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Financial Stress after Critical Illness: an Unintended Consequence of High-Intensity Care

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For patients with chronic, life-limiting illness, deterioration in health can result in admission to the ICU, with the goal of restoration of health back to or near their prior quality of life. However, such patients may also receive costly, high intensity care that they find burdensome and inconsistent with their values and goals.¹ Further, this high intensity care may be ineffective,² and place unnecessary psychological and physical burden on patients and their family.³ For patients who survive, they may be at risk for experiencing an outcome that they consider to be worse than death, such as permanently needing help with activities of daily living like toileting or bathing.⁴ These unfortunate realities raise the question of whether there is an important opportunity to apply the principle of “less is more” in the care of some patients with chronic, life-limiting illness.

As intensivists, we aim to provide goal-concordant care by informing patients and family members of expected outcomes, as well as potentially adverse effects of high intensity treatments, with the hope of helping patients and family members decide whether or not the care we offer and the achievable outcomes are consistent with patients’ values, goals and preferences. We also continue to seek new interventions that may improve the physical, cognitive and psychological outcomes for critically ill patients and their family members. Yet, there is a potentially harmful adverse effect of high intensity care that never makes it to the goals-of-care discussions or family conference –that is, the financial burden that critically ill patients and their family members can experience.

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Current research and the dialogue on financial “toxicity”, a term used to describe the harmful financial side effects of treatment,⁵ remain limited primarily to patients with cancer in the U.S. However, even in settings with universal health coverage, patients with serious illness are not protected against financial hardship.⁶ Key components of financial toxicity include both objective financial burden (e.g. out-of-pocket costs, lost income, unemployment) and subjective financial distress (e.g. perceived future financial prospects).⁷ Among patients with cancer, the outcomes of increased financial distress and decreased health-related quality of life are strongly correlated, indicating that financial toxicity is a clinically-relevant patient-centered outcome.⁸ In this population, financial toxicity has been associated with decreased treatment adherence⁹ and quality of life,¹⁰ as well as increased symptoms^{10,11} and even mortality¹²—all outcomes that are of great importance to critically ill patients and their family members.

Although there are fewer studies in the context of critical illness, the prevalence of finance-related stress is also high among patients requiring intensive care and their families and this stress is a mediator of symptoms of anxiety and depression.¹³ There is a complex relationship at play between critical illness, the need for high intensity care, family and patient financial stress, and important patient- and family-centered outcomes (Figure 1). This relationship is magnified for patients who are admitted to the ICU with an underlying chronic, life-limiting illness who are at particularly high risk of death or at high risk of needing continued high-intensity care after ICU discharge for an outcome that they may consider to be less than desirable.

In the U.S., out-of-pocket spending on health care is increasing for patients, through higher deductibles and increases in copayments. With the lack of an out-of-pocket maximum and a relatively high co-payment for hospitalizations, traditional Medicare fee-for-service alone does not insulate individuals from the financial burden of high intensity care and repeated hospitalizations.¹⁴ Although the high burden of out-of-pocket costs is less of an issue in many other countries, these costs are only one of the many contributors to financial stress. In a multicenter longitudinal study, nearly one-half of previously employed survivors of acute respiratory distress syndrome (ARDS) were jobless 12 months later, and over the 12-month follow-up, 70% suffered lost earnings averaging 60% of pre-ARDS annual earnings.¹⁵

Family member caregivers of ICU survivors also experience financial burden that impacts their quality of life and psychological well-being.^{13,16} Although out-of-pocket costs have less of an impact in countries with universal healthcare coverage, the post-discharge costs (e.g. home care, equipment, time away from work for medical appointments), loss of wages, and changes in employment resulting from family caregiving for seriously ill loved ones is substantial. In a study conducted in the UK in patients with advanced disease, informal care increased the total healthcare cost by >250%.¹⁷

Seriously-ill patients report that one of their top concerns is having healthcare costs covered to avoid placing a financial burden on loved ones.^{18,19} Therefore, we must acknowledge this important goal and source of stress that permeates many aspects of our patients’ and their family members’ lives and directly impacts many of the outcomes we seek to improve, such as quality of life and psychological distress. Further, although there is evidence that financial

stress affects quality of life, the opposite causal pathway is also possible. Conceptually, lower quality of life could decrease earning power and capacity to provide care to family members. This is an important area for future research.

Critics may argue that even if financial stress is prevalent, it is not easily modifiable by clinicians and others who work in the healthcare setting. That may be true to some extent for out-of-pocket costs and aspects of the objective burden; however, prior research has demonstrated that the presence of social support significantly improves quality of life and decreases the extent to which financial concerns are important stressors for patients, suggesting that interventions targeted at improving support systems for critically ill patients and their family members in and after an ICU stay may provide benefit.¹³ Additionally, reducing the perception of financial stress that originates from uncertainty and the lack of information about the types of costs to expect during and after a hospitalization and what to prepare for, may be modifiable with better access to financial counselors and post-discharge financial navigators.²⁰

For patients with chronic and life-limiting illnesses, admission to the ICU near the end of life or specific high-intensity treatments in the ICU may not be consistent with patients' values, goals and preferences and may be non-beneficial. In this context, advance care planning and palliative care interventions are designed to clarify values, goals and preferences and ensure that the medical care delivered is goal-concordant. We should also consider how these and other interventions can acknowledge and address financial stress and help mitigate the impact it has on the lives of patients and their family members. If avoiding unwanted or non-beneficial care can help reduce this stress, this may be another context where "less is more".

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Figure 1: Conceptual model demonstrating the complex relationship between critical illness, the need for high intensity care, family and patient financial stress, and important patient- and family-centered outcomes.