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Perspective

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Where We Die

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Related article, p. 2506

Until well into the 20th century in the United States, the appropriate place to die was a foregone conclusion: by expectation and practice, it was at home, surrounded by family and friends (Fig. 1).

A case in point was death from consumption (tuberculosis) in pre–Civil War New England. In tightly knit, homogeneous communities, a network of friends, neighbors, relatives, and clergymen comforted the dying, expecting, as Sheila Rothman has written, to walk with them "down to the borders of the River of death."[1] Physicians, once they had ascertained that the disease was in its last stages, were peripheral to the process.

Swansea Museum.

Figure 1. Dying at Home.
Sarah Dillwyn's Deathbed, by Charles Robert Leslie.

There were, of course, exceptions. Since consumption, it was believed, might be curable in warm climates, men and occasionally women traveled southward to Georgia, Cuba, or Bermuda. Although some survived the round-trip voyage, others died far from home, much to their families' anguish. It was unbearable, as one brother wrote to another, "that your eyes would be finally closed by foreign hands in a foreign country."[1]

The most serious challenge to these shared expectations, however, was the Civil War (Fig. 2). Soldiers who were wounded on the battlefield represented, as Drew Faust puts it, "an exemplary text on how not to die."[2]

Figure 2. Dying on the Battlefield.
"Petersburg, Va., April 1865; Dead South Carolina soldier in trenches," by Thomas C. Roche.

Library of Congress.

Fellow soldiers and nurses made great efforts to serve as surrogate families, which provided some consolation to parents. In one popular Civil War song, a dying solider asks his nurse to "be my mother till I die." Even more troubling was that both Union and Confederate units left many dead soldiers unburied or interred in unnamed blocks. After the hostilities ended, families undertook the grim task of traveling to the battlefields to try to locate their kin and arrange proper burials.[2]

The norm of dying at home persisted even through the extensive societal transformations brought about by immigration and urbanization. Ethnic origins and social class increasingly divided communities, but each group typically took care of its own. Again there were exceptions. Indigent people lacking families or friends, for instance, had no choice but to face death in public hospitals that were indistinguishable from almshouses. More portentously, in the era after Robert Koch discovered *Mycobacterium tuberculosis*, patients with tuberculosis were frequently confined (often against their will) to sanatoriums as part of a campaign to cure their disease and prevent contagion. The staffs of these institutions made only limited efforts to discharge patients before they died, and when they did so, their aim was as much to reduce institutional mortality as to allow patients to return to a comforting environment for their final days.

The phenomenon that transformed both public expectations and experience was the emergence of the hospital as the locus for scientific medicine. In the early 20th century, hospitals began to deliver curative care, and patients began to willingly occupy their beds. Inevitably, in the course of treatment, some of them died there.

The shift to a hospital death, however, was not immediate: into the 1940s, most people still died at home. In 1949, only 40% of Americans older than 65 years of age died in the hospital. But over the next several decades, as the hospital increasingly monopolized acute care delivery and its reputation for cure soared, the trend toward hospital deaths accelerated (Fig. 3). In the late 1970s and early 1980s, more than half of U.S. deaths occurred in hospitals, while the proportion occurring at home dropped to 15%. Even in 1989, which was 6 years after the implementation of the prospective payment system (whose predetermined and fixed reimbursements might have encouraged hospital discharges) and the introduction of Medicare reimbursement for hospice care, 49% of deaths still occurred in hospitals and only 15% occurred at home.[3]

In fact, within the hospital, death and dying were increasingly segregated from routine inpatient care through the introduction of intensive care units (ICUs) equipped with novel medical technologies and staffed with new types of specialists. The iron lung of the 1950s gave way to the respirators of the 1960s, along with innovative imaging and monitoring devices. The early ICUs served not only to render care more efficient and effective but also to isolate the sickest pa-

Figure 3. Dying in the Hospital.

A patient with end-stage pancreatic cancer and her husband and physician, Lebanon, NH, June 4, 2011.

Ed Kashi/VII/Corbis.

tients. The units, sealed off by heavy double doors, seemed mysterious and frightening. Visiting hours were either nonexistent or very brief, and even when a patient was dying, family access was limited. Thus, the process of death and dying was twice removed and rendered invisible, once through hospitalization and then through ICUs.

An audio interview with Dr. Rothman is available at NEJM.org

It was probably inevitable that reaction would set in. Beginning in the 1980s, a movement to desegregate death and dying from hospitals and other health care services took hold in the United States, and its impact has mounted steadily. The benchmarks are well known: Dame Cicely Saunders pioneered the hospice movement in Britain and helped bring it to the United States. Elisabeth Kübler-Ross (author of *On Death and Dying*) renewed the case for dying at home. The Medicare hospice-benefit program expanded, and palliative care became a recognized and widely practiced specialty. Foundation programs, including the Project on Death in America (the Open Society Foundations) and Last Acts (the Robert Wood Johnson Foundation), helped to fund relevant physician training and promote public responsiveness.

The data on where we now die testify to the scope of the changes that have followed, even as they provide food for thought and render the article by Cook and Rocker about dying with dignity in the ICU (pages 2506–2514) all the more salient. Although samples and methods vary, by all accounts the percentage of Americans older than 65 who die at home has increased. The Centers for Disease Control and Prevention (CDC) reckons that between 1989 and 2007, the proportion of deaths that occurred at home increased from 15 to 24%. Teno et al. calculate growth from 30.7% in 2000 to 33.5% in 2009. And the percentage of people dying in hospitals is shrinking — according to CDC data, from 49 to 35%, and according to Teno et al., from 32.6 to 26.9%. Clearly, the dominance of hospital deaths is fading.[4]

Yet simultaneously, the likelihood of an ICU stay is growing. Dartmouth Atlas data indicate that the proportion of patients with an ICU stay lasting 7 days or more during the last 6 months of life rose from 15.2% in 2007 to 16.7% in 2010. Teno et al. also found that "the rate of ICU use in the last month of life has increased," from 24.3% in 2000 to 29.2% in 2009.

What are we to make of these seemingly contradictory trends — more deaths at home and fewer in hospitals, but greater ICU use? First, a cultural shift back to dying at home has occurred, not only in terms of preferences expressed in polls but also in actual decision making. Second, by common agreement, hospitals are no longer the best place to die. But third, however strongly patients prefer to return home, they are often reluctant to do so until the most advanced medical technologies have been tried. The result is that a substantial number of patients die in ICUs in the midst of extraordinary interventions to save them.

> ***In the mid-20th century, the process of death and dying was twice removed and rendered invisible, once through hospitalization and then through ICUs.***

Under these circumstances, and however anomalous it may seem, the idea of bringing death with dignity to the ICU is highly germane. I believe that not only should the barriers between family and patient in the unit be minimized (and indeed many ICUs have now implemented such policies), but the process of decision making should also more fully reflect the principles of palliative care. Such an ICU culture would not only promote aggressive treatment but also help patients and their families make wise decisions about managing the end of life. This approach, as Cook and Rocker observe, may seem paradoxical, but it is nevertheless altogether essential.

Disclosure forms provided by the author are available with the full text of this article at NEJM.org.

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Drug Safety in the Digital Age

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The Internet is increasingly redefining the ways in which people interact with information related to their health. The Pew Internet Project estimates that more than half of all Americans sought health information online in 2013, mostly through search engines such as Google and websites such as Wikipedia and WebMD.

In this digital age, engaging with new media offers an unparalleled opportunity for medical and public health professionals to find information they need and to interactively reach out to patients and their support networks. One domain where these capabilities may have far-reaching effects that are currently undefined is drug safety. As the volume of health-related information on the Internet has grown, important questions have emerged. How are messages from regulators — for example, warnings against using a drug in a specific patient population — diffused digitally? And are the messages still accurate when they reach the general population?

To explore these questions, we selected new drug-safety communications related to prescription medicines that were issued by the U.S. Food and Drug Administration (FDA) over a 2-year period between January 1, 2011, and December 31, 2012 (see Table S1 in the Supplementary Appendix, available with the full text of this article at NEJM.org). Despite debates over its credibility, Wikipedia is reportedly the most frequently consulted online health care resource globally[1]: Wikipedia pages typically appear among the top few Google search results and are among the references most likely to be checked by Internet users.[2] We therefore evaluated Google searches and Wikipedia page views for each drug in our sample. We also examined the content of Wikipedia pages, looking specifically for references to safety warnings. To control for secular trends, we examined results from a 120-day window around the date of the announcement (from 60 days before the announcement to 60 days after it) and constructed a baseline period for comparison that ran from 60 days to 10 days before the period of interest began.[3]

We identified safety warnings for 22 prescription drugs that are indicated for a range of clinical conditions, including primary hypertension, chronic myelogenous leukemia, and hepatitis C. Collectively, these drugs triggered 13 million searches on Google and 5 million Wikipedia page views annually during the study period. FDA safety warnings were associated with an 82% increase, on average, in Google searches for the drugs during the week after the announcement and a 175% increase in views of Wikipedia pages for the drugs on the day of the announcement, as compared with baseline trends (see line graph and Fig. S1 in the Supplementary Appendix).

Did users find accurate information on the drugs' safety? We found that 41% of Wikipedia pages pertaining to the drugs with new safety warnings were updated within 2 weeks after the warning was issued with information provided in the FDA an-

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REVIEW ARTICLE

CRITICAL CARE MEDICINE

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Dying with Dignity in the Intensive Care Unit

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THE TRADITIONAL GOALS OF INTENSIVE CARE ARE TO REDUCE THE morbidity and mortality associated with critical illness, maintain organ function, and restore health. Despite technological advances, death in the intensive care unit (ICU) remains commonplace. Death rates vary widely within and among countries and are influenced by many factors.[1] Comparative international data are lacking, but an estimated one in five deaths in the United States occurs in a critical care bed.[2]

In this review, we address the concept of dignity for patients dying in the ICU. When the organ dysfunction of critical illness defies treatment, when the goals of care can no longer be met, or when life support is likely to result in outcomes that are incongruent with patients' values, ICU clinicians must ensure that patients die with dignity. The definition of "dying with dignity" recognizes the intrinsic, unconditional quality of human worth but also external qualities of physical comfort, autonomy, meaningfulness, preparedness, and interpersonal connection.[3] Respect should be fostered by being mindful of the "ABCDs" of dignity-conserving care (attitudes, behaviors, compassion, and dialogue)[4] (Table 1). Preserving the dignity of patients, avoiding harm, and preventing or resolving conflict are conditions of the privilege and responsibility of caring for patients at the end of life. In our discussion of principles, evidence, and practices, we assume that there are no extant conflicts between the ICU team and the patient's family. Given the scope of this review, readers are referred elsewhere for guidance on conflict prevention and resolution in the ICU.[5,6]

The concept of dying with dignity in the ICU implies that although clinicians may forgo some treatments, care can be enhanced as death approaches. Fundamental to maintaining dignity is the need to understand a patient's unique perspectives on what gives life meaning in a setting replete with depersonalizing devices. The goal is caring for patients in a manner that is consistent with their values at a time of incomparable vulnerability, when they rarely can speak for themselves.[7] For example, patients who value meaningful relationships may decline life-prolonging measures when such relationships are no longer possible. Conversely, patients for whom physical autonomy is not crucial may accept technological dependence if it confers a reasonable chance of an acceptable, albeit impaired, outcome.[8] At issue is what each patient would be willing to undergo for a given probability of survival and anticipated quality of life.

ON THE NEED FOR PALLIATIVE CARE

The coexistence of palliative care and critical care may seem paradoxical in the technological ICU. However, contemporary critical care should be as concerned with palliation as with the prevention, diagnosis, monitoring, and treatment of life-threatening conditions.

The World Health Organization defines palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."[9] Palliative care, which is essential regardless of whether a medical condition is acute or chronic and whether it is in an early or a late stage, can also extend beyond the patient's death to bereaved family members[10] (Fig. 1).

ELICITING THE VALUES OF PATIENTS

Sometimes it is too late. A precipitating event prompting an ICU admission that occurs within a protracted downward trajectory of an illness may be irreversible. When clinicians who are caring for a patient in such a scenario have not previously explored whether the patient would want to receive basic or advanced life support, the wishes of the patient are unknown, and invalid assumptions can be anticipated. Effective advance care planning, which is often lacking in such circumstances, elicits values directly from the patient, possibly preventing unnecessary suffering associated with the use of unwelcome interventions and thereby preserving the patient's dignity at the end of life.

Regardless of the rate and pattern of decline in health, by the time that patients are in the ICU, most cannot hold a meaningful conversation as a result of their critical condition or sedating medications. In such cases, family members or other surrogates typically speak for them. In decisions regarding the withdrawal of life support, the predominant determinants are a very low probability of survival, a very high probability of severely impaired cognitive function, and recognition that patients would not want to continue life support in such circumstances if they could speak for themselves.[11] Probabilistic information is thus often more important than the patient's age, coexisting medical conditions, or illness severity in influencing decisions about life-support withdrawal.

Discussions can be initiated by eliciting a narrative from patients (or more commonly, from family members) about relationships, activities, and experiences treasured by the patient. The use of engaging, deferential questions, such as "Tell me about your . . ." or "Tell us what is important to . . . ," is essential. Clinician guidance for constructing an authentic picture of the incapacitated patient's values is offered in the Facilitated Values History,[8] a framework that provides clinicians with strategies for expressing empathy, sensitively depicting common scenarios of death, clarifying the decision-making role of surrogates, eliciting and summarizing values most relevant to medical decision making, and linking these values explicitly to care plans.

Table 1. Examples of the ABCDs of Dignity-Conserving Care.*

Attitudes and assumptions can affect practice.
Reflect on how your own life experiences affect the way in which you provide care.
Be aware that other clinicians' attitudes and assumptions can affect their approach to patients.
Teach learners to be mindful of how their perspectives and presumptions can shape behaviors.
Behaviors should always enhance patient dignity.
Demonstrate with nonverbal methods how patients and their families are important to you.
Do not rush; sit down and make eye contact when talking with patients and their families.
Turn off digital devices and avoid jargon when talking with patients and their families.
Compassion is sensitivity to the suffering of another and the desire to relieve it.
Elicit the personal stories that accompany your patient's illness.
Acknowledge the effect of sickness on your patient's broader life experience.
Recognize and relieve suffering.
Dialogue should acknowledge personhood beyond the illness.
Explore the values that are most important to your patients.
Ask who else should be involved to help your patients through difficult times.
Encourage patients and their families to reflect and reminisce.

* This approach is adapted from Chochinov.[4]

COMMUNICATION

Before a critical illness develops, patients' perceptions about what matters most for high-quality end-of-life care vary, but human connections are

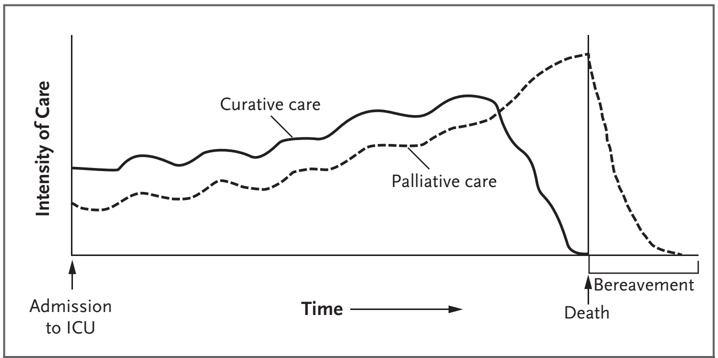

Figure 1. Curative and Palliative Approaches to Care throughout a Critical Illness. This diagram, which is adapted from a policy statement of the American Thoracic Society,[10] illustrates the relative intensity of curative and palliative approaches to the care of patients at different stages of a critical illness. In the palliative care model, the intensity of care increases at the end of life, and support of the patient's family continues beyond the patient's death.

key. Many seriously ill elderly patients cite effective communication, continuity of care, trust in the treating physician, life completion, and avoidance of unwanted life support.[12] After critical illness develops, most patients or their surrogates find themselves communicating with unfamiliar clinicians in a sterile environment at a time of unparalleled distress. Challenges in communication are magnified when patients die at an early stage of critical illness, before rapport has been well established.

Clear, candid communication is a determinant of family satisfaction with end-of-life care.[13] Notably, measures of family satisfaction with respect to communication are higher among family members of patients who die in the ICU than among those of ICU patients who survive, perhaps reflecting the intensity of communication and the accompanying respect and compassion shown by clinicians for the families of dying patients.[14] The power of effective communication also includes the power of silence.[15] Family satisfaction with meetings about end-of-life care in the ICU may be greater when physicians talk less and listen more.[16]

DECISION MAKING

Decision-making models for the ICU vary internationally but should be individualized. At one end of the continuum is a traditional parental approach, in which the physician shares information but assumes the primary responsibility for decision making. At the other end of the continuum, the patient makes the decisions, and the physician has an advisory role. In North America and in some parts of Europe,[17] the archetype is the shared decision-making model, in which physicians and patients or their surrogates share information with one another and participate jointly in decision making.[18]

Although preferences for decision-making roles vary among family members,[19] physicians do not always clarify family preferences.[20] Family members may lack confidence about their surrogate decision-maker role, regardless of the decision-making model, if they have had no experience as a surrogate or no prior dialogue with the patient about treatment preferences.[21] Decision-making burden is postulated as a salient source of strain among family members of patients who are dying in the ICU; anxiety and depression are also prevalent.[22,23]

PROVIDING PROGNOSTIC INFORMATION

Valid prognostic information is a fundamental component of end-of-life discussions. Understanding the predicted outcome of the critical illness and recognizing the uncertainty of that prediction are helpful in making decisions that reflect the patient's values. However, when it comes to prognosticating for seriously ill patients, families and physicians sometimes disagree.[24] In one study, surrogate decision makers for 169 patients in the ICU were randomly assigned to view one of two videos of a simulated family conference about a hypothetical patient.[25] The videos varied only according to whether the prognosis was conveyed in numerical terms ("10% chance of survival") or qualitative terms ("very unlikely to survive"). Numerical prognostic statements were no better than qualitative statements in conveying the prognosis. However, on average, surrogates estimated twice as often as physicians that the patient would survive.

In another study, when 80 surrogates of patients in the ICU interpreted 16 prognostic statements, interviews suggested an "optimism bias," in which the surrogates were likely to interpret the physicians' grim prognostication as positive with respect to the patient's condition.[26] Clinicians should recognize that family members who are acting as spokespersons for patients in the ICU are often "living with dying" as they face uncertainty while maintaining hope.[27] Hope should be respected during prognostic disclosure[28] while a realistic view is maintained, an attitude that is aptly expressed by the simple but profound notion of "hoping for the best but preparing for the worst."[29]

MAKING RECOMMENDATIONS

Physicians in the ICU sometimes make recommendations to forgo the use of life-support technology. In one study involving surrogates of 169 critically ill patients, 56% preferred to receive a physician's recommendation on the use of life support, 42% preferred not to receive such a recommendation, and 2% stated that either approach was acceptable.[30] A recent survey of ICU physicians showed that although more than 90% were comfortable making such recommendations and viewed them as appropriate, only 20% reported always providing recommendations to surrogates, and 10% reported rarely or never doing so.[31] In this study, delivering such recommendations was associated with perceptions about the surrogate's desire for, and agreement with, the physician's recommendations. Other potential influences are uncertainty, personal values, and litigation concerns.

Asking families about their desire for recommendations from physicians can be a starting point for shared deliberations about care plans.[32] Eliciting preferences for how patients or their families wish to receive information, particularly recommendations concerning life support, is not an abnegation of responsibility but rather an approach that is likely to engender trust. Physicians should judiciously analyze each situation and align their language and approach with the preferred decision-making model, understand interpersonal relationships, and avoid overemphasizing a particular point of view. For example, in the shared decision-making model of care for dying patients, family discussions typically include a review of the patient's previous and present status and prognosis, elicitation of the patient's values, presentation of the physician's recommendations, deliberations, and joint decision making about ongoing levels of care.

PROVIDING HOLISTIC CARE

Cultivating culturally and spiritually sensitive care is central to the palliative approach. The pillars of both verbal and nonverbal communication are crucial. Conscious nonverbal communication is rarely practiced yet can be as powerful as verbal communication during end-of-life decision making. Physicians should be aware of the cultural landscape reflecting an institution's catchment area, how cultural norms can influence admissible dialogue, and what is desirable versus dishonoring in the dying process.[33]

The meaning assigned to critical illness, particularly when death looms, is frequently interpreted through a spiritual lens. For many people, critical illness triggers existential questions about purpose (of life, death, and suffering), relationships (past, present, and future), and destiny. Clinicians should be able to pose questions about spiritual beliefs that may bear on experiences with respect to illness. Introductory queries can open doors, such as "Many people have beliefs that shape their lives and are important at times like this. Is there anything that you would like me to know?"[34] A useful mnemonic for obtaining ancillary details is SPIRIT, which encompasses acknowledgment of a spiritual belief system, the patient's personal involvement with this system, integration with a spiritual community, ritualized practices and restrictions, implications for medical care, and terminal-events planning[34] (Table 2).

Although it is unrealistic to expect that clinicians will be familiar with the views of all the world religions regarding death, they should be cognizant of how belief systems influence end-of-life care.[35] Physicians may recommend different approaches to similar situations, depending on their religious and cultural backgrounds, as has been self-reported[36] and documented in observational studies.[37] Insensitivity to faith-based preferences for discussion and decision making may amplify the pain and suffering of both patients and their families. Clinicians should understand how spirituality can influence coping, either positively or negatively.[38] Chaplains are indispensable for addressing and processing existential distress, conducting life review, and facilitating comforting prayers, rituals, or other observances.

Table 2. Taking a Spiritual History.*

S for spiritual belief system
P for personal spirituality
I for integration with a spiritual community
R for ritualized practices and restrictions
I for implications for medical care
T for terminal-events planning

* This approach is adapted from Maugans.[34] The mnemonic SPIRIT can be used to elicit a spiritual history from a patient as part of the goal of providing sensitive, compassionate end-of-life care.

THE FINAL STEPS

If a shift is made in the goals of care from cure to comfort, it should be orchestrated with grace and should be individualized to the needs of the patient.[39] Before proceeding with end-of-life measures, it is necessary to prepare staff members and the patient's room, as well as the patient (Table 3). The panoply of basic and advanced life-support equipment and the mechanics of their deployment or discontinuation are chronicled in multiple studies, as well as in discussion documents, consensus statements from professional organizations, and task-force reports.[10,17,32,40] Strategies should be openly discussed and informed by the same balance of benefits, burdens, and respect for the preferences of patients and their surrogates that apply to other aspects of end-of-life care.[10]

There is no single, universally accepted technical approach. Admissible strategies in most settings include variations and combinations of nonescalation of current interventions, withholding of future interventions, and withdrawal of some or all interventions, except those needed for comfort. When life-support measures are withdrawn, the process of withdrawal — immediate or gradual discontinuation — must be considered carefully. Mechanical ventilation is the most common life-support measure that is withdrawn.[11] However, even in the case of mechanical ventilation, legal or faith-based requirements, societal norms, and physician preferences influence decisions about withdrawal.[32] The initiation of noninvasive ventilation with clear objectives for patients who are not already undergoing mechanical ventilation can sometimes reduce dyspnea and delay death so that the patient can accomplish short-term life goals.[41] Whatever approach is used, individualized pharmacologic therapy, which depends on prevailing levels of analgesia and sedation at the time of decisions to forgo life support, should ensure preemptive, timely alleviation of dyspnea, anxiety, pain, and other distressing symptoms.[42] Clinicians can mitigate the stress of family members by discussing what is likely to happen during the dying process (e.g., unusual sounds, changes in skin color, and agonal breathing). Physician attendance is paramount to reevaluate the patient's comfort and talk with the family as needed (Table 4).

CONSEQUENCES FOR CLINICIANS

Dying patients and their families in the ICU are not alone in their suffering. For some clinicians, views about the suitability of advanced life support that diverge from those of the patient or family can be a source of moral distress. Clinicians who detect physical or psychic pain and other negative symptoms may suffer indirectly, yet deeply. Vicarious traumatization results from repeated empathic engagement with sadness and loss,[43] particularly when predisposing characteristics amplify clinicians' response to this workplace stress. Clinicians should be aware of how their emotional withdrawal or lability and "compassion fatigue" can jeopardize the care of dying patients and their families.

Informal debriefing or case-based rounds,[44] local meetings with other professionals, modified work assignments, and other strategies may help clinicians to cope with the distress.[45] Formal bereavement counseling that is designed especially for involved clinicians can enhance awareness about vicarious traumatization and encourage adaptive personal and professional coping strategies.

END-OF-LIFE CARE AS A QUALITY-IMPROVEMENT TARGET

Palliative care is now a mainstream matter for quality-improvement agendas in many ICUs. A decade ago, the Robert Wood Johnson Foundation Critical Care End-of-Life Peer Workgroup and 15 associated nurse–physician teams in North America conducted a review of reported practices

Table 3. Practical Preparatory Procedures to Ensure Patient Dignity before Withdrawal of Life Support.

- Prepare staff members
    - Review the planned procedures in detail with all relevant staff members.
    - Ensure that the referring physician is aware of the plans, if not already engaged.
    - Ensure that spiritual care services are offered, if not already engaged.
    - Remind staff members that all their actions should ensure the dignity of the patient.
    - Remind staff members that the patient and family are the unit of care.
    - Prepare a staffing schedule to maximize the continuity of care during the dying process, if possible.
    - Ensure that the bedside nurse has not been assigned to care for another acutely ill patient, if possible.
    - Ensure that the bedside nurse is experienced in palliative care; if not, change the assignment or arrange for supervision to be provided by a nurse experienced in palliative care.
    - Ensure that physicians are readily available and do not abandon the patient or family.
    - Introduce the relevant housestaff members to the patient and family.
    - Introduce the respiratory therapist to the patient and family, when applicable.
    - Ensure that staff members minimize unnecessary noise immediately outside the room.
- Prepare the patient's room
    - Consider the comfort of the patient and family (e.g., lighting, temperature, personal items).
    - Liberalize visiting restrictions (e.g., timing, duration, number of visitors).
    - Remove unnecessary equipment.
    - Bring additional chairs into the room, if necessary.
    - Secure a quiet room for the family away from the bedside.
- Prepare the patient
    - Position the patient as comfortably as possible.
    - Honor requests for cultural, spiritual, and religious rituals.
    - Dim the lighting on screens required for monitoring (e.g., electrocardiography).
    - Discontinue unnecessary monitoring (e.g., oximetry), unnecessary devices (e.g., feeding tubes), unnecessary tests (e.g., blood work), and unnecessary treatments (e.g., enteral nutrition).
    - Discontinue medications that do not provide comfort and provide those that do.
    - Ensure that the patient is as calm and distress-free as possible before proceeding to withdraw life support.

for end-of-life care and named seven key domains for quality improvement: patient- and family-centered decision making, communication, continuity of care, emotional and practical support, symptom management, spiritual support, and emotional and organizational support for ICU clinicians.[46] More than 100 potential interventions were identified as part of this project, directed at patients and their families, clinicians, ICUs, and health care systems. Candidate quality indicators and "bundled indicators" can facilitate measurement and performance feedback in evaluating the quality of palliative care in ICU settings.[47]

In a multicenter, randomized trial involving critically ill patients who were facing value-related conflicts, ethics consultations helped with conflict resolution and reduced the duration of nonbeneficial treatments that the patients received.[48] In a subsequent cluster-randomized trial involving 2318 patients in which investigators evaluated a five-component, clinician-focused end-of-life strategy,[49] there were no significant differences between groups with respect to family satisfaction with care, family or nurse ratings of the quality of dying, time to withdrawal of mechanical ventilation, length of stay in the ICU, or other palliative care indicators.

Favorable assessments of palliative care interventions in the ICU are beginning to emerge. In one study, family members of 126 dying patients in 22 ICUs were randomly assigned to participate

Table 4. Considerations and Cautions in the Withdrawal of Life Support.*

Variable	Considerations	Cautions
Discontinuation of renal-replacement therapy	Confers a low risk of physical distress	Death may take several days if this is the only advanced life support withdrawn
Discontinuation of inotropes or vasopressors	Confers no risk of physical distress Death may occur quickly if the patient requires high doses, with or without withdrawal of mechanical ventilation	Death may not occur quickly if the patient requires low doses, particularly if mechanical ventilation is ongoing
Weaning from inotropes or vasopressors	Confers no risk of physical distress	May prolong the dying process, particularly if the patient requires low doses and this is the only life support withdrawn
Discontinuation of mechanical ventilation	Confers risk of dyspnea Death may occur quickly if the patient requires high pressure settings or high oxygen levels	Preemptive sedation is typically needed to blunt air hunger due to rapid changes in mechanical ventilation Death may not occur quickly if the patient requires low pressure settings or low oxygen levels
Weaning from mechanical ventilation	Confers low risk of dyspnea	May prolong the dying process, particularly if the patient requires low pressure settings or low oxygen levels and this is the only life support withdrawn
Extubation	Confers risk of dyspnea Avoids discomfort and suctioning of endotracheal tube Can facilitate oral communication Allows for the most natural appearance	Informing families about possible physical signs after extubation can prepare and reassure them Secretions may cause noisy breathing, which may be reduced with the use of glycopyrrolate; the use of glucocorticoids may reduce stridor Airway obstruction may occur; jaw thrust or repositioning of the patient may help Not advised if the patient has hemoptysis

* The choice regarding the type and dose of medications depends on prevailing levels of analgesia and sedation at the time of the decision, the mode and sequence of the planned withholding or withdrawal of life support, and myriad other factors.[42] These factors preclude any specific dose recommendations. Physician availability for the family during the dying process is as important as individualized adjustment of medication.

in a standard end-of-life family conference or to participate in a proactive family conference and receive a brochure on bereavement.[50] The mnemonic "VALUE" framed the five objectives of the proactive family conference: value and appreciate what family members say, acknowledge the family members' emotions, listen to their concerns, understand who the patient was in active life by asking questions, and elicit questions from the family members. Patients whose family members were assigned to the proactive-conference group were treated with significantly fewer nonbeneficial interventions after the family conference than were those whose family members were assigned to the standard-conference group, with no significant between-group difference in the length of stay in the ICU or the hospital. Caregivers in the proactive-conference group, as compared with the standard-conference group, were less negatively affected by the experience and were less likely to have anxiety, depression, and symptoms of post-traumatic stress 90 days after the patients' deaths.

CONCLUSIONS

Palliative care in the ICU has come of age. Its guiding principles are more important than ever in increasingly pluralistic societies. Ensuring that patients are helped to die with dignity begs for reflection, time, and space to create connections that are remembered by survivors long after a patient's death. It calls for humanism from all clinicians in the ICU to promote peace during the final hours or days of a patient's life and to support the bereaved family members. Ensuring death with dignity in the ICU epitomizes the art of medicine and reflects the heart of medicine. It demands the best of us.

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