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The critical importance of symptoms during and after intensive care

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I have been working as an intensivist for over 20 years and over that time I have also been a physician–scientist conducting clinical research to measure and improve the quality of palliative and end-of-life care in the intensive care unit. I have given many lectures about integrating palliative care into the ICU and have focused my research and my lectures on the importance of communication about palliative and end-of-life care. I have often thought that of the many different components of palliative care that are important in the ICU, symptom assessment and management are not a top priority because symptoms are generally well understood and managed by ICU clinicians. This was part of the reason I have focused my research on communication—an area that is often not well managed by intensive care unit clinicians.

However, more recently, I have also worked as a palliative care consultant. It was an interesting experience for me to be called to the ICU where I have worked for many years as an intensivist, but for the first time in the role of a palliative care consultant. In fact, my very first palliative care consult in the ICU was an eye-opening experience for me. I was asked to see a 70-year-old man admitted

with an empyema who was 7 days out from a video-assisted thoracoscopy. He was still in the ICU with two chest tubes. He had told the ICU team that he was tired of ICU care and wished to have all life-sustaining treatment stopped. He had no friends or family, making this a particularly complex decision for a critically ill patient. I was asked to talk with him about his goals of care and to help transition him to “comfort measures only”. When I arrived at the bedside and asked him some questions, he reported 10 out of 10 pain at the chest tube sites and severe dyspnea with turning or moving. I asked if he would be interested in continuing life-sustaining treatments if we were able to control his pain and dyspnea and he reported that he certainly would. In defense of the ICU team, they had been minimizing his pain and dyspnea medications so that he would have decisional capacity when he talked with the palliative care team about his goals of care. However, it was also clear that his lack of symptom control did not allow him to have the capacity for this difficult and important discussion.

This story unfolded in one of the best ICUs in the world. The physicians and nurses in this ICU are outstanding and they view the patient and family experience of intensive care as a high priority. However, the fact that this could occur in one of the best ICUs in the world highlighted for me the fact that symptom assessment and management remains an important target for high quality intensive care and that we need to continue to strive to improve our ability to measure and to treat these symptoms. Observational studies have shown that acutely critically ill patients have a high burden of symptoms and these symptoms are diverse and include not just pain and dyspnea, but also fatigue, anxiety, depression, thirst, hunger, sleep disturbance, delirium, and others [1, 2]. There is also significant pain and discomfort associated with ICU procedures that is frequently unrecognized and that varies from ICU to ICU, suggesting important opportunities for quality improvement in many ICUs

[1, 3]. In addition, emerging research documents the significant burden of symptoms associated with chronic critical illness that includes both physical and psychological symptoms [4, 5]. There is also compelling evidence of the important burden of symptoms for survivors of critical illness in the first year after critical illness [6, 7] and more recent studies demonstrate that this symptom burden can persist for more than 5 years [8, 9]. These symptoms include pain and fatigue as well as significant reductions in quality of life and cognitive function [10, 11]. There is also a significant and important burden of psychological symptoms after critical illness, including depression and post-traumatic stress [12, 13]. Although the science of measuring pain is advancing, there is still much work to be done [14] and for many other symptoms we are still in our infancy for reliable and valid measurement.

In this issue of *Intensive Care Medicine*, Puntillo and colleagues [15] report the results of an important randomized trial documenting the benefit of a simple “thirst bundle”—a low cost, low-tech intervention that significantly reduced patients’ symptoms of thirst. This is an important trial for several reasons. First, it assesses an

intervention to improve an underappreciated and poorly studied symptom that is common and often very distressing for critically ill patients [3]. Second, this study uses state-of-the-art methods to assess thirst among critically ill patients and—in doing so—advances the science of symptom assessment among the critically ill. Finally, this positive randomized trial provides compelling evidence that the intervention improves patient outcomes and provides support for a simple and generalizable intervention that can be implemented in ICUs across the world.

In our quest to improve outcomes for critically ill patients and their families, research and quality improvement focused on symptom assessment and management must remain in the forefront. Symptom management is an important battle that we have not yet won. Intensive care has made dramatic progress in the past 20 years that I have been an intensivist, and yet in this basic and important area we still have much work to do.

Conflicts of interest The author has no financial conflicts of interest to report.

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