Hastened death in ALS

Damaged brains and bad decisions?

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Currently, 1 of every 6 Americans resides in a state where physician-assisted suicide/hastened death is legal, a denominator that appears to be shrinking.1 In 2015, fully half of state legislatures considered legalization of hastened death practices.1 These statistics are particularly relevant to neurologists who care for patients afflicted with amyotrophic lateral sclerosis (ALS). Hastened death interest among patients with ALS has been repeatedly reported both in the United States and in Western Europe, exceeding that of patients with other terminal illnesses by 2- to 10-fold.2,4 Among physicians who care for patients with ALS, a substantial majority of surveyed American Academy of Neurology members residing in lawful physician assisted suicide jurisdictions endorse the concept that hastened death is an ethically permissible action in terminally ill patients (J.A. Russell for the Ethics, Law and Humanities Committee [a joint committee of the American Academy of Neurology, American Neurological Association, and Child Neurology Society], unpublished survey, 2014). It is plausible, however, that the conscience of those physicians who might otherwise morally endorse hastened death, and who might accede to the request of their dying patients by their own participation, could waver with the knowledge that their patient’s judgment and decision-making capacity were adversely influenced by their disease.

In ALS, with its known association with both depression and cognitive impairment, these considerations are relevant. In a recent study of 274 patients with ALS, more than half were identified as having some degree of cognitive impairment and more than 6% had possible dementia.5 In a different report of essentially the same population, 7% of 329 patients with ALS were identified as having minor depression and 5% with major depression, 19% of whom expressed a wish to die.6 Multiple previous attempts have been made to understand the association between depression and interest in hastened death in patients with ALS. No consensus exists.5 The potential role of frontotemporal dementia in the interest in hastened death in ALS is less well studied. A clearer understanding of whether depression and cognitive impairment reduce decision-making capacity, specifically pertaining to interest in hastened death, would be of value to neurologists caring for patients with ALS.

In this issue of Neurology®, Rabkin et al.7 report on the interrelationships among cognitive impairment, behavioral impairment, and depression, as well as the potential correlation of these variables with patient wish to die. In their study of 247 patients with ALS, 59% had mild to moderate impairment of executive function, a prevalence that exceeds the majority of previously reported studies. Only 15 of these 247 (6% of the total population or 10% of the cognitively impaired cohort) were classified as having possible frontotemporal dementia. As reported previously, 12% of their population was identified as being depressed to some extent.6 As the authors point out, “most patients who expressed a wish to die were not clinically depressed.” The authors found no correlation between depression or hopelessness (a more prevalent measure of distress than depression in prior ALS studies) and cognitive impairment.7 Furthermore, the authors identified no correlation of executive dysfunction or depression, and patient wish to die. In addition, there was no identified correlation found between depression or cognitive impairment and disease severity as assessed by the ALS Functional Rating Scale–Revised and forced vital capacity determination.

Unfortunately, the authors did not assess potential correlations longitudinally to ascertain the durability of their conclusions throughout the course of the illness in individual patients. In addition, their conclusions are gleaned from only 247 of an original pool of 832 patients within the original cohort of the COSMOS (Multicenter Cohort Study of Oxidative Stress). Nonetheless, their cross-sectional analysis at differing disease stages suggests that the lack of correlation between patient interest in hastened death, cognitive dysfunction, and depression is not variable and appears unaffected by the degree of disease morbidity. Other limitations included (1) the use of a screening tool rather than a comprehensive assessment to assess cognitive capacity, (2) the use of a singular question...
embedded in a depression screening tool to assess patient wish to die, and (3) absence of any knowledge regarding treatment of depression or emotional liability that may have influenced depression, cognitive function, or behavior and wish to die.

Lawful physician hastened death is, and will undoubtedly remain, a polarizing subject. Current trends, however, suggest an increasing public, legal, and perhaps even professional acceptance of this practice that cannot be ignored. Neurologists caring for patients with ALS in jurisdictions where it has been legalized will have their consciences challenged by requests for hastened death and will remain uncertain in many cases regarding the moral boundaries of their fiduciary responsibility to their patients. Although Rabkin et al. have not untied this Gordian knot, they have aided those of us who care for patients with ALS in gaining a better grasp on it.

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REFERENCES