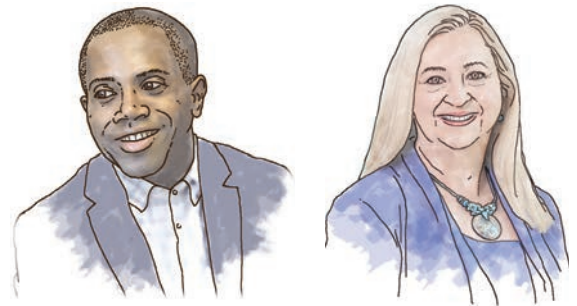


# Editorial

## UNDERSTANDING AND IMPROVING BEREAVEMENT SUPPORT IN THE INTENSIVE CARE UNIT

By Aluko A. Hope, MD, MSCE, and Cindy L. Munro, PhD, RN, ANP



As skilled as we have become in delivering highly technical care in the intensive care unit (ICU), death remains a frequent outcome for many of our patients. The loss of those we have diligently worked to restore serves as a stark reminder of other forms of loss: the premature departure of parents or grandparents, the erosion of youthful vigor due to chronic illness, the disappointment of unfunded grants and rejected papers, and the upheaval of immigration or exile to new cities. We resist the temptation to become numb to the loss or to merely put on a facade of moving forward. Instead, we embrace it, we confront it, we cry out against the profound injustice of it. And then, eventually, we start the process of repair, our knees sore, our eyes swollen, another patient gone, our bodies bearing the bruises of yet another stumble, another missed milestone. Let us acknowledge this as grief. In grief, we are never alone. It is through grief that our family members must navigate when their loved ones die in the ICU. It is our capacity to experience grief that enables us to empathize with our family members as they cope with the loss of a loved one in the ICU.

Although *grief* encompasses the emotional and affective facets of coping with the loss of a loved one,

we use the term *bereavement* to describe the biopsychosocial state and lived experience of losing a significant person to death.<sup>1</sup> Contemporary theories of bereavement acknowledge that the nature of the connection with the deceased and an intricate mix of biological, psychological, social, and external factors shape how families cope with the loss.<sup>1</sup> Adapting to the crisis of bereavement challenges families to process the past—the story of their loved one's death; the backstory of their lives with the departed—while they attempt to look ahead to a future without them. Questions such as “What am I going to do?” and “How will I ever come to terms with this?” are addressed concurrently with questions like “What exactly happened?” and “Did I do everything I could during the illness?”

Why should we care about post-ICU family bereavement outcomes? The very family members who engage in shared decision-making with us in the ICU are the ones vulnerable to the adverse effects of bereavement. Indeed, multiple observational studies have shown that psychological distress symptoms such as depression, anxiety, and acute stress symptoms start early during the time family members are navigating the complex decisions in the ICU.<sup>2-4</sup> For most families, heightened psychological distress is transient, lasting only a few weeks or months following the hospitalization before gradually returning to baseline. However, multiple

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cross-sectional and longitudinal studies have revealed that a significant proportion of families remain at elevated risk for depression, anxiety, posttraumatic stress symptoms, and prolonged grief disorder in the months following a loved one’s death in the ICU. The diagnosis of prolonged grief disorder, recently added into the *Diagnostic and Statistical Manual of Mental Disorders* (Fifth Edition, Text Revision), requires that grief symptoms, including intense yearning for the deceased person and preoccupation with thoughts and memories of the loved one, persist for a minimum of 12 months after the death.<sup>5</sup>

So far, the ongoing research suggests that there may be modifiable factors related to patients, families, and ICU care that may influence the level and trajectory of bereavement symptoms in our families.<sup>2,3</sup> In an early groundbreaking study examining the prevalence and factors related to subjective distress in family members 90 days after an ICU experience, distress levels were higher among family members involved in end-of-life decisions (vs those family members who were not involved in such decisions).<sup>6</sup> In addition, family members who perceived incomplete information during the ICU decision-making process were more likely to experience elevated distress at this 90-day juncture.<sup>6</sup> In a longitudinal observational study involving more than 300 family members of deceased ICU patients across 2 ICUs in Taiwan, clinically significant symptoms of posttraumatic stress decreased significantly during the first year after discharge, from 11% at 1 month to 1.6% at 13 months after the loss.<sup>7</sup> Notably, stronger perceived social support and the issuance of a do-not-resuscitate order before the patient’s death were associated with a reduced likelihood of clinically significant symptoms of posttraumatic stress; longer ICU stays, family members reporting financial strain,

or prior long-term use of pain medication in the year preceding the patient’s critical illness were associated with a higher likelihood of clinically significant symptoms of posttraumatic stress.<sup>7</sup> In a recent multicenter cohort study examining family bereavement outcomes across multiple ICUs in France, prolonged grief symptoms were present in about 50% of the study sample at 6 months after hospital discharge, and this high proportion persisted in the study sample at the 12-month mark.<sup>8</sup> In this same study, families who perceived poor communication with the ICU team were more likely to report these complicated grief symptoms.<sup>8</sup>

There remains a great deal left to understand regarding the long-term experiences of family members following the death of a loved one in the ICU. Many of the observational studies available rely on convenient samples of participants and are often hampered by high rates of loss to follow-up. Of particular significance is the fact that the very nature of many of the symptoms—intrusive thoughts and memories of the loved ones, avoidance of reminders, hyperarousal, and heightened reactivity—can potentially impede both the capacity and inclination of families with these types of symptoms to engage in longitudinal research.<sup>9</sup> Furthermore, only a limited number of studies have had the capacity to account for baseline psychiatric history, levels of social support, personality traits, and other pertinent factors that influence how individuals cope with loss. Although bereavement research outside of the ICU setting has revealed associations between psychological symptoms during bereavement and the emergence of other adverse health outcomes, such as the development of conditions like cancer, high blood pressure, and changes in dietary habits, relatively little investigation has addressed the link between psychological distress symptoms and other health outcomes in families following the death of an ICU patient.<sup>10</sup>

What strategies can be employed to enhance bereavement outcomes for families following the death of a loved one in the ICU? Much of the research has focused on improving our communication and family support processes in the ICU as a

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means to improve bereavement outcomes. In a classic study, a proactive and structured communication approach for families of terminally ill patients, combined with the distribution of a bereavement leaflet, was associated with a reduction in symptoms of anxiety, depression, and posttraumatic stress.<sup>11</sup> Quality improvement initiatives aimed at enhancing end-of-life care in the ICU, such as the 3 Wishes Program (3WP), which involves health care professionals fulfilling small wishes of dying patients and their families, have resulted in improvements in families’ experiences of spiritual and emotional support during the dying process.<sup>12</sup> In a multicenter clinical trial evaluating the impact of a handwritten condolence letter written by the ICU nurse and physician and sent to family members approximately 2 weeks after the death of their loved one, researchers found that the intervention was associated with worse symptoms of depression and posttraumatic stress disorder 6 months after discharge.<sup>13</sup> Qualitative investigations into these surprising findings suggested that although some family members felt supported and acknowledged by the letter, others experienced hesitation, social obligation, and doubts regarding the condolence letter.<sup>14</sup> Subsequently, French investigators tested the efficacy of a high-touch, physician-driven, nurse-assisted family support intervention for reducing symptoms of prolonged grief in families of terminally ill patients; that intervention was associated with a reduced prevalence of prolonged grief symptoms 6 months after the patient’s death.<sup>15</sup> Key components of the intervention included a structured proactive interdisciplinary end-of-life family meeting that allowed for information sharing and expectation setting, expressions of nonabandonment by both physicians and nurses during the dying process, and a family support meeting after the loved one’s death to address any questions or concerns.<sup>15</sup>

Mastering the art of losing patients to death is hard for us and even harder for our patients’ families.<sup>16</sup> The need for innovative and effective strategies to support families in the ICU that can help them navigate loss is more urgent than ever.

The statements and opinions contained in this editorial are solely those of the coeditors in chief.

**FINANCIAL DISCLOSURES**  
None reported.

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