

- 7 Arkema EV, Eklund A, Grunewald J, Bruze G. Work ability before and after sarcoidosis diagnosis in Sweden. *Respir Med* 2018;144S:S7–S12.
- 8 Harper LJ, Love G, Singh R, Smith A, Culver DA, Thornton JD. Barriers to care among patients with sarcoidosis: A qualitative study. *Ann Am Thorac Soc* 2021;18:1832–1838.
- 9 Sharp M, Brown T, Chen ES, Rand CS, Moller DR, Eakin MN. Association of medication adherence and clinical outcomes in sarcoidosis. *Chest* 2020;158:226–233.
- 10 Evans MK. Health equity - are we finally on the edge of a new frontier? *N Engl J Med* 2020;383:997–999.
- 11 Baughman RP, Field S, Costabel U, Crystal RG, Culver DA, Drent M, *et al*. Sarcoidosis in America. Analysis based on health care use. *Ann Am Thorac Soc* 2016;13:1244–1252.
- 12 Bailey ZD, Feldman JM, Bassett MT. How structural racism works - racist policies as a root cause of U.S. racial health inequities. *N Engl J Med* 2021;384:768–773.
- 13 Cox CE, Donohue JF, Brown CD, Kataria YP, Judson MA. Health-related quality of life of persons with sarcoidosis. *Chest* 2004;125:997–1004.
- 14 Kampstra NA, Grutters JC, van Beek FT, Culver DA, Baughman RP, Renzoni EA, *et al*. First patient-centred set of outcomes for pulmonary sarcoidosis: a multicentre initiative. *BMJ Open Respir Res* 2019;6:e000394.

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Understanding the Impact of Critical Illness on Families: A Call for Standardization of Outcomes and Longitudinal Research

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Over the past decade, our understanding of the challenges encountered by those who survive a hospitalization that required critical care has grown substantially (1). Although alive, many survivors face new or exacerbated physical, social, and emotional problems (2, 3). More recently, researchers have identified broader challenges related to survivorship, including a lasting impact on informal caregivers and family members (4, 5). However, the long-term problems experienced by family members, and the risk factors and trajectories of these symptoms, remain poorly understood.

In this issue of *AnnalsATS*, Wendlandt and colleagues (pp. 1868–1875) provide an important contribution to this literature with their study of potential risk factors for mental health outcomes among surrogate decision-makers (6). Using data from a multicenter randomized trial of a communication intervention for patients with chronic critical illness (CCI), the authors examined the presence and severity of symptoms of post-traumatic stress disorder (PTSD) among surrogate decision-makers at 90 days after hospital discharge. The association between patient health status at 90 days and surrogates' symptoms was also explored. In their study, CCI was defined as having received at least 7 days of mechanical ventilation during the index hospitalization without an expectation of being liberated or dying in the proceeding 72 hours. Patients' follow-up health statuses were assessed at 90 days using a 6-level categorical variable. These categories, which are based on the Centers for Medicare and Medicaid Services categories of care determinations, included 1) living at home; 2) living at an acute rehabilitation facility; 3) living at a skilled nursing facility or nursing home; 4) living at a long-term acute care facility; 5) being in a short-term acute care hospital; and 6) death (7). In the cohort of 224 patients and 306

surrogates with complete follow-up data available at 90 days, nearly a third ($n = 91$ [30%]) of surrogates demonstrated symptoms of PTSD suggestive of a probable diagnosis (6). Guided by a causal conceptual model, the authors adjusted for several potential confounders and found higher levels of PTSD symptoms among surrogates of patients readmitted to the acute care environment and the surrogates of patients who had died compared with surrogates of patients living at home.

This study provides new insight into the mental health of surrogates and family members more broadly in the months after critical care discharge. Specifically, Wendlandt and colleagues have identified an important association between patient health status and the mental health of the surrogate decision-

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Conceptual model for family caregiver long-term outcomes

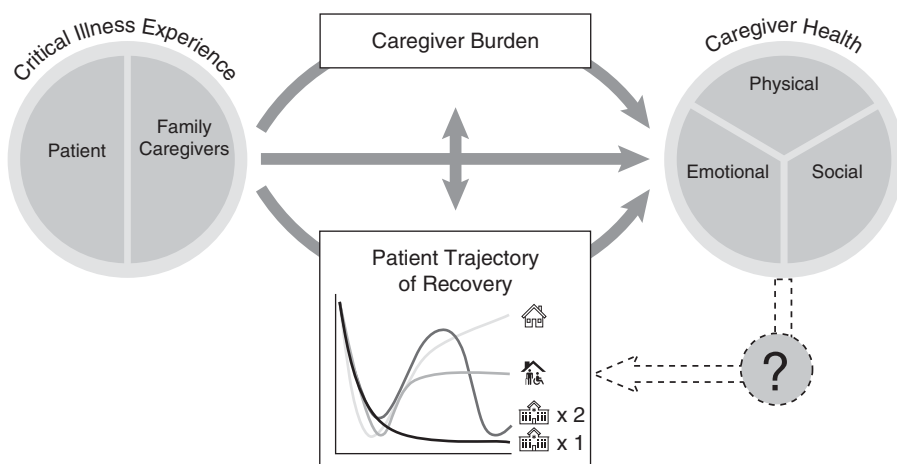


Figure 1. A conceptual model for family caregiver long-term outcomes. Family caregivers and surrogate decision-makers are at risk for new or exacerbated deficits in physical, emotional, and social health after a loved one's critical illness experience. The mechanisms of these deficits and their relationships to caregiver burden and patients' trajectories of recovery remain poorly understood. We hypothesize that deficits in caregivers' health may also influence a patient's recovery.

maker. The impact of acute care rehospitalization on PTSD is important as rehospitalization is common in survivors of critical illness (8, 9). The potential pathways in which an acute care readmission may cause caregiver distress are numerous, ranging from financial hardships to the exacerbation of emotional trauma originating from the initial hospital admission. It will be important for future research to examine the mechanisms behind this increase in symptomology with a goal of identifying and tailoring targeted interventions, such as enhanced emotional support, as suggested by the authors.

As with any analysis, there are of course some limitations. The cross-sectional assessment of both the primary outcome and the predictor (both assessed a single time point 90 days after hospital discharge) restricts a truly causal interpretation of the current study. Yet these findings suggest that 1) there are likely complex interactions between patients' trajectories of recovery and family long-term outcomes and 2) familial distress and impairments in caregivers' own physical and mental health may themselves contribute to worsened patient outcomes. To support further thinking and research, we created a draft conceptual framework regarding this potential interaction between the recovery

trajectories of patients and caregivers (Figure 1).

The findings from the analysis conducted by Wendlandt and colleagues raise several interesting future research questions. For example, although the authors have adjusted for potential confounders in their analysis, important details such as surrogate health and the nature of patient care needs at 90 days have not been assessed. Those with CCI have complex and dynamic needs after the acute hospital stay (10). Although measuring and capturing these needs is complex, it is essential to understand how effective interventions can be developed and delivered. Future longitudinal studies capturing a broader range of patient and family outcomes at multiple time points are necessary to understand the trajectory of these symptoms and their interaction with patient health status.

To improve support for surrogate decision-makers in the intensive care unit (ICU) and inform the development of interventions for caregivers, a coherent and structured research agenda is needed. We propose that a key first step is to establish consensus on the standardization of outcomes to be measured in future work. Just as a core set of outcome measures has been developed for studies of patients after acute respiratory failure, consensus building around the key

measures that capture the impacts of acute and chronic critical illness for surrogate decision-makers and family caregivers should be prioritized (11, 12). The absence of a codified set of outcomes impairs conceptual and empirical synthesis across studies for this population, which has spillover effects in delaying the development and testing of caregiver interventions. Moreover, while most research has been limited to the measurement of emotional and mental health outcomes, the wider impact for family members and caregivers has yet to be fully explored. The creation of a core outcome set for this family cohort will help synthesize the evidence in this field and identify opportunities for interventions.

Greater recognition of the long-term outcomes of patients with CCI and caregivers could also benefit the profession of critical care. Many clinicians may not consider long-term patient and caregiver outcomes the priority or responsibility of acute care (13). However, the provision of aftercare by critical care clinicians may provide multiple benefits, not only to the patient and caregivers but also to the critical care team. For example, rehabilitation specialists in isolation may not have a full understanding of the ICU environment and may not be able to accurately reconstruct the critical illness journey, a process that is known to be valued by patients (14). Recent data also highlight that understanding the whole patient and caregiver journey may alleviate symptoms of burnout in ICU clinicians, a concept that is becoming increasingly important in the coronavirus disease (COVID-19) era (15).

In conclusion, Wendlandt and colleagues have identified an important association between the health status of ICU patients and the mental health outcomes of their surrogates. Their work highlights the need for ongoing study in this field to better understand the challenges and needs of patients and their caregivers and how those may affect the long-term outcomes of patients and families impacted by critical illness. Moving forward, the development and measurement of standardized longitudinal outcomes will help advance this understanding for both patients with CCI and caregivers. ■

Author disclosures are available with the text of this article at www.atsjournals.org.

References

- 1 Mikkelsen ME, Still M, Anderson BJ, Bienvenu OJ, Brodsky MB, Brummel N, *et al.* Society of Critical Care Medicine's International Consensus Conference on prediction and identification of long-term impairments after critical illness. *Crit Care Med* 2020;48:1670–1679.
- 2 Needham DM, Davidson J, Cohen H, Hopkins RO, Weinert C, Wunsch H, *et al.* Improving long-term outcomes after discharge from intensive care unit: report from a stakeholders' conference. *Crit Care Med* 2012;40:502–509.
- 3 Hauschildt KE, Seigworth C, Kamphuis LA, Hough CL, Moss M, McPeake JM, *et al.*; National Heart, Lung, and Blood Institute (NHLBI) Prevention and Early Treatment of Acute Lung Injury (PETAL) Network. Financial toxicity after acute respiratory distress syndrome: A national qualitative cohort study. *Crit Care Med* 2020; 48:1103–1110.
- 4 Johnson CC, Suchyta MR, Darowski ES, Collar EM, Kiehl AL, Van J, *et al.* Psychological sequelae in family caregivers of critically ill intensive care unit patients. A systematic review. *Ann Am Thorac Soc* 2019;16:894–909.
- 5 Sevin CM, Boehm LM, Hibbert E, Bastin AJ, Jackson JC, Meyer J, *et al.* Optimizing critical illness recovery: Perspectives and solutions from the caregivers of ICU survivors. *Crit Care Explor* 2021; 3:e0420.
- 6 Wendlandt B, Ceppe A, Cox CE, Hanson LC, Nelson JE, Carson SS. The association between patient health status and surrogate decision maker post-traumatic stress disorder symptoms in chronic critical illness. *Ann Am Thorac Soc* 2021;18:1868–1875.
- 7 Gage B, Pilkauskas N, Dalton K, Constantine R, Leung M, Hoover S, *et al.* Long-term care hospital (LTCH) payment system monitoring and evaluation: phase II report. RTI International; 2007. CMS Contract No. 500-00-0024, TO#20.
- 8 Prescott HC, Langa KM, Liu V, Escobar GJ, Iwashyna TJ. Increased 1-year healthcare use in survivors of severe sepsis. *Am J Respir Crit Care Med* 2014;190:62–69.
- 9 McPeake J, Quasim T, Henderson P, Leyland AH, Lone NI, Walters M, *et al.* Multimorbidity and its relationship with long-term outcomes following critical care discharge: a prospective cohort study. *Chest* [online ahead of print] 18 Jun 2021; DOI: 10.1016/j.chest.2021.05.069.
- 10 Dubin R, Veith JM, Grippi MA, McPeake J, Harhay MO, Mikkelsen ME. Functional outcomes, goals, and goal attainment amongst chronically critically ill long-term acute care hospital patients. *Ann Am Thorac Soc* [online ahead of print] 13 May 2021; DOI: 10.1513/AnnalsATS.202011-1412OC.
- 11 Blackwood B, Ringrow S, Clarke M, Marshall JC, Connolly B, Rose L, *et al.* A core outcome set for critical care ventilation trials. *Crit Care Med* 2019; 47:1324–1331.
- 12 Needham DM, Sepulveda KA, Dinglas VD, Chessare CM, Friedman LA, Bingham CO III, *et al.* Core outcome measures for clinical research in acute respiratory failure survivors. An international modified Delphi consensus study. *Am J Respir Crit Care Med* 2017; 196:1122–1130.
- 13 Meyer J, Brett SJ, Waldmann C. Should ICU clinicians follow patients after ICU discharge? Yes. *Intensive Care Med* 2018;44:1539–1541.
- 14 McPeake J, Boehm LM, Hibbert E, Bakhrum RN, Bastin AJ, Butcher BW, *et al.* Key components of ICU recovery programs: What did patients report provided benefit? *Crit Care Explor* 2020;2:e0088.
- 15 Haines KJ, Sevin CM, Hibbert E, Boehm LM, Aparanji K, Bakhrum RN, *et al.* Key mechanisms by which post-ICU activities can improve in-ICU care: results of the international THRIVE collaboratives. *Intensive Care Med* 2019;45:939–947.

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