



who are cognitively impaired). Some under-treatment stems from fears about addiction as well as concerns about the possibility of hastening death. When patients with prior addiction problems are excluded, the incidence of new addictive behavior when opioids are used to treat pain in those with a well-defined, serious illness is rare. Similarly, there is very little data to suggest that properly prescribed opioids hasten death. In fact, current evidence supports the idea that opioids may prolong life in these patients and enhance quality of life in those with advanced illness and major pain or dyspnea.

Addiction and diversion exist in medically ill populations. Alcoholism and substance abuse exist in medically ill populations as they do in all other parts of society. When patients with such risk factors develop painful, potentially life-limiting medical conditions, they deserve adequate pain treatment, but with extreme caution because of the risk of reactivating or aggravating abuse behavior, including diversion of prescription drugs for recreational purposes. Prescribing contracts that specify one single medical prescriber, set amounts around the clock and as needed limits, face-to-face encounters for all renewals, and dose adjustments only after direct conversation with the prescriber, are all essential parts of the plan. Consultations with experts in palliative care and/or substance abuse should be requested if there is any difficulty adhering to the contract.

When Patients and Families Want Near Futile Treatment

The patient autonomy movement in medicine has led to patients and families taking an active role in their own medical decision making. This is generally a positive development except in two circumstances: 1) when physicians stop taking an active role using their expertise to guide patients in their decision making, thereby abdicating their professional responsibility of advocating for the best possible treatment based on the patient's medical condition and personal values, and 2) when patients or their families want and even demand near futile treatment toward the end of their lives despite physician's advice that treatment has much more burden than benefit. Physicians might try to respond to patients who want "everything" by suggesting that they want to try everything that is "more likely to help than harm," but avoid any treatment that is most likely to "do more harm than good." However, some patients and families will accept no limits on treatment no matter what the burden and the improbability of success. Of course, truly futile treatment should not be offered or provided upon request, but absolute futility has been difficult to define in many cases.

Feeding Tube Questions When Patients Stop Eating and Drinking

Many patients gradually stop eating and drinking as a natural part of the dying process, but this can be very hard for patients and families to accept in light of fears about "starving to death" and in view of seemingly simple technologies that can potentially combat and even reverse the problem. In fact, with few exceptions, feeding tubes have not been shown to prolong life in most advanced illnesses such as metastatic cancer or advanced Alzheimer disease. It is important to know about the exceptions (e.g. esophageal and oropharyngeal cancers, amyotrophic lateral

sclerosis, acute stroke), but also to have an open discussion about the naturalness of diminished eating and drinking as many illnesses progress. If there is uncertainty about whether a particular patient might benefit from a feeding tube, and patient and family are clear about wanting to give it a try, the clinician can frame the decision as a "time-limited trial" to see how the patient tolerates tube feeding psychologically as well as physiologically in a specified timeframe. A nasogastric tube has a built-in time limit of about a month before a PEG tube needs to be inserted as a potential framework for such a trial. Explaining to patients and families about the positive aspects of natural feeding, even in small amounts, of real food (smell, taste, and enjoyment) may help focus the decision on important quality of life issues (that may otherwise be ignored), rather than more technical, physiological issues.

LAST HOURS AND DAYS OF LIVING

An integral aspect of palliative care is preparing and guiding the patient and caregivers through the dying process. When prognosis is measured in hours to days there are typical signs and symptoms that usually occur. Patients become weak and fatigued and gradually lose mobility. There is also a gradual and predictable decrease in food and fluid intake. Most patients do not experience hunger and thirst, and the associated mouth dryness that occurs is easily palliated with small sips or sponges of cold water. Caregivers will frequently ask about intravenous hydration. In rare instances, intravenous or subcutaneous fluids may temporarily improve mental status and energy in the final days of life. Most of the time, however, the benefits are difficult to discern and the excessive fluids may contribute to end-of-life physiologic conditions (edema, ascites, effusions, and pulmonary secretions) that do not improve longevity and may worsen comfort.

As patients become weaker, there is a predictable decrease in the level of consciousness with increasing periods of somnolence eventually giving way to a comatose state. Education about this process should include associated changes in respiratory patterns and to anticipate progressive periods of apnea, interspersed with episodes of hyperpnea and deep breathing (Cheyne-Stokes respirations). During this process caregivers often feel they are on "a roller-coaster ride" and gentle guidance on what to expect can allay concerns. As consciousness wanes, swallowing slows and the cough reflex weakens. As a result, saliva pools in the oropharynx and can result in noisy respiration ("death rattle"), which can usually be palliated to some degree with transdermal scopolamine, glycopyrrolate (PO, IV, SC) or sublingual atropine ophthalmic drops. Families should be reminded that these symptoms are a natural part of the dying process, and that persistent shortness of breath is relatively uncommon, but can be treated with opiates and benzodiazepines, if needed.

As death approaches, reduced perfusion causes cooling and cyanosis of the extremities and a decrease and darkening of the urine. Most deaths are relatively peaceful, but a few can be preceded by periods of intense agitation and restlessness (hyperactive terminal delirium). Antipsychotic medications and conventional doses of benzodiazepines can usually treat terminal delirium. Prior to and when death occurs, families should be encouraged to carry out cultural or religious rituals that are important to them. Providers should express condolences, be