

# Where do we go from here? A palliative care perspective

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**Key principles of palliative care shed light on future opportunities and challenges for improving patient care and family support within critical care. Interdisciplinary team approaches to patient comfort and family support, coordination and continuity of care, communication as an ethical and therapeutic modality, assistance with emotional, social and spiritual experience, including issues of life completion, bereavement support to families and attention to staff well-being are all foci for future clinical and**

**programmatic development and research. By collaborating to care well for the critically ill or injured patients and extend support for their families, the disciplines of critical care and palliative care can complete one another. (Crit Care Med 2006; 34[Suppl.]:S416–S420)**

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

**D**uring the past decade, substantial progress has been made in developing strategies and interventions for improving palliative care in the intensive care unit, many of which have been described in this supplement of *Critical Care Medicine*. In this article, I describe a palliative care perspective on the future, identifying opportunities for integrating palliative aspects of care within critical care and forecasting challenges we will likely encounter along the way. The shared, long-term goal of both clinical disciplines remains that of providing the best care possible to patients with life-threatening illness and injury and optimal support for their families.

A palliative perspective on the future of intensive care can best be discerned by applying criteria rooted in established principles of palliative care. Principles or precepts of a professional discipline are distilled over time through a process of successive discussion, review, and comment. Principles articulate the values and goals that motivate professional practice. The principles of palliative care express the values, aspects of patient (and family)

experience, and define domains of quality, core professional skills and scope of practice consistent with the goals and priorities of the specialty (1). Collectively, these principles provide a framework for addressing a palliative care perspective on the future of critical care (Table 1).

The discussion that follows builds from the experience of demonstration projects and applies selected principles of palliative care to identify potential barriers and prospects for desired change within anticipated demographic and healthcare trends.

## The Patient with His or Her Family Comprise the Unit of Care

Serious illness or injury strikes an individual but affects everyone to whom the affected person matters. Palliative care recognizes the responsibility of attending to the needs and experience of the patient *with* his or her family. In contemporary society, the meaning of “family” is not restricted to relatives by blood or marriage; operationally, family is understood to comprise a person’s relatives and close friends.

Indeed, there are many situations in which a patient’s family may suffer more acutely than the person whose life is threatened. An elderly woman with advanced dementia, who is admitted to the ICU with recurrent pneumonia, may have little interest in eating and be physically comfortable and exhibit no signs of distress, whereas her children struggle with decisions about ventilation, antibiotics,

and artificial nutrition, simultaneously resisting and grieving her coming death. A middle-aged man, who remains ventilatory-dependent in a deep coma days after a sudden large intracranial hemorrhage, may be insensate and beyond suffering, whereas his wife, children, and friends experience the agony of sudden loss. These families would benefit from palliative aspects of care no less than fully conscious patients.

ICUs of the future will have few restrictions on family visits. Closed units are already anachronistic and will disappear from critical care settings in the near future. The opening of units to family visits will be resisted by many institutions; nevertheless, organizations will only be able to forestall this change for so long. Individuals do not forfeit their right to be accompanied by people they love when they are admitted to a hospital. Reluctant clinicians and managers need only imagine how they would feel personally if their own parent, sibling, or child were seriously ill in an ICU bed to recognize that forced separations of patients from their families must be brief and based on authentic therapeutic requirements.

Because many patients in ICUs are unable to effectively interact or fully understand their circumstances, communication with patients’ families is especially important. Communicating with families can seem like a chore to busy critical care physicians and nurses. Providing information about a patient’s condition and explaining the risks and potential benefits of treatment options are ethical respon-

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Table 1. Principles of palliative care

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Clinical principles
○ Patient and family comprise unit of care
○ Ethical, shared decision making
○ Symptoms routinely assessed and well managed
○ Interdisciplinary team approach
○ Coordination and continuity of care
○ Dying recognized as difficult, but normal, and quality of life is a core goal
○ Spiritual distress (patient and family) assessed; spiritual well-being is a goal
○ Affirms life; neither hastens nor prolongs death
○ Extends bereavement support to patient's family
Operational principles
○ Preserves and enhances well-being of clinicians, support staff, volunteers
○ Engages in continuous quality improvement and research efforts
○ Advocates for patients and families
○ Advances public policy to improve access to needed services and quality of care

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sibilities. However, communication is also a therapeutic modality that advances important clinical goals.

Formal family meetings are increasingly recognized within critical care as an important means of improving clarity of decision making, quality of care, and efficiency of healthcare delivery (2–6). Typically, at such meetings, the patient's condition is reviewed, the current treatment regimen and plan of care is presented, the patient's prognosis can be updated, and options for future treatment can be outlined. Although not every family meeting will concern critical decision making, these updates can prepare families for future decisions in the days ahead.

From a palliative care perspective, a family meeting constitutes an important clinical procedure. Each meeting is an opportunity to build a therapeutic alliance with the patient's family. This process begins with listening and becoming familiar with the culture, traditions, and interpersonal style of a seriously ill person's family. The process of taking a social history from the patient's relatives and close friends can be extended by asking who the patient is as a person, eliciting descriptions and brief stories about the patient's early history, work life, personal interests, and notable characteristics. This process can help a patient's family to view the critical illness and ICU experience within the larger context of the individual's and family's life.

Family meetings also provide a chance to assess the well-being of family members, to inquire whether family members are attending to their own physical health by getting enough sleep, adequate nutrition, and taking their own medications, and to assess members' fatigue and emotional

strain. Family meetings give clinicians a chance to extend basic supportive counseling related to physical, emotional, and even spiritual care for the family. By building trust and maintaining this level of communication, clinicians can help the family prepare for the possibility of the patient's death.

Most family meetings can be conducted by a critical care team led by the attending medical or surgical intensivist, with or without a palliative care consultant. Some meetings that involve complicated families and therapeutic interventions with families may be best conducted by palliative care specialists with involvement of the critical care team. In many institutions, supportive counseling of families will likely be the purview of a social worker or palliative care consultant on the critical care team. However, it is not the exclusive province of any one individual and is well within the skill set of many nurses and physicians.

### Decisions Regarding Treatments Are Made in an Ethical Manner

Honesty and integrity are cornerstones of clinical practice. An overarching principle of health care requires decisions regarding medical treatments to be made in an honest and ethical manner and with respect for people's rights.

Clinicians have a responsibility to provide accurate information to patients and families, conveyed in words they can understand, about the patient's condition and treatment options and to guide them in a decision-making process that respects the individual's and family's ethnic and cultural values. Ultimately, clinicians must respect the autonomy rights of in-

dividual patients to choose between available options for care and to refuse any indicated treatment that is offered.

For patients who lack decision-making capacity, treating teams must identify a proper surrogate decision maker. It is important to determine whether the patient has completed an advance directive and named a healthcare agent or power of attorney. For a patient who has decision-making capacity and has not yet completed an advance directive, an early goal should be to ascertain the patient's choice for a healthcare proxy in the event of future incapacity and, if possible, complete such a document. In addition to naming a healthcare agent, advance directives can convey an individual's values and treatment preferences. These documents are generally not meant to provide explicit medical instructions, and several randomized trials have shown that these directives do not change the medical care received when implemented without in-depth advance care planning (7, 8). However, in a growing number of states, changes in law have codified requirements for withholding or withdrawing life-prolonging treatments and made it important for individuals' advance directives to include their specific statements of their preferences regarding medically administered nutrition and hydration and treatment for sudden cardiac or respiratory arrest. From a palliative care perspective, a completed advance directive document is often an invaluable resource in counseling and guiding a family through the process of making difficult decisions affecting a person they love. Advance directives can reduce the emotional burden on families and may prevent family conflicts (9).

Policies and practices related to cardiopulmonary resuscitation remain a challenge for critical care. A do-not-resuscitate order means that in circumstances of a sudden or impending cardiac or respiratory arrest, components of cardiopulmonary resuscitation, including emergency intubation, chest compressions, anti-arrhythmic medications, and electrical defibrillation or cardioversion, are to be withheld. However, in the minds of many clinicians and trainees, "do not resuscitate" is interpreted to mean that the patient is expected to die and care is not to be escalated. In fact, all other matters related to escalations of care require separate decisions. Properly implemented, a do-not-resuscitate order does not obviate therapeutic trials of ventilation or even vasopressor medications in nonarrest

situations. To protect individuals' rights and maintain the quality of care, these distinctions must be clear in policies and clinical protocols teaching, and they should be modeled in practice.

### **Symptoms Are Routinely Assessed and Carefully Managed**

Patient comfort has become an important focus for research and quality improvement in critical care. In many units, pain is now approached as a vital sign, frequently assessed and recorded. However, patients with serious illness and injury remain at high risk of suffering from pain, dyspnea, nausea, fatigue, or a myriad of other results of physiologic disturbances.

In addition to the direct effects of disease and injury, iatrogenic causes of physical discomfort and emotional suffering are also common in an ICU. Invasive treatments (such as intubation, ventilation, placement of central venous and arterial catheters) can be painful. Some critical care practices, such as daily spontaneous breathing trials for ventilated patients, may have significant physiologic benefit but cause predictable discomfort. Patients discharged from an ICU also identified routine elements of care, such as finger sticks, urinary catheters, and suctioning, as sources of physical suffering and emotional distress (10, 11). Common environmental factors, such as noise, light, disruption of sleep and diurnal rhythms, and lack of privacy, can add to stress experienced by patients. These factors can contribute to feelings of fear, helplessness, depersonalization, inability to communicate, and isolation.

Symptom management and patient comfort will be fertile areas for future collaborative research between the disciplines of palliative and critical care.

### **Care Is Planned and Provided Through an Interdisciplinary Team Approach**

Critical care and palliative care have in common the principle that care is best delivered by a variety of professionals from different disciplines working together in a coordinated team. In this realm of clinical practice, the whole is more than the sum of its parts. No amount of knowledge, expertise, or compassion on the part of a single clinician can fully substitute for the lack of a team.

In a well-developed team, professionals from medicine, nursing, spiritual care, social work, psychology, and pharmacy work together in a collaborative process to create plans of care that are predictably more integrated and comprehensive than a composite of individual recommendations.

Cross-training is encouraged within interdisciplinary teams. Every member of a clinical team can be alert for physical problems, such as uncontrolled pain or constipation, and any member of a team can listen to a patient's or family member's fears or spiritual concerns.

Opportunities and challenges exist for incorporating the skill sets and services of therapeutic communication, anticipatory guidance, psychosocial and spiritual assessment and care, and family support within critical care teams.

### **Care Is Coordinated with Attention to Continuity**

Fragmentation of health care has been an unintended consequence of modern advances in medical knowledge and technical sophistication. As the complexity of diagnostic workups and treatments has increased, health services and settings of care have become ever-more specialized. Faced with serious illness, patients and families can feel lost in a maze of options and complicated plans of care. Patients and their families experience fragmentation as a problem that detracts from quality of care. The Promoting Excellence in End-of-life Care Intensive Care Peer Workgroup specified continuity as a core quality domain (12).

Despite recognition of its importance, structural elements of prevailing health systems and delivery models will make continuity of care difficult to achieve. Even oversight and accreditation processes are currently organized around sites of care, which makes problems related to fragmentation of care nearly invisible to the audit process, difficult to measure, or even detect. Progress in improving continuity of care will require a substantial shift to a patient-centered approach. One strategy may have a critical illness coordinator assigned to each patient and family unit at admission to the ICU. That clinician could follow individual patients and families through a hospitalization and, for patients requiring ongoing care, effect hand-offs to the community-based case managers or clinical providers. In many institutions, palliative

care teams will be able to assist patients and families as they make the transition between sites of care.

### **Dying Is Recognized as a Normal Part of Life**

Palliative care regards dying as a normal part of life for every individual. This principle and its corollaries comprise a distinguishing stance of palliative care with important clinical implications. It is a feature of palliative care that can initially seem antithetical to critical care, but here again, on closer inspection, the principle is applicable across settings.

Dying under almost any circumstance is difficult and typically unwanted. Dying in an ICU can be particularly difficult and tragic. Patients in ICUs arrived as the result of sudden injuries or acute medical or surgical crises or complications. It may seem almost disrespectful to consider death in an ICU as normal.

However, there are consequences to considering death in an ICU abnormal or unnatural. Culturally, what we consider abnormal tends to be associated with lack of dignity, shame, regret, and guilt. In the 20th century, inevitable biological acts involving human reproduction and breastfeeding were once associated with embarrassment and shame, but these became culturally accepted as natural and normal. Increasingly, human biological needs and drives have been normalized in contemporary culture. Advertisements for tampons, adult diapers, and medications for erectile dysfunction that would have been unthinkable 20 yrs ago are now seen every day on television. Because death is unavoidable, it seems culturally unwise to pathologize common patterns of dying. At a time when nearly one in five Americans die during or just after treatment in an ICU, it is essential that clinicians incorporate dying in an ICU within the range of normal conclusions of human life. It will be a challenge for the discipline of critical care to acknowledge that death in an ICU is, in fact, a normal contemporary mode of dying. For the sake of the patients and families we serve, this challenge must be met.

Dying is only one part of life, but it is the one in which spiritual dimensions of the human condition are most clearly revealed (13, 14). Spirituality is not confined to religion or belief in deity. Palliative care regards spirituality as an inherent human trait. The confrontation with death often evokes normal drives to make meaning of circumstances and to seek

connection to something larger and more enduring than oneself. Evaluation of these aspects of a patient's and family's experience must be incorporated in routine procedures and supported by education, resources, and documentation tools. Patients and families who are active in faith communities may well value ongoing contact with their own clergy. Because of perceived barriers imposed by laws and rules designed to protect patient confidentiality, the clinical team may have to make specific effort to inform and invite clergy to visit. Full integration of palliative care within critical care will entail availability of pastoral care professionals with training in palliative care and experience in critical care settings.

The principle of approaching the patient with his or her family as the unit of care applies. From a palliative care perspective, the death of an individual is an unwanted but also an inevitable and *normal* event within the life of every family. In addition to responding to family members' suffering, when a patient is not expected to survive, supportive counseling of families extends to offering suggestions for interacting, touching, or spending time with the patient and, when appropriate, encouraging culturally consonant ways of completing relationships, celebrating shared lives, and saying goodbye (15). Many families appreciate factual explanations about the physical signs and symptoms of impending death. They also deserve basic information about grief.

### **Bereavement Support Is Extended to Deceased Patients' Families**

The palliative care principle of providing bereavement support is a logical extension of seeing each patient's family as a focus of care. A family's experience of a critical illness or injury does not end if a patient dies. Indeed, particularly when a patient was expected to survive, the distress of family members may increase in the wake of the person's death. Particularly in sudden catastrophic illness or injury, when there has not been time to prepare, families are at higher risk of feeling that their loved one was "amputated" from them. In fact, recent data suggest a high prevalence of symptoms of posttraumatic stress disorder among family members of critically ill patients (16). As important as bereavement support is, it is an aspect of palliative care that currently proves difficult for many hospital-based palliative care programs,

and even many hospice programs, to implement in practice.

Extending support to families of patients who have died challenges existing intensive care delivery systems. When a patient dies, his or her family naturally stops coming to the ICU, and interactions between the family members and clinicians typically cease. Some families may experience the sudden lack of contact with the clinical team as another loss. Bereavement support takes place away from the ICU and requires personnel to reach out in some way to members of the family, making contact and inviting response.

Effective bereavement programs need not be complicated or expensive. As emotionally painful as it frequently is, for most bereaved persons, grief is not an illness, and relatively few people require formal grief counseling. Basic support to bereaved families includes sending a personalized card on behalf of the unit and clinical team that acknowledges the death and expresses sympathy. Many hospitals send information about normal symptoms and patterns of grief and suggestions for self-care. With basic support, accurate information, and time, most people eventually accommodate to the death of someone they loved. Some bereaved people are at risk for pathologic grief reactions, a serious, preventable, and treatable cause of suffering (17–19). Availability of grief counseling varies widely in communities. Existing services may be provided by hospitals or hospice programs; most rely on self-referral. There is an important public health need to acknowledge and respond to complicated grief, yet few medical centers and health systems screen the population of communities they serve.

Except for patients who die shortly after admission to the ICU, attention to family grief begins before death through general attention to palliative aspects of care. The sadness of loss is inherently, inevitably painful, but it is made worse by feelings of regret, worries about things left unsaid, and doubts about the decisions that were made and the care that people received. Clear communication, shared decision making, efforts to resolve conflicts and strengthen family relationships, and attention to issues of life completion can contribute to preventing complicated grief.

When death is anticipated, many patients and families appreciate guidance with expressing feelings and achieving a sense of completion in relationships with

people important to them. Families often appreciate a chance to reminisce and review life.

### **Care Affirms Life and Does Not Hasten Death**

Events of recent years have exposed a cultural schism that divides many Americans regarding dying and care before death. On one hand, the social and political movement to legalize physician-assisted suicide remains active, with polls showing that 60–70% of Americans believe that, in some circumstances, physicians should be legally able to end the life of a patient. On the other hand, in the wake of the Terri Schiavo case, a vibrant movement of religious conservatives has introduced legislation in >20 states to require cardiopulmonary resuscitation be performed and nutrition and hydration be medically administered to dying patients unless such treatments have been specifically refused by a cognizant patient or included in the individual's advance directive.

Palliative care has been careful to distinguish intensive efforts to improve patient comfort and quality of life from hastening death. The commitment to do whatever is necessary to alleviate severe suffering, including employing palliative sedation, when other treatments have been ineffective in controlling physical distress, is fully consistent with the life-affirming credo that was forcefully stated by Dr. Cicely Saunders, the founder of palliative care: "You matter because you are you. You matter to the last moment of your life, and we will do all we can not only to help you die peacefully, but also to live until you die" (20).

### **Attention Is Paid to the Well-Being of Clinicians and Support Staff**

The health and well-being of providers has been recognized as a key domain of quality and a feature of high-functioning microsystems (21, 22). The importance of this principle to critical care was recognized by the Promoting Excellence Critical Care Workgroup, which included "emotional and organizational support for ICU clinicians" as a domain of quality in end-of-life care (12).

Critical care is not only technically difficult work; it is physically exhausting and emotionally draining. Moral distress has been recognized as an endemic problem among critical care nurses and a

common reason for nurses to leave the field (23).

In a manner analogous to prevention of complicated grief among family members, it is possible that attention to communication, clear decision making, and patient comfort can improve agreement about treatment goals within the clinical team and reduce staff distress (24). Debriefing sessions for ICU clinicians can offer these clinicians the opportunity to discuss their feelings and concerns related to caring for dying patients and their families and have been found to be useful in some settings (25).

### Importance of Continuous Quality Improvement and Research

Efforts to integrate palliative aspects of care within mainstream critical care will both stimulate and be accelerated by research.

Basic science related to pathophysiology of pain, delirium, and other symptoms and studies into the human psychology of patients and families affected by critical illness and injury are needed to effectively respond to suffering. Clinical research will span pharmacologic and physical modalities of symptom prevention and management to developing and refining effective modalities of emotional, social, and spiritual counseling.

Health service research is required to develop and evaluate programmatic strategies for delivering palliative aspects of care within busy critical care settings. In efforts to date, two distinct programmatic strategies have emerged. One approach seeks to enhance the knowledge and skills of critical care clinicians in delivering palliative aspects of care. The other expands access to palliative care specialists within critical care teams and units. Palliative care specialists may consult and may contribute to continuing care and co-management. These approaches are not mutually exclusive, but complementary. We are at an early stage of development, and innovation is to be encouraged. As programmatic models are developed and tested, the outcomes we measure must be sharply focused on the subjective experience of patients and families.

Health systems research is needed to implement desired changes in practical, efficient, and cost-effective ways. In the strained environment of contemporary health care, it is not sufficient to identify a problem and develop a solution. For any change to be successful, it is necessary "to make the right way the easy way." New

systems must respond to workday needs of time-pressured clinicians and managers by incorporating assessment of patient and family experience into routine policies, protocols, and procedures. Electronic medical records and computerized physician order entry technology can foster practice consistent with established institutional guidelines.

Although there is much work to be done, rapid improvement is possible given the complementary goals and skill sets of both critical care clinicians and palliative care clinicians (26). This area of research and development well warrants support by governmental and private funders.

### Conclusion

By collaborating to care well for critically ill or injured patients and extend support for their families, the disciplines of critical care and palliative care can complete one another. In the process of incorporating expert attention to people's comfort and emotional, social, and even spiritual well-being within intensive efforts to save life, clinicians and thought leaders from both disciplines can foster a healthy cultural maturation in society's orientation toward life-threatening illness and injury, one that acknowledges our shared mortality while affirming life through to its very end.

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