ALS and physician-assisted suicide

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Patients with a new diagnosis of amyotrophic lateral sclerosis (ALS) may struggle with uncertainty about progression and the realization that they will lose key functions and how they will ultimately cope. Eventually, most lose abilities to talk, walk or transfer, swallow, and feed themselves, and are increasingly dependent on others. Thus, the diagnosis creates a complex psychodynamic and existential struggle based on current disabilities and future fears. It follows that patients with ALS elect physician-assisted death (PAD) with greater frequency than cancer.[1,2]

The article by Abrahao et al.[3] in this issue of *Neurology*® surveyed providers at Canadian ALS centers regarding attitudes toward PAD in anticipation of a law legalizing the practice. Participants generally agreed that PAD should be available for patients with ALS with severe or moderate disability, loss of independence, short expected survival, or intolerable suffering. They supported requirements for psychiatric input and a second expert opinion, but only a minority was willing to actively participate by providing the prescription or administering an injection.

We wonder if ALS is unique in its diverse phenotypes and unpredictable progression, making it necessary to consider many factors in fashioning policy (table). It is not surprising that providers showed the strongest support for PAD in a severe case scenario marked by advanced weakness, bulbar dysfunction, and near constant reliance on noninvasive ventilation. However, PAD was presented as a stand-alone option, rather than posed against other effective and available palliative options, such as discontinuing respiratory support while starting oxygen and opiates. Prior work shows that patients consider PAD to control the circumstances of death or to avoid a state of dependence.[4] But these concerns indicate a fear of future events. For patients in earlier stages, clinicians might be less willing to support PAD if it were clear that a patient might not act later. Conversely, the experience in the Netherlands shows that 20% of patients with ALS opt for hastened death, which has led Dutch clinicians to express concern about poorly understood social phenomena and misconceptions about future discomfort.[1] Survey responses might have changed if the survey asked about PAD for a patient who was only fearful of future disability or who had just learned about high utilization rates.

The very nature of terms like "physician-assisted" in this case, or "death with dignity" in others,[5] make tacit and possibly misleading assertions that function to legitimize the practice, or to legally distance suicide in terminal diseases from other chronic disorders such as addiction or depression. It should be clear that terms can be designed to influence or create bias, and this can easily creep into survey designs. A name like "regulated death using prescription medications in ALS" would have ensured that survey takers consider regulatory aspects specific to this condition. A new law legalizing PAD in California requires patients to physically administer the medication to themselves, probably aiming to ensure that this is actually suicide. The law could backfire for ALS, since it excludes cases with advanced upper limb and bulbar dysfunction[6] and creates pressure to act early that runs counter to the likelihood that patients can change their mind.[7] From a societal standpoint, we must also consider the concept of being a burden,[8] which is a common reason patients with ALS choose suicide, and to what extent it contains subtle financial elements or creates conflict between patients and caregivers. In this regard, PAD could eventually collide with slippery issues about how a society provides resources to the needy. Likewise, inconsistent rules requiring that a truly suffering patient has short expected survival ensures that the individual must suffer even longer.

Finally, the study found the large majority of ALS clinicians were unwilling to practice PAD despite support of the law. ALS practitioners follow practice parameters that advocate for treatments providing hope and longer survival,[9] but the findings hint that they do not see termination of suffering as part of their job. The tendency towards nonparticipation in PAD could simply reflect that keeping dying separate is generally viewed as good practice. However, it could indicate that despite death being universal in ALS,

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Table Nine amyotrophic lateral sclerosis scenarios that could potentially affect caregiver attitudes about physician-assisted death laws and participating in the practice

1. Patient who would die "quickly" using available palliative means
2. Patient who admits that financial burden is a key concern
3. Family doctors and palliative specialists provide service independent of multidisciplinary clinic
4. Patient who does not have advanced disease but has felt hopeless for a year despite treatment
5. Patient who is clearly suffering, but is probably more than a year from dying
6. Patient who is unable to put medication in feeding tube and it is not legal to help
7. You learn that over 20% of patients are electing suicide in your area
8. You learn that the suicide rate at your center is 5% but it much higher at the center across town
9. Patient who says "I am suffering, but I need you to do this with me"

practitioners are personally uncomfortable with taking part in the active process of dying, and it will be important to learn if this matters to patients, who might feel abandoned when they cannot turn directly to those that they have entrusted with their care up to such a delicate time. Patients may become distressed when they learn that the practitioner has distinct personal interests or beliefs about taking the final step. Taken to an extreme, new laws may open a path to a Kevorkian-like environment,[10] where self-selected PAD providers and ALS centers work under distinct policies and rely on inefficient or inconsistent referral procedures. Had the survey forced the surveyed providers to reflect more on suffering—such as a patient who is barely able to communicate, has complete paralysis of limb and bulbar muscles, head drop, pseudobulbar affect, diffuse pain, and insomnia, but maintains normal respiratory function—it is possible that clinicians would have considered playing an active role.

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