

# Improving palliative care in intensive care units: Identifying strategies and interventions that work

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The disciplines of critical care and palliative care may initially seem to be polar opposites, yet they share fundamental features. Both focus on the sickest patients in the healthcare system. Each discipline's primary goal—extending life for critical care and comfort and quality of life for palliative care—represents an important secondary goal for the other. A tremendous body of work in the last decade has laid the foundation for improving palliative care in intensive care units of the future. Pioneering projects have demonstrated the feasibility and acceptance of

integrating palliative aspects of care within critical care settings and practice. This article introduces this special supplement of *Critical Care Medicine*, which describes the developments that have occurred moving us toward integration of palliative and critical care, and lays the foundation for the articles published in this supplement. (Crit Care Med 2006; 34[Suppl.]:S302–S305)

**KEY WORDS:** palliative care; intensive care; critical care; moral distress; symptom management; spiritual care; communication; family care; continuity of care

## The Future Is Already Here

When palliative care clinicians take stock of recent developments in our field, it feels like the future has already arrived. Physicians and nurses who were involved in hospice care during the late 1970s and early 1980s remember discussions at meetings of the young National Hospice Organization and nascent American Academy of Hospice Physicians that included conferees envisioning a bright future in which hospice and palliative medicine would be formally recognized as a specialty, in which there would be fellowship programs to train specialists, palliative care clinical teams in academic medical centers, and finally, in which routine care of the most seriously ill and injured patients would include attention to their comfort and emotional and spiritual well-being and support for their families.

Now, in 2006, the American Board of Medical Specialties is poised to grant formal specialty status to Hospice and Palliative Medicine. The Accreditation

Council for Graduate Medical Education (ACGME) will begin certifying fellowship-training programs in palliative medicine in 2007 (1). Hospice programs now serve >1 million American patients and families each year. More than 1,000 hospital-based palliative care programs now exist, and many more are in development (2). The American College of Surgeons Commission on Cancer requires palliative care involvement in a cancer center as a condition for earning the Commission's certification. There is also growing recognition of the field's value outside of professional circles. *U.S. News and World Report* now includes hospice and palliative care as a criterion in selecting institutions for its annual list of 50 best hospitals. Pain is recognized as a vital sign in many healthcare institutions, and pain management and spiritual support are basic components of care required for accreditation (3).

Of course, when the future arrives, we call it the present. Although much has been achieved, there remains much to be done to advance the defining values and goals of palliative care. The integration of palliative aspects of care within critical care is an important focus of those efforts.

## Palliative and Critical Care: The Appearance of Divergence

The general public and most healthcare professionals view palliative care and

critical care as polar opposites. It is easy to understand why.

Critical care was fueled by technical advances of the 1940s and 1950s and represents a pinnacle of mainstream medicine. In contrast, hospice, the incubator of palliative care, arose in the 1970s as a counter-cultural response to mainstream medicine's unrelenting battle against disease—a battle in which the dying person was perceived to be an innocent victim.

Critical care is the epitome of scientific and technical prowess of medicine and symbolizes efforts to save human life. Intensive care units (ICUs) are where the most highly trained and technically sophisticated doctors and nurses strive to preserve life at all costs. To this day, hospice and palliative care are often referred to as a philosophy of care—one that embraces death.

The two areas of clinical practice are delivered and reimbursed in very different ways. Critical care is practiced in ICUs and operating rooms, in close coordination with emergency departments, and by extension, with prehospital air or ground "mobile ICUs." Although palliative care is increasingly available in hospitals through consultation services and through a small but growing number of inpatient units and freestanding hospice facilities, it is still most commonly practiced in patients' homes through hospice programs. Critical care is generally well reimbursed by government and private insurers. In contrast, hospice and pallia-

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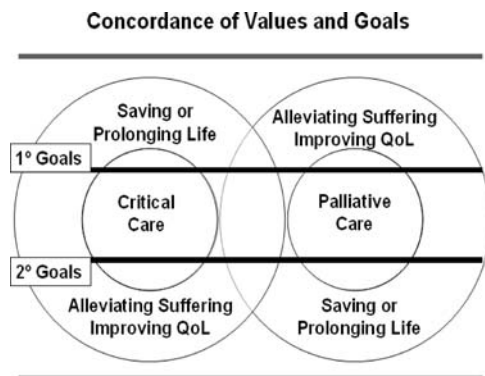


Figure 1. Concordance of values and goals in critical care and palliative care. *QoL*, quality of life.

tive care programs commonly rely on philanthropic contributions to supplement substantial portions of their operating budgets.

### The Reality of Concordance

Despite these differences in origin, emphases, and locales of service delivery, critical care and palliative care recognize important similarities and a fundamental concordance of clinical goals (Fig. 1). Most basically, intensivists and palliative care professionals both care for the sickest patients in the healthcare system. As with patients in an ICU, those referred for palliative care consultation or admitted to hospice programs have life-threatening conditions, often involving multiple organ system failure or insufficiency. Critical care and palliative care patients typically are taking 8–15 prescribed medications, despite efforts to avoid polypharmacy and drug–drug interactions. Although the primary foci for palliative care and critical care may initially seem divergent, on inspection, strong concordance of therapeutic values and goals is apparent. Indeed, the primary goal of each discipline is the secondary goal of the other.

The priority of ICU practice is to save life, but the experience of clinicians in both critical and palliative care strongly suggests that the goals of life-prolongation, comfort, and quality of life are fully compatible, indeed, complementary (4, 5). Critical care physicians and nurses know that a patient in pain is less likely to move in bed or expand their lungs and is at higher risk for atelectasis, deep vein thrombosis, and deconditioning. Many experienced clinicians believe that a loss of will that can accompany persistent pain complicates recovery and heightens a patient's risk of dying (5).

Although Medicare and most other reimbursement systems see life-prolonga-

tion and palliation as dichotomous, experienced palliative care clinicians believe that good palliative care often extends life. This observed survival advantage occurs, first, by direct intention. Although comfort and quality of life are the primary goals for palliative care, consistent with individualized patient plans of care, acute complications of illness, such as febrile bronchitis or acute fluid overload, are commonly treated both to prolong life and alleviate physical distress. Second, by supporting patients physically and emotionally and by supporting families in provision of care and in their own adjustment to illness, patients are often better able to endure rigorous treatments for their diseases. In this manner, patients who might have forgone salvage chemotherapy or home-based dobutamine for heart failure, or epoprostenol for pulmonary hypertension, or given up on the complicated, uncomfortable daily routine required of someone with cystic fibrosis or end-stage liver disease, are able to tolerate these modalities and realize the survival advantage they represent.

Clinical experience and a growing body of evidence suggest that palliative goals can be advanced in critical care settings. In a community-based study that administered the Quality of Dying and Death survey to relatives of decedents, dying at home or in a preferred place was associated with higher ratings of quality. However, it is not determinative, and a number of other factors ameliorated or compensated for negative influences of being in an ICU on the individual's perceived experience (6).

Mularski et al. (7) employed an ICU version of the Quality of Dying and Death survey to assess close relatives' perceptions of patients' deaths in the ICU. Their study confirmed perceived problems of inadequate symptom management and communication. Importantly, they also found that

aspects of care and experience associated with highest ratings were whole-person concerns, including pain relief and having control of events, feeling at peace with dying, being unafraid, retaining dignity and self-respect, and finding meaning and purpose.

### Acting on Concordance: Formation of the Promoting Excellence Critical Care Workgroup

Once the concordance of fundamental goals and the complementary nature of efforts to enhance survival and quality of life are acknowledged, collaborative opportunities abound and a merger of approaches and cultures begins to seem natural.

In 1999, Promoting Excellence in End-of-Life Care, a national program of the Robert Wood Johnson Foundation, convened physician and nurse thought leaders in critical care to examine the potential for integrating palliative aspects of care within mainstream critical care. The Workgroup was charged with conducting an environmental scan of existing resources, analyzing what elements were lacking, and developing a set of recommendations to the field for advancing palliative aspects of care for the benefit of critically ill or injured patients and their families. The Critical Care Workgroup first developed a research agenda for improving end-of-life care and palliative care in the ICU (8). The Workgroup then tackled the task of applying the conceptual framework and core principles of palliative care to the practice reality of contemporary critical care. The resulting domains of quality defined for end-of-life care pertain and need to be applied to all critically ill or injured patients (9). The group also conducted an observational study identifying the prevalence of death in the ICU, finding that a staggering 20% of Americans die in the ICU or shortly after a stay in the ICU (10). Additional studies from this Workgroup examined the content in ICU order forms, pathways, protocols, and policies in a number of institutions, finding relatively little palliative care content (11). Finally, this Workgroup undertook a survey of a national sample of physician and nurse ICU directors to identify the barriers to good-quality palliative care (11a).

In the process of this work, the Critical Care Workgroup recognized that prognostic uncertainty and a culture of rescue were

facts of life and practice in the ICU and, therefore, that the only way for end-of-life care to improve was for palliative aspects of care to be routinely addressed for all ICU patients (12). This recognition became the foundation for a funding initiative for demonstration projects to improve palliative care in the ICU.

### **Acting on Concordance: Promoting Palliative Care Excellence in Intensive Care**

Building on the experience and advice of the Critical Care Workgroup, in the spring of 2002 the Promoting Excellence in End-of-Life Care program issued a call for proposals for an initiative entitled Promoting Palliative Care Excellence in Intensive Care: "The projects selected under this initiative will serve medical and surgical adult or pediatric patients. The target population should be *all* patients in the ICU, rather than patients with a particular diagnosis or prognosis" (13).

The stated purpose of this initiative was to support the development of new delivery models that incorporate palliative care practices in ICUs, evaluate their effect, and build a knowledge base to guide future critical care services. Proposals were required to have a nurse and physician serving as co-principal investigators.

In response to this request for proposals, 242 letters of intent were received and four grants were awarded to teams at Harvard University–Massachusetts General Hospital, University of Washington, Lehigh Valley Medical Center, and University of Medicine and Dentistry of New Jersey. This special supplement of *Critical Care Medicine* contains a report from each of these sites, describing their respective program, their experience, and preliminary results.

These four Promoting Excellence–supported sites, along with a handful of other centers, have established the practicality of integrating palliative aspects of care within critical care (14–26). Collectively, in a variety of critical care settings and patient populations, pioneering clinician-researchers have demonstrated the feasibility and acceptability of their programs to clinicians, management, and most importantly, patients and families. Programmatic interventions have included formalizing processes for symptom assessment and management; mandatory routine family meetings; iterative, patient-specific goal setting; advance care planning; and addressing emotional and spiritual well-

being of the patient and family. Each of these interventions were successfully implemented and seem to have improved quality of care, while using resources efficiently, reducing discord, and enhancing staff satisfaction.

For the reasons cited, it seems natural to integrate palliative aspects of care within critical care. However, as these programs have found, affecting change of this nature presents systemic and cultural challenges.

Elements essential for programmatic success that were gleaned from earlier Promoting Excellence grant-supported projects, which established innovative palliative care projects within a variety of health systems, were applied by the Promoting Palliative Care Excellence in Intensive Care sites (27). These include:

- A well-defined vision for the project
- A well-planned implementation strategy
- Unwavering support from clinical and administrative leaders
- Ongoing efforts to bridge the differences between palliative and acute care
- A focus on making "the right way the easy way"
- Ongoing education, support, and team building
- Attention to diverse ethnic and religious cultures of individual patients and families
- Targeted data collection
- A communications strategy for succinctly presenting relevant data to stakeholders

The final project of the Critical Care Workgroup, under the auspices and with funding of the Robert Wood Johnson Foundation, was to work in partnership with the Society of Critical Care Medicine to conduct a 2-day conference in Miami entitled "Improving the Quality of End-of-life Care in the ICU: Interventions that Work." The conference attracted national attention, exceeding projected attendance of 200 registrants, which necessitated turning away a number of late potential registrants. The current supplement of *Critical Care Medicine* comprises articles from each of the conference faculty. It provides background on the nature of the problem, describes the four demonstration projects funded by the Promoting Palliative Care Excellence in Intensive Care program and other approaches and interventions that improve end-of-life care, and finishes with some perspectives on where we go from here. This supplement, like the conference from which it

derived, provides a comprehensive, up-to-date overview of palliative and end-of-life care in ICUs and supplies specific directions for improving care for seriously ill and injured patients and their families in critical care settings.

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