

INTERVENTIONS It is imperative to inquire about unmet needs and to try to ensure that those needs are met either through the family or by paid professional services when possible. Community assistance through houses of worship or other community groups often can be mobilized by telephone calls from the medical team to someone the patient or family identifies. Sources of support specifically for family caregivers should be identified through local sources or nationally through groups such as the National Family Caregivers Association (www.nfcares.org), the American Cancer Society (www.cancer.org), and the Alzheimer's Association (www.alz.org).

EXISTENTIAL NEEDS AND THEIR MANAGEMENT

Frequency Religion and spirituality are often important to dying patients. Nearly 70% of patients report becoming more religious or spiritual when they became terminally ill, and many find comfort in religious or spiritual practices such as prayer. However, ~20% of terminally ill patients become less religious, frequently feeling cheated or betrayed by becoming terminally ill. For other patients, the need is for existential meaning and purpose that is distinct from and may even be antithetical to religion or spirituality. When asked, patients and family caregivers frequently report wanting their professional caregivers to be more attentive to religion and spirituality.

ASSESSMENT Health care providers are often hesitant about involving themselves in the religious, spiritual, and existential experiences of their patients because it may seem private or not relevant to the current illness. But physicians and other members of the care team should be able at least to detect spiritual and existential needs. Screening questions have been developed for a physician's spiritual history taking. Spiritual distress can amplify other types of suffering and even masquerade as intractable physical pain, anxiety, or depression. The screening questions in the comprehensive assessment are usually sufficient. Deeper evaluation and intervention are rarely appropriate for the physician unless no other member of a care team is available or suitable. Pastoral care providers may be helpful, whether from the medical institution or from the patient's own community.

INTERVENTIONS Precisely how religious practices, spirituality, and existential explorations can be facilitated and improve end-of-life care is not well established. What is clear is that for physicians, one main intervention is to inquire about the role and importance of spirituality and religion in a patient's life. This will help a patient feel heard and help physicians identify specific needs. In one study, only 36% of respondents indicated that a clergy member would be comforting. Nevertheless, the increase in religious and spiritual interest among a substantial fraction of dying patients suggests inquiring of individual patients how this need can be addressed. Some evidence supports specific methods of addressing existential needs in patients, ranging from establishing a supportive group environment for terminal patients to individual treatments emphasizing a patient's dignity and sources of meaning.

MANAGING THE LAST STAGES

WITHDRAWING AND WITHHOLDING LIFE-SUSTAINING TREATMENT

LEGAL ASPECTS For centuries, it has been deemed ethical to withhold or withdraw life-sustaining interventions. The current legal consensus in the United States and most developed countries is that patients have a moral as well as constitutional or common law right to refuse medical interventions. American courts also have held that incompetent patients have a right to refuse medical interventions. For patients who are incompetent and terminally ill and who have not completed an advance care directive, next of kin can exercise that right, although this may be restricted in some states, depending how clear and convincing the evidence is of the patient's preferences. Courts have limited families' ability to terminate life-sustaining treatments in patients who are conscious, incompetent, but not terminally ill. In theory, patients' right to refuse medical therapy can be limited by four countervailing interests: (1) preservation of life, (2) prevention of suicide, (3) protection of third parties such as children, and (4) preservation of the integrity of

the medical profession. In practice, these interests almost never override the right of competent patients and incompetent patients who have left explicit and advance care directives.

For incompetent patients who either appointed a proxy without specific indications of their wishes or never completed an advance care directive, three criteria have been suggested to guide the decision to terminate medical interventions. First, some commentators suggest that ordinary care should be administered but extraordinary care could be terminated. Because the ordinary/extraordinary distinction is too vague, courts and commentators widely agree that it should not be used to justify decisions about stopping treatment. Second, many courts have advocated the use of the substituted-judgment criterion, which holds that the proxy decision-makers should try to imagine what the incompetent patient would do if he or she were competent. However, multiple studies indicate that many proxies, even close family members, cannot accurately predict what the patient would have wanted. Therefore, substituted judgment becomes more of a guessing game than a way of fulfilling the patient's wishes. Finally, the best-interests criterion holds that proxies should evaluate treatments by balancing their benefits and risks and select those treatments in which the benefits maximally outweigh the burdens of treatment. Clinicians have a clear and crucial role in this by carefully and dispassionately explaining the known benefits and burdens of specific treatments. Yet even when that information is as clear as possible, different individuals can have very different views of what is in the patient's best interests, and families may have disagreements or even overt conflicts. This criterion has been criticized because there is no single way to determine the balance between benefits and burdens; it depends on a patient's personal values. For instance, for some people, being alive even if mentally incapacitated is a benefit, whereas for others, it may be the worst possible existence. As a matter of practice, physicians rely on family members to make decisions that they feel are best and object only if those decisions seem to demand treatments that the physicians consider not beneficial.

PRACTICES Withholding and withdrawing acutely life-sustaining medical interventions from terminally ill patients are now standard practice. More than 90% of American patients die without cardiopulmonary resuscitation (CPR), and just as many forgo other potentially life-sustaining interventions. For instance, in ICUs in the period 1987–1988, CPR was performed 49% of the time, but it was performed only 10% of the time in 1992–1993. On average, 3.8 interventions, such as vasopressors and transfusions, were stopped for each dying ICU patient. However, up to 19% of decedents in hospitals received interventions such as extubation, ventilation, and surgery in the 48 h preceding death. However, practices vary widely among hospitals and ICUs, suggesting an important element of physician preferences rather than objective data.

Mechanical ventilation may be the most challenging intervention to withdraw. The two approaches are *terminal extubation*, which is the removal of the endotracheal tube, and *terminal weaning*, which is the gradual reduction of the or ventilator rate. One-third of ICU physicians prefer to use the terminal weaning technique, and 13% extubate; the majority of physicians use both techniques. The American Thoracic Society's 2008 clinical policy guidelines note that there is no single correct process of ventilator withdrawal and that physicians use and should be proficient in both methods but that the chosen approach should carefully balance benefits and burdens as well as patient and caregiver preferences. Physicians' assessment of patients' likelihood of survival, their prediction of possible cognitive damage, and patients' preferences about the use of life support are primary factors in determining the likelihood of withdrawal of mechanical ventilation. Some recommend terminal weaning because patients do not develop upper airway obstruction and the distress caused by secretions or stridor; however, terminal weaning can prolong the dying process and not allow a patient's family to be with him or her unencumbered by an endotracheal tube. To ensure comfort for conscious or semiconscious patients before withdrawal of the ventilator, neuromuscular blocking agents should be terminated and sedatives