

Depression prevalence and wish to die in late-stage ALS

Rabkin et al. assessed 80 hospice-eligible ALS patients at monthly intervals until death or tracheostomy. Although transient depressive symptoms were observed, depressive disorders were uncommon (9% had symptoms consistent with major depression, 10% with minor depression). Rates did not increase as death approached. In monthly follow-up of 53 ALS patients who died, Albert et al. found that 10 (18.9%) expressed the wish to die and three (5.7%) requested sedatives explicitly to hasten dying. The wish to die was associated with pessimism, less comfort in religion, and greater hopelessness, but not with depression.

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ALS, depression, and desire for a hastened death: (How) are they related?

Commentary by Timothy E. Quill, MD

Patients with ALS must have a high incidence of depression (*Wouldn't you be depressed under these circumstances?*), and certainly those who express a desire for a hastened death must have a high incidence of depression (*No one in their right mind would make that choice.*). These two pervasive myths are challenged in this issue of *Neurology* in two articles from the Eleanor & Lou Gehrig MDA/ALS Research Center in New York. The first article reports the results of prospective monthly depression assessments of 80 hospice-eligible ALS patients; the authors found that while transient episodes of depression occurred in 43%, only 9% of patients had sustained symptoms of major depression, and the incidence of depression did not significantly increase as death approached. The second article reports the frequencies of a genuine wish to die (18.9%) and of subsequent acts to hasten death (5.7%) in the 53 patients who died from the same cohort. These authors found that the wish to die correlated with pessimism, decreased comfort in religion, and hopelessness, but much less so with depression. The patients who hastened death reported decreased suffering and increased sense of control over disease during their final weeks. In an associated editorial, Olney and Lomen-Hoerth ask whether subtle cognitive impairment from unrecognized frontotemporal dementia might have confounded the picture.

Depression scales clearly need to be adjusted when they are applied to severely ill, potentially dying patients. Thinking about death and preparing for it are essential parts of this phase of life, and symptoms such as fatigue, anorexia, sleep disturbance, and poor concentration are common in the terminally ill, yet in unadjusted depression scales designed for physically healthy persons such features may overdiagnose depression. Similarly, the

Beck Hopelessness Scale has items such as *I can't imagine what my life would be like in 10 years*, or *The future seems vague and uncertain to me*, or *Things just won't work out the way I want them to*, each of which assesses the responder's orientation toward the future, which takes on a different meaning when one has a severe progressive illness such as advanced ALS.¹ It is not surprising that the authors found a high incidence of hopelessness in those ALS patients who had a strong wish for death, but depression, particularly when adjusted for suicidality, did not strongly correlate. The Mini-Mental Status examination is clearly inadequate to assess subtle cognitive impairment that may be present in ALS patients who appear cognitively intact.

Many ALS patients contemplate potentially hastening their death, and a majority endorse legalization of physician-assisted suicide.² Yet contemplators must be distinguished from those who seriously consider the options, from those who genuinely explore the wish to die, from those who act on those feelings. The 5.7% who actively hastened death in this study were an interesting subgroup. None of these three patients used feeding tubes or ventilators, and none carried out physician-assisted suicide. Instead, "the hospice team titrated sedatives, progressing from oral to transdermal morphine preparations, usually for 2–3 days," presumably at the patient's request. This act would probably be considered a variant of "terminal sedation," with medication doses being increased until complete sedation is achieved, allowing the patient to escape from his or her suffering.³ This practice seems to be legally acceptable, though its moral status is currently being debated. We know there is tremendous variation in its availability, with a range of 0 to 50% of hospice deaths depending on the program.

Table Palliative options of last resort

Aggressive pain or shortness of breath management
Not starting or stopping life-sustaining therapy
Voluntarily stopping eating and drinking
Terminal sedation
Physician-assisted suicide

One of the biggest challenges for clinicians caring for ALS patients who want to explore their end-of-life choices is to learn how to discuss potential last-resort options with them (table).³ Feeding tubes and mechanical ventilation are almost always part of the discussion, and we have found that having a willingness to discuss stopping them once started allows some patients who fear chronic dependence to try these treatments in a time-limited way that keeps them in control of the process. Sometimes knowledge that there could be an escape allows some patients to keep going in circumstances under which they would otherwise feel trapped. Assessing for depression is always a piece of the assessment puzzle, but as these two articles demonstrate, trying to understand the patient's dilemma and view of the present and future requires a much broader inquiry into existential and personal domains with which the patient is trying to come to grips.

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