

Clinical Cases

Physicians' Role in Physician-Assisted Suicide Discussions

Physicians of patients who request physician-assisted suicide should not avoid the subject and should try to discuss the patients' specific concerns and fears with them.

Commentary by Wendy Johnston, MD, and Paul Bascom, MD

Four years ago, Jonathan Witlaw's internist referred him to neurologist Bob Ferris for a work up. At the time, Mr. Witlaw reported having stumbled on several occasions over the span of 6 or 8 weeks. At first, he paid no attention, thinking he was just being careless or not looking at the pavement, but then he stumbled in his own apartment and knew he needed to check it out.

The work-up, including nerve conduction and electromyographic studies confirmed that Mr. Witlaw had amyotrophic lateral sclerosis (ALS). When Dr. Ferris called Mr. Witlaw to the office to discuss the test results, he had much information to share about support services—physical, psychological, and social. He told Mr. Witlaw that the disease progressed a little differently in each patient, but he was honest about the stages of the disease, what Jonathan could expect, and what would, eventually, cause death. Dr. Ferris explained the sorts of interventions that could help—physical therapy, speech and swallowing therapy, counseling, and the pharmacologic agents that together would help him manage his illness.

It turned out that the rate of Jonathan Witlaw's ALS progress was on the slow end of the continuum, and he fought it with all he had. A computer applications designer who lived alone, Mr. Witlaw was able to continue going to work for many months. When his leg strength deteriorated but his arm control still allowed him to type, he worked from home for a few more months.

About 2 years after confirmation of his diagnosis, Mr. Witlaw went on long-term disability. He received a portion of his pay, and his medical bills were mostly covered. He had been working with his therapists and counselors and had consulted a lawyer to "get his affairs in order." His living will stated that he does not want to be put on a ventilator or to receive a feeding tube when he was no longer able to swallow.

Dr. Ferris sees Jonathan every few weeks. A home nursing agency provides someone to accompany Jonathan in his wheelchair to the neurology clinic. On one visit, Mr. Witlaw asks Dr. Ferris to prescribe a barbiturate and tell him how best to use it "just in case." He wants to be able to commit suicide before he loses the ability to do it on his own.

"I don't have any family," Jonathan says. "No one's pleading for me to stay alive for those last few months of deterioration. And my decision is not influenced by depression—you know me well enough to know that, Doc," Mr. Witlaw says. "What I'm suggesting is pretty sane, under the circumstances, isn't it?"

Not comfortable with participating in Mr. Witlaw's plan, Dr. Ferris said, "Well, I'm told you can get information from many of those death with dignity organizations. Is that true?"

"Yeah, probably, but you've been my doctor through all this and I trust you. Tell me what's the best thing to take and

then give me a prescription. I'll save them up from several prescriptions, if necessary. I won't make you look bad, I promise."

"Jonathan," Dr. Ferris said, compassionately, "I can't argue with anything you say, but, as a physician, I just can't participate in helping you commit suicide.

"Patient's best interest, Doc. Remember that?" was Jonathan's final attempt.

Commentary 1

by Wendy S. Johnston, MD

Patients with amyotrophic lateral sclerosis (ALS) have been prominent in the both the medical and public discussions of physician-assisted suicide.

ALS is a relentlessly disabling disease that leads to death, in the majority of cases, within 5 years of diagnosis. Although generally perceived as a rare neurological illness, the annual mortality from ALS approaches that of HIV-related diseases in many states in the US.

In the course of the illness, the individual eventually loses all voluntary motor activity, including the use of all 4 limbs, the voice, and head control. Technology provides many ways to overcome the disabilities, but assistance from caregivers to access technology (eg, transferring from bed to wheelchair, setting up computer-assisted communication) is still necessary when the disease is advanced. Autonomy is possible, but can be compromised by insensitive or inexperienced caregivers or failures of technology. Supporting and maintaining autonomy is critically important to quality of life for many with ALS and can be a major factor in end-of-life decisions.

Unlike patients with many ultimately terminal disorders, those with ALS commonly are aware of their fate from the outset. The lack of significant disease-altering therapy and the steady, measurable losses impose the need for ongoing accommodation by both the patient and his or her loved ones. Awareness of the inevitability of dying, however, doesn't translate into actual knowledge about end-of-life care, and patients, families, and those caring for them frequently are unprepared for the decisions and symptom management in the final months. Even when living-wills are in place, the decisions to limit or forgo interventions may have been made with little or no discussion of how to manage without the unwanted intervention. Symptoms of respiratory failure may still prompt intubation and ventilation, in spite of an advanced directive, if no plan for symptom management is in place.

Therefore, any query on the part of patient or family about an end-of-life issue is an opening for discussion of care. A request for assisted suicide needs to be seen first and foremost as such a query.

Requests for assisted suicide are not uncommon. Of 100 ALS patient surveyed in Oregon and southwest Washington, 56 percent would consider PAS [1]. This interest is sustained through the last month of life [2]. Compared to other terminal diseases, those with ALS use assisted suicide and euthanasia at higher rates, as reported from jurisdictions where it is legal and statistics are available [3].

Interest in PAS correlated with higher education, less religious practice, male sex, and higher hopelessness scores in the earlier, cross-sectional study [1]. There was a corresponding lack of interest in other life-prolonging therapies, for example feeding tubes. There didn't seem to be a correlation with disease characteristics, current symptoms, suffering, or depression. Fears of future suffering and of being a burden were significant.

High levels of suffering overall were found in the last month of life; however, interest in hastening death correlated with poor symptom control [4]. Subsequently, Albert et al, in a prospective study of ALS patients followed in a hospice setting, found 23 percent hastened death, one by suicide [5]. Those who hastened dying reported poorer mood and were less religious; they were more likely to have depressive symptoms of clinical significance, and to feel less in control and more hopeless.

It is important to consider that the patient making the query may be suffering from depression, may fear uncontrolled

symptoms while dying, and may be misinformed about the terminal stages of the disease. Realistic concerns about loss of autonomy, privacy, and fear of being a burden may have arisen. Substantial losses of pleasurable activities, financial resources, and personal contacts may have already occurred.

Rather than focus on the legal or moral issues, the physician should take a step back, asking why the request was made. When Mr. Witlaw says, "You know me well enough" and "what I am suggesting is pretty sane" he is giving openings to Dr. Ferris to say something like, "I know you in some ways, but tell me why you think you will need this?" or "What is your understanding of the last months with ALS?" Dr. Ferris can be supportive ("Yes, you are sane"), without having to commit immediately to the request.

Mr. Witlaw is relying on Dr. Ferris, having seen him every few weeks throughout his illness, to take care of him in the terminal phase. Although the advance directives are done (living will) it appears that there has been little of substance discussed regarding his care. Mr. Witlaw, living alone, with an aide to bring him to appointments, may not see any other option but to take his own life.

On the other hand, Dr. Ferris, it would seem, may not be prepared to take care of Mr. Witlaw at the end of life. Neurology textbooks don't cover it; neurology residencies only recently added end-of-life care to the curriculum. CME courses are available, and there are on-line resources, but, frankly, they aren't much help when it comes to the actual face-to-face discussions. The issues facing Dr. Ferris are difficult for any solo practitioner to face in a busy practice. The issues and practicalities of his care may be best dealt with by a palliative care team, which may include or support Dr. Ferris in his care of Mr. Witlaw.

Dr. Ferris's response could be interpreted as fearful, and rejecting. In staking out his own values in opposition to Mr. Witlaw's perceived plan, he distances himself further from Mr. Witlaw's needs. Physicians should not feel compelled or coerced to comply with requests for assisted suicide. A physician can honestly state that he or she can't supply a lethal prescription. It is important to proactively attempt to understand the basis of the request and address the underlying concerns, rather than cut off discussion with too quick a denial.

Establishing the basis of quality of life in the present ("what do you live for now") as a bridge to what to continue to hope for in the future, addressing current concerns similarly, will strengthen the trust that allows for the best end-of-life care. For a minority of individuals, controlling the timing and means of death through suicide, assisted or not, may still be their final choice. For others, offering continuity of care to the end of life and the promise that they will receive the best of end-of-life care may be the answer to the question of assisted suicide.

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Commentary 2

by Paul Bascom, MD

Patient requests for physician-assisted suicide (PAS) are common. Fifty percent of patients with ALS report being willing to consider PAS. Far fewer ALS patients ultimately make an explicit request for PAS, and fewer still end their lives by PAS. Yet ALS patients are substantially overrepresented compared to patients with other terminal diseases in Oregon's experience with legal PAS.

Physicians need not initially respond to a patient request for PAS with a yes/no answer. In the case, Dr. Ferris's first response Mr. Witlaw's plan is to express his moral opposition to PAS by recommending that Mr. Witlaw seek information from death with dignity organizations. Dr. Ferris responds as if the patient's request were fixed and unyielding. Data shows, however, that many more patients consider, and even explicitly request, PAS than ultimately use PAS to end their lives. Therefore, the appropriate first response to a patient request for PAS is to explore the request further.

An exploration of the following areas will usually uncover some underlying motivation for the request, which, when addressed, will meet patient goals without PAS.

Expectations and fears. Mr. Witlaw states that he wants PAS "just in case." He worries about "those last months of deterioration." Dr. Ferris should explore what scenario Mr. Witlaw envisions for his future that would warrant him to end his life by PAS.

Options for end-of-life care. Mr. Witlaw has already indicated his desire for no tube feedings or mechanical ventilation. He would benefit from knowing that he will likely lose the ability to swallow as he deteriorates, and that the inability to take food and fluids will prevent the lingering deterioration that he seems to fear.

Patient goals. Medical treatments, even PAS, can be evaluated based on their ability to meet certain patient goals. The rare patient who chooses PAS to end his/her life often expresses the explicit goal of controlling the time and place of death. Mr. Witlaw expresses the wish to "commit suicide before he loses the ability to do it on his own." But it is not clear from the case whether the primary goal is control the time and manner of death or to avoid lingering deterioration.

Family concerns and burdens. Many patients fear being a burden on family. Mr. Witlaw reports "I don't have any family." As an independent spirit, Mr. Witlaw may fear becoming dependent on others for care.

Suffering and physical symptoms. Uncontrolled physical symptoms such as pain, rarely influence a desire for PAS. In some patients, fear of future pain may play a role.

Sense of meaning and quality of life. ALS is perhaps unique in that patient decisions about treatment will vastly affect longevity. The patient with ALS who chooses gastrostomy feeding and mechanical ventilation can live years longer than those who refuse such treatments. Some patients may continue to report meaningful life and good quality of life despite the extraordinary limitations imposed by their infirmity. Alternatively, others will find that even modest restrictions in independence will create such a poor quality of life that death is preferable, either by refusal of life-sustaining treatments or PAS.

Depression. Patients who request PAS do not have an increased prevalence of depression. Rather, they score high on ratings of hopelessness, of finding no meaning or purpose in ongoing life. Sometimes the direct question, "Are you depressed?" is as effective a screen for depression as multiple question instruments.

The ethical controversy over PAS will continue. There is no simple answer to Mr. Witlaw's assertion of his right to PAS as "patient's best interest." Is it in the patient's interest to hasten death? And if so, does the patient's individual

interest outweigh concerns that increased acceptability of PAS will cause harm to vulnerable populations?

Dr. Ferris should respond to the request with a detailed exploration with the patient of the areas noted above. Frequently, this exploration will lead to identification of concerns and goals that can be met without PAS. At times, requests for PAS will persist. The rare patient who chooses PAS usually has the goal of controlling the time and manner of death, and is motivated by the desire to avoid dependency. These are goals even the best medical intervention cannot help a patient accomplish. Death is by nature unpredictable, and, except for the rare sudden cardiac or traumatic death, requires one to be tended to by others. If indeed Mr. Witlaw persists in his desire for PAS, then Dr. Ferris may need to inform the patient that personal moral beliefs will prevent him from providing the prescriptions as requested.

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