Challenges for ICU Survivors and Their Caregivers

Advances in technology and therapeutics continue to improve survival of critically ill patients. However, with improved survival has come the recognition that many ICU survivors face a complex recovery trajectory following discharge from the ICU.^{1,2} Numerous studies document that critical illness can impact ICU survivors' physical, psychological, and cognitive function.³ Recovery can be prolonged and unpredictable.^{2,4} Many ICU survivors require substantial assistance from informal caregivers, mostly family members. From one of the largest longitudinal cohort studies that recruited 817 ICU subjects who required mechanical ventilation for ≥ 48 h, Chelluri et al⁵ reported that the majority (75%) required caregiver assistance 2 months after the onset of mechanical ventilation, and over half (57%) who survived to 12 months continued to require caregiver assistance. Family caregivers are vital care partners in providing this assistance but may, themselves, experience depressive symptoms,⁶⁻⁹ caregiver burden,^{8,10} post-traumatic stress,¹¹⁻¹³ and poor physical health.¹⁴⁻¹⁶ Knowledge of these consequences following critical illness has prompted growing interest in ICU survivorship, with the goal of improving patient and caregiver outcomes. We have learned that the complex sequelae of critical illness affect both ICU survivors and family caregivers. The terms post-ICU syndrome (PISC) and post-ICU syndrome family (PICS-F) have been proposed to describe this outcome.^{17,18} PICS is defined as new or worsening impairment in physical, cognitive, or mental health status arising and persisting after hospitalization for critical illness.^{17,18}

To better understand ICU survivorship and provide targeted support to this population, it is important to investigate the experience of ICU survivors and their family caregivers as dyads, because challenges faced by survivors impact caregivers and vice versa. However, relatively few studies have included both ICU survivors and family caregivers when describing outcomes following critical illness. From a longitudinal descriptive study, Choi et al¹⁰ reported the experience of 69 family caregivers of ICU sur-

vivors. Caregivers reported greater lifestyle restrictions and psychological distress when ICU survivors required prolonged institutionalization and experienced difficulty regaining functional independence. In a second longitudinal study, Choi et al¹⁹ described physical symptoms in ICU

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survivors for the first 4 months post-ICU discharge and the influence of these symptoms on family caregivers. Greater symptom burden, defined as the number of symptoms subjects experienced, was significantly correlated with family caregivers' depressive symptoms at 2 weeks post-ICU discharge.¹⁹ Although not significant, probably because of the small sample size, trends suggested an association between ICU survivors' overall symptom burden and caregivers' health risk behaviors and sleep quality up to 4 months post-ICU discharge.

In this issue of *RESPIRATORY CARE*, Comini et al²⁰ present interesting findings from their study of physical and psychological outcomes in ICU survivors and strain and information needs in family caregivers at 2 time points: (1) hospital discharge after an in-patient rehabilitation program ($n = 23$) and (2) 6 months post-hospital discharge ($n = 16$). The authors also explored relationships between outcomes in ICU survivors and caregivers' strain, defined as the severity of stress experienced by family caregivers. Study participants remained in the ICU for ≥ 20 days and were recruited after completion of an in-hospital rehabilitation program. Thus, they experienced an extended ICU stay and underwent similar rehabilitation before their transition from ICU to home. Despite completion of the in-hospital rehabilitation program and probably because of their extended ICU stay, reduced physical function was profound in the majority of cases. This supported prior findings^{19,21} that those who experienced more severe decrements in physical function rated their quality of life less positively, and their caregivers experienced greater strain. In a subgroup of dyads ($n = 16$) that included subjects alive at 6 months post-hospital discharge, Comini et al²⁰ reported that ICU survivors reported significant improvement in measures of physical function (eg, sit-to-stand test, 6-min walk distance, Takahashi test, and Barthel index). However, despite improvement in physical function, there were no significant changes in ICU survivors' psy-

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chological outcomes (eg, overall quality of life and general perceived self-efficacy) or caregiver strain and information needs.

The study has a number of limitations, including the small sample and single-center recruitment. However, the study findings are consistent with other reports that describe the challenges faced by ICU survivors. Notably, the study findings suggest that the pace of psychological recovery may not be synchronous with the pace of physical recovery. Comini et al²⁰ found that, despite notable improvement in physical function, there was no change in perceived quality of life or self-efficacy in the first 6 months post-hospital discharge. Consistent with reports from previous studies,²¹⁻²³ these findings suggest that the impact of critical illness persists for an extended period of time and even after recovering physical independence, distress from remaining physical symptoms (eg, fatigue) may still be present.¹⁹ Because of profound deconditioning after critical illness, it is easy to focus on attempting to restore physical function. This can be difficult if the patient is experiencing depressive symptoms or recovery is viewed as not meeting expectations. Periodic assessment and support of ICU survivors' psychological needs should be included as a part of their care after home discharge as a means to assist them to regain the ability to self-manage their health and optimally return to their prior role in the community. The respiratory therapist can play an important role in this assessment in their role as home care providers.

Of importance, strain and information needs in family caregivers may remain regardless of progress in the ICU survivor's physical recovery. Given the small sample size, Comini et al²⁰ were not able to examine factors that might be associated with greater strain and information needs. We can, however, speculate that strain in family caregivers of ICU survivors was influenced by varied factors in addition to physical function. To best understand how to intervene to assist in recovery, it is important to enroll both ICU survivors and family caregivers in future studies and to investigate relationships between burden and recovery in both. Future studies should also examine a broad variety of potentially influencing factors, including impairment in physical and cognitive function and mental health status, as noted in the definition of PICS, as well as the impact of prolonged institutionalization, transitions between care settings, available social support, and other resources and patient/caregiver goals and expectations following recovery.

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