs that examined the effect of a flexible family visiting model (up to 12 h/d) compared with usual practice of a restrictive visiting model (median of 1.5 h/d) on the incidence of delirium. During the intervention phase, family members also attended a structured meeting and were provided education on the ICU environment, common procedures, the multidisciplinary team, and delirium; received an informational brochure; and were given access to a website that provides information about critical illness, care processes, and bedside visits. Patients in the flexible visiting model group had a median duration of family visiting of 4.8 hours per day vs 1.4 hours per day in the restricted visiting group (P < .001), but the number of visitors per day was not affected. Despite this increase in visitor time, there were no differences in the primary outcome of incident delirium (18.9% of patients in the flexible visiting model vs 20.1% in the restricted visiting model; P = .44) or any of the patient-related secondary outcomes.

However, the flexible visiting model reduced the level of psychological distress of family members, measured by the Hospital Anxiety and Depression Scale (HADS) scale, and increased family satisfaction. Because the intervention included several components, as is often the case with biobehavioral interventions, it cannot be determined if the positive effects for family members were due to flexible visiting hours and improved adaptation to the ICU environment or whether the mechanism involved greater engagement in shared decision-making. The benefit for family members did not come at the expense of clinician distress or dissatisfaction, as assessed by the Maslach Burnout Inventory.

Despite the high ICU-level adherence to flexible visiting hours, the intervention may not have increased family members' presence or involvement in bedside care sufficiently to influence patient-level outcomes. Family members enrolled in the study spent less than half of the maximum possible visiting time at the bedside, likely because of competing commitments. Additionally, even though the intervention group received additional education about the ICU environment, no specific instruction about strategies to reduce delirium was reported. Although family members' self-reported involvement in patient care was a tertiary outcome, the trial did not document bedside activities by family

members and analyses did not consider associations between family involvement in care and patient-level outcomes. Arguably, the quality and not the quantity of family visits may influence patient outcomes, and the intervention may have only allowed the presence of the family without enabling them to direct and participate in the delivery of care in a family-centered approach.7 In addition, there was a suggestion that the flexible model may reduce delirium more in patients with greater illness severity (P value for interaction of intervention with severity of illness, .09), but additional research is needed to evaluate this observation.

Also in this issue of JAMA, Garrouste-Orgeas and colleagues⁸ report the results of a multicenter (35 French ICUs) randomized clinical trial that examined use of an ICU diary completed by both clinicians and family members. In the intervention group, the diary was provided to the patient, or the family member if the patient was confused, on or close to the day of ICU discharge. If the patient died, the diary and a condolence letter were mailed to the family. Unlike in other trials, 9,10 routine use of a diary was uncommon in participating centers and distribution of the diary was not linked to a postdischarge follow-up visit to provide context and support. The control group received usual care without a diary.

The trial recruited 657 patients and their family members and found no between-group difference in the primary outcome of PTSD symptoms in ICU survivors (29.9% of patients in the ICU diary group vs 34.3% in the control group; P = .39), measured 90 days after ICU discharge by a blinded psychologist and defined by a score on the Impact of Events Scale-Revised (IES-R) scale greater than 22 (range, 0-88; higher scores indicate more severe symptoms). There were also no differences in secondary outcomes of PTSD in family members, anxiety or depression symptoms (measured with HADS scores) of patients or family members, or patient recall of memories (factual or delusional) of the ICU. Moreover, and for unclear reasons, the risk of mortality in the ICU among patients in the intervention group was higher than in the control group (P > .01), although the difference was attenuated at hospital discharge (*P* values not reported).

As found with other studies that examined the effect of ICU diaries on PTSD11 and anticipated in the study design, loss to follow-up at 90 days among patient participants was almost 50%; in family member participants, loss to follow-up was only 14.6%. Notably, 46.4% of family members had PTSD symptoms compared with 32.2% of patients. These risks of PTSD may be underestimated because participants with PTSD may be more avoidant of follow-up that reminds them

of the ICU. A high prevalence of PTSD in family members of patients in the ICU in France has been reported¹² and attributed to a more paternalistic medical decision-making style that can create discordance with the preferences of family members. 13 The findings of this trial underscore the need for effective psychological support for patient survivors of the ICU and their family members.

This study found no evidence of harm from ICU diaries, and therefore provides no reason for ICUs that provide them to stop using them, particularly if their implementation includes other plausibly effective cointerventions, such as mental health support during a structured follow-up visit. However, ICUs that do not provide diaries will find no compelling reason to adopt them. Because Garrouste-Orgeas and colleagues tested the intervention in predominantly diary-naive ICUs, it is possible that the content and instructions to participants were not sufficiently detailed, at least in the beginning of the trial. An analysis that considers the order of patient enrollment in each center to reflect experience in delivering the intervention would be informative, as done for other complex interventions.14

Perhaps it should come as no surprise that improving psychological outcomes of critically ill patients and their family members may be as challenging as improving survival in patients with acute respiratory distress syndrome, sepsis, or cardiac arrest. The interventions depend on context; for example, the flexible visitation intervention tested by Rosa et al⁶ in Brazil was standard in most ICUs in the study conducted by Garrouste-Orgeas et al in France,8 and the effect of diaries that require written language commonly understood by the patients, family members, and health care team may depend on cultural and geographic factors. Future research may require a precision framework to risk-stratify patients and family members for postdischarge anxiety, depression, or PTSD symptoms and a tailored ladder of interventions to prevent these outcomes. These interventions may include lower-intensity approaches, such as flexible visiting hours with family participation in patient care and- a patient diary and telephone follow-up, and more intensive approaches that include frequent meetings with ICU clinicians and follow-up after ICU discharge with mental health professionals. Although it would be easy to be dismissive of these 2 trials to improve post-ICU outcomes in patients and families^{6,8} because of the statistically nonsignificant primary outcome findings, their results highlight the high risk of poor psychological outcomes and the heterogeneity of the patients and families at risk.

ARTICLE INFORMATION

Author Affiliations: Nursing, Midwifery and Palliative Care, King's College London, London, United Kingdom (Rose); Department of Critical Care Medicine, Sunnybrook Health Sciences Centre, Toronto, Ontario, Canada (Rose, Adhikari); Interdepartmental Division of Critical Care Medicine, University of Toronto, Toronto, Ontario, Canada (Rose, Adhikari); Center for Global Child Health, Hospital for Sick Children, University of Toronto, Toronto, Ontario, Canada (Muttalib).

Corresponding Author: Neill K. J. Adhikari, MDCM, MSc, Department of Critical Care Medicine, Sunnybrook Health Sciences Centre, 2075 Bayview Ave, Room D1.08, Toronto, ON, Canada M4N 3M5 (neill adhikari@utoronto.ca)

Conflict of Interest Disclosures: None reported.

REFERENCES

1. Karnatovskaia LV, Schulte PJ, Philbrick KL, et al. Psychocognitive sequelae of critical illness and

correlation with 3 months follow up. J Crit Care. 2019;52:166-171. doi:10.1016/j.jcrc.2019.04.028

- 2. Svenningsen H, Tønnesen EK, Videbech P, Frydenberg M, Christensen D, Egerod I. Intensive care delirium: effect on memories and health-related quality of life. J Clin Nurs. 2014;23(5-6):634-644. doi:10.1111/jocn.12250
- 3. Pandharipande PP, Ely EW, Arora RC, et al. The intensive care delirium research agenda: a multinational, interprofessional perspective.

- Intensive Care Med. 2017;43(9):1329-1339. doi:10. 1007/s00134-017-4860-7
- 4. van Beusekom I, Bakhshi-Raiez F, de Keizer NF, Dongelmans DA, van der Schaaf M. Reported burden on informal caregivers of ICU survivors: a literature review. *Crit Care*. 2016;20:16. doi:10. 1186/s13054-016-1185-9
- 5. McIlroy PA, King RS, Garrouste-Orgeas M, Tabah A, Ramanan M. The effect of ICU diaries on psychological outcomes and quality of life of survivors of critical illness and their relatives: a systematic review and meta-analysis. *Crit Care Med*. 2019;47(2):273-279. doi:10.1097/CCM. 0000000000003547
- **6**. Rosa RG, Falavigna M, da Silva DB, et al. Effect of flexible family visitation on delirium among patients in the intensive care unit: the ICU visits randomized clinical trial. *JAMA* [published July 16, 2019]. doi: 10.1001/jama.2019.8766
- **7**. van Mol MM, Boeter TG, Verharen L, Kompanje EJ, Bakker J, Nijkamp MD. Patient- and

- family-centred care in the intensive care unit: a challenge in the daily practice of healthcare professionals. *J Clin Nurs*. 2017;26(19-20):3212-3223. doi:10.1111/jocn.13669
- **8**. Garrouste-Orgeas M, Flahault F, Vinatier I, et al. Effect of an ICU diary on posttraumatic stress disorder symptoms among patients receiving mechanical ventilation. *JAMA* [published July 16, 2019] doi:10.1001/jama.2019.9058
- **9.** Knowles RE, Tarrier N. Evaluation of the effect of prospective patient diaries on emotional well-being in intensive care unit survivors: a randomized controlled trial. *Crit Care Med*. 2009;37(1):184-191. doi:10.1097/CCM.0b013e31819287f7
- 10. Jones C, Bäckman C, Capuzzo M, et al; RACHEL group. Intensive care diaries reduce new onset post traumatic stress disorder following critical illness: a randomised, controlled trial. *Crit Care*. 2010;14(5): R168. doi:10.1186/cc9260
- **11**. Jackson JC, Hart RP, Gordon SM, Hopkins RO, Girard TD, Ely EW. Post-traumatic stress disorder

- and post-traumatic stress symptoms following critical illness in medical intensive care unit patients: assessing the magnitude of the problem. *Crit Care*. 2007;11(1):R27. doi:10.1186/cc5707
- **12.** Petrinec AB, Daly BJ. Post-traumatic stress symptoms in post-ICU family members: review and methodological challenges. *West J Nurs Res.* 2016; 38(1):57-78. doi:10.1177/0193945914544176
- **13.** Pochard F, Azoulay E, Chevret S, et al; French FAMIREA Group. Symptoms of anxiety and depression in family members of intensive care unit patients: ethical hypothesis regarding decision-making capacity. *Crit Care Med*. 2001;29 (10):1893-1897. doi:10.1097/00003246-200110000-00007
- **14.** Meade MO, Young D, Hanna S, et al. Severity of hypoxemia and effect of high-frequency oscillatory ventilation in acute respiratory distress syndrome. *Am J Respir Crit Care Med.* 2017;196(6):727-733. doi:10.1164/rccm.201609-1938OC