

dysfunction. Olanzapine has the disadvantage that it is available only orally and that it takes a week to reach steady state. The usual dose is 2.5–5 mg PO bid. Chlorpromazine (10–25 mg every 4–6 h) can be useful if sedation is desired and can be administered IV or PR in addition to PO. Dystonic reactions resulting from dopamine blockade are a side effect of neuroleptics, although they are reported to be rare when these drugs are used to treat terminal delirium. If patients develop dystonic reactions, benztropine should be administered. Neuroleptics may be combined with lorazepam to reduce agitation when the delirium is the result of alcohol or sedative withdrawal.

If no response to first-line therapy is seen, a specialty consultation should be obtained with a change to a different medication. If patients fail to improve after a second neuroleptic, sedation with an anesthetic such as propofol or continuous-infusion midazolam may be necessary. By some estimates, at the very end of life, as many as 25% of patients experiencing delirium, especially restless delirium with myoclonus or convulsions, may require sedation.

Physical restraints should be used with great reluctance and only when the patient's violence is threatening to self or others. If they are used, their appropriateness should be reevaluated frequently.

**Insomnia • FREQUENCY** Sleep disorders, defined as difficulty initiating sleep or maintaining sleep, sleep difficulty at least 3 nights a week, or sleep difficulty that causes impairment of daytime functioning, occur in 19–63% of patients with advanced cancer. Some 30–74% of patients with other end-stage conditions, including AIDS, heart disease, COPD, and renal disease, experience insomnia.

**ETIOLOGY** Patients with cancer may have changes in sleep efficiency such as an increase in stage I sleep. Other etiologies of insomnia are coexisting physical illness such as thyroid disease and coexisting psychological illnesses such as depression and anxiety. Medications, including antidepressants, psychostimulants, steroids, and  $\beta$  agonists, are significant contributors to sleep disorders, as are caffeine and alcohol. Multiple over-the-counter medications contain caffeine and antihistamines, which can contribute to sleep disorders.

**ASSESSMENT** Assessment should include specific questions concerning sleep onset, sleep maintenance, and early-morning waking as these will provide clues to the causative agents and to management. Patients should be asked about previous sleep problems, screened for depression and anxiety, and asked about symptoms of thyroid disease. Caffeine and alcohol are prominent causes of sleep problems, and a careful history of the use of these substances should be obtained. Both excessive use and withdrawal from alcohol can be causes of sleep problems.

**INTERVENTIONS** The mainstays of intervention include improvement of sleep hygiene (encouragement of regular time for sleep, decreased nighttime distractions, elimination of caffeine and other stimulants and alcohol), intervention to treat anxiety and depression, and treatment for the insomnia itself. For patients with depression who have insomnia and anxiety, a sedating antidepressant such as mirtazapine can be helpful. In the elderly, trazodone, beginning at 25 mg at nighttime, is an effective sleep aid at doses lower than those which cause its antidepressant effect. Zolpidem may have a decreased incidence of delirium in patients compared with traditional benzodiazepines, but this has not been clearly established. When benzodiazepines are prescribed, short-acting ones (such as lorazepam) are favored over longer-acting ones (such as diazepam). Patients who receive these medications should be observed for signs of increased confusion and delirium.

## SOCIAL NEEDS AND THEIR MANAGEMENT

**Financial Burdens • FREQUENCY** Dying can impose substantial economic strains on patients and families, causing distress. In the United States, with one of the least comprehensive health insurance systems among the developed countries, ~20% of terminally ill patients and their families spend >10% of family income on health care costs over and above health insurance premiums. Between 10 and 30% of families

sell assets, use savings, or take out a mortgage to pay for the patient's health care costs. Nearly 40% of terminally ill patients in the United States report that the cost of their illness is a moderate or great economic hardship for their family.

The patient is likely to reduce and eventually stop working. In 20% of cases, a family member of the terminally ill patient also stops working to provide care. The major underlying causes of economic burden are related to poor physical functioning and care needs, such as the need for housekeeping, nursing, and personal care. More debilitated patients and poor patients experience greater economic burdens.

**INTERVENTION** This economic burden should not be ignored as a private matter. It has been associated with a number of adverse health outcomes, including preferring comfort care over life-prolonging care as well as consideration of euthanasia or physician-assisted suicide. Economic burdens increase the psychological distress of families and caregivers of terminally ill patients, and poverty is associated with many adverse health outcomes. Importantly, recent studies found that "patients with advanced cancer who reported having end-of-life conversations with physicians had significantly lower health care costs in their final week of life. Higher costs were associated with worse quality of death." Assistance from a social worker, early on if possible, to ensure access to all available benefits may be helpful. Many patients, families, and health care providers are unaware of options for long-term care insurance, respite care, the Family Medical Leave Act (FMLA), and other sources of assistance. Some of these options (such as respite care) may be part of a formal hospice program, but others (such as the FMLA) do not require enrollment in a hospice program.

**Relationships • FREQUENCY** Settling personal issues and closing the narrative of lived relationships are universal needs. When asked if sudden death or death after an illness is preferable, respondents often initially select the former but soon change to the latter as they reflect on the importance of saying goodbye. Bereaved family members who have not had the chance to say goodbye often have a more difficult grief process.

**INTERVENTIONS** Care of seriously ill patients requires efforts to facilitate the types of encounters and time spent with family and friends that are necessary to meet those needs. Family and close friends may need to be accommodated with unrestricted visiting hours, which may include sleeping near the patient even in otherwise regimented institutional settings. Physicians and other health care providers may be able to facilitate and resolve strained interactions between the patient and other family members. Assistance for patients and family members who are unsure about how to create or help preserve memories, whether by providing materials such as a scrapbook or memory box or by offering them suggestions and informational resources, can be deeply appreciated. Taking photographs and creating videos can be especially helpful to terminally ill patients who have younger children or grandchildren.

**Family Caregivers • FREQUENCY** Caring for seriously ill patients places a heavy burden on families. Families frequently are required to provide transportation and homemaking as well as other services. Typically, paid professionals such as home health nurses and hospice workers supplement family care; only about a quarter of all caregiving consists of exclusively paid professional assistance. The trend toward more out-of-hospital deaths will increase reliance on families for end-of-life care. Increasingly, family members are being called upon to provide physical care (such as moving and bathing patients) and medical care (such as assessing symptoms and giving medications) in addition to emotional care and support.

Three-quarters of family caregivers of terminally ill patients are women—wives, daughters, sisters, and even daughters-in-law. Because many are widowed, women tend to be able to rely less on family for caregiving assistance and may need more paid assistance. About 20% of terminally ill patients report substantial unmet needs for nursing and personal care. The impact of caregiving on family caregivers is substantial: both bereaved and current caregivers have a higher mortality rate than that of non-caregiving controls.