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Palliative care in the ICU of 2050: Past is prologue

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With the pace of recent health care change, ICU palliative care will likely have its own transformation in the next three decades. A look back may help bring the future into clearer view.

Past: From defining death to shared decision-making

Three decades ago, we struggled to define death in the face of technology that supported respiratory and cardiovascular function beyond previously imagined boundaries. We had to come to terms with intensive care in relation to the end of life. Initially, a new definition of death, based on brain function, provided a rationale for discontinuing mechanical ventilation and other therapies despite a beating heart and stable hemodynamics.[1] As time went on, we accepted the reality that our own decisions to use, withhold, or withdraw intensive care had life and death consequences. We focused on how those decisions would be made and implemented, seeking a rational and fair process, based on intensive monitoring and sophisticated modeling to predict the patient's outcome.

Palliative care as a field emerged in the 1990s, thrust into national focus by the Study to Understand Prognoses and Preferences for Treatment ("SUPPORT") aiming to improve end-of-life experience for seriously ill patients.[2] The failure of the SUPPORT intervention and, more importantly, the harsh light it shone on the way patients were dying in the ICU and elsewhere, became a call to action. We resolved to relieve the suffering, communicate better with patients and families about goals of care, align treatments more closely with their values and preferences, and limit burdensome therapies. In those early years, the field focused primarily on dying and death. Trigger criteria were created to identify patients at highest mortality risk and engage palliative care specialists.[3] We learned how to "save deaths" as well as save lives—tell families that their loved ones were approaching the end, maintain comfort while limiting life support, and alleviate our own emotional and moral distress.[4,5,6]

Present: Palliative care emerges, evolves, and thrives

In 2017, the perspective is already different and substantially more expansive. Palliative care is not simply a synonym for end-of-life care. Today it addresses how patients live in the face of life-threatening illness. It is based on need rather than prognosis and ideally delivered together with disease-directed/restorative treatment. In addition, as critical care therapies and associated outcomes continue to improve, we are looking beyond the ICU to survivorship,[7] seeing as post-ICU life is often accompanied by impairments and distress for both patients and families.[8] Thus, the advances in critical care have confronted us with new palliative care challenges. Among the hardest is the need to balance combined but often conflicting pressures placed by patients and families who demand all life-sustaining therapies, clinicians struggling with death and limitation of therapy as a personal failure, and the goal of acceptable survivorship.

It is also clear that palliative care is not only the job of consultants but an approach to care at the “primary” level, e.g., by intensivists, nurses, and other clinicians, as well as by specialists in this field.[9] ICU clinicians at the front lines need knowledge, skills, and systems to support their essential palliative care role. For primary palliative care, we already know that the optimal approach is interprofessional, interdisciplinary, and interwoven within the ICU work environment. At the present time, end-of-life and palliative care practices remain variable between individual hospitals and across regions, states, and countries.[10] However, international consensus is increasingly coalescing around common core principles and definitions, while respecting unique cultural norms and the personhood of each critically ill individual.[11] It is widely agreed that comprehensive critical care must address distressing symptoms, include effective communication, and align ICU care with patient values.

Future: Patient-centric goals in the context of precision medicine

We can anticipate continued advances in technology and precision treatment that enable better outcomes including lower mortality from critical illness. Big data, “-omics” approaches, and the health record of the future will help us understand the impact of ICU interventions across diverse populations and care settings, match individuals more accurately with targeted therapies, and optimize healthcare utilization.[12] Advances will likely extend to ICU survivorship, as the nature and determinants of post-ICU syndromes become clearer. High-risk survivors will be identified, guided to, and supported by augmented palliative care services before and after discharge. The demand for preservation of cognition and function will compel us to develop, evaluate, and deploy approaches in and after the ICU that achieve more ambitious, patient-centric goals.

Strategies for communicating with patients and families in preparation for the aftermath of intensive care will be ever more essential. We will still need to assist patients and families facing an uncertain future and ensure an ongoing exchange of information about what is likely to be achievable in relation to what the patient defines as core values and acceptable quality of life.[13] The trend, fortunately, is toward more multi-directional communication among patients, families, and comprehensive care teams, all seeking treatment goals that

respect the personhood of the patient as well as the clinical data.[14] Greater openness to family presence and participation will enhance our ability to address the unique needs of the patients as well as those of the families, decreasing distrust and conflict, both within the ICU team and with caregivers.[15] Disruptive design thinking could help transform the ICU environment and experience in ways that support staff, patients, and families alike.

In 2050, mortality from today's critical illnesses will be lower and recovery more complete. However, the ICU will still be the setting for patients in extreme jeopardy from illnesses we can't yet overcome and probably some that don't yet even exist. We will not stop caring for patients who die or become debilitated. Nor will we escape the need to attend to our own burdens, such as burnout and cognitive/emotional strain, as well as those of the patients and families. The agenda for both research and clinical initiatives includes strategies for humane end-of-life care in the ICU of 2050, with all of its additional precision and technology, as well as for more acceptable recovery by survivors.

Recent decades have brought us the tools and philosophy of palliative care, while broadening our view beyond death to survivorship. In the coming decades, evidence and knowledge translation in palliative care, intensive care, and their integration, will expand further. (See Figure.) These developments will provide a platform for normalizing discussion and treatment planning around patient-centered goals to the same extent as future versions of molecular markers, genetic profiling, and predictive analytics. Advances in all of these areas will help us address the combined challenges of unstable physiology, complex ethical issues, and the imperative of patient-centric care, while attending to both the increasing power and the limits of therapy in the ICU of the future. Sensitivity to the individual needs of patients, families, and colleagues, will remain paramount in achieving these goals. We will have more information to use and share, but how we listen will continue to be more important than what we know or say.

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Figure.

A conceptual timeline of developments in ICU palliative care.

The figure shows a view of key components of philosophy, practice, and process in critical care and palliative care as they have evolved individually and together from the 1980s to the 2050s.