Palliative Care Files

Can't we get this over with?

An approach to assessing the patient who requests hastened death

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Margery was an 83-year-old woman who was diagnosed with amyotrophic lateral sclerosis 2 years ago. She had presented with slurred speech, which rapidly progressed to weakness of her cranial nerves and her lower limbs. In time she had marked trunk and lower limb weakness and was unable to walk. She could no longer speak clearly but was able to write effectively and communicate her needs. Her pharyngeal reflexes became weaker and eventually a percutaneous endoscopic gastrostomy tube was inserted to provide her with food and reduce the risk of aspiration. Despite the tube, she struggled with swallowing saliva and was very afraid of choking, so she kept portable suction close at hand.

Margery had been an independent woman living on her own for many years after she and her husband divorced. She had raised 2 daughters alone while working and in her retirement had remained active and capable of caring for herself and making her needs known.

Her family physician made home visits for some time and enjoyed conversing with Margery. Margery's daughter Linda had stayed with her for several weeks and was present when Margery wrote that she was tired and spending most of her day in bed. She was not hungry and often wished the feeds to be turned down so she did not feel full. She had suction at hand, despite her saliva volume being reduced by glycopyrrolate started with the insertion of her percutaneous endoscopic gastrostomy tube. She had had 1 mild choking episode the day before that visit but was otherwise only using the suction occasionally. She wrote for a moment and handed the paper to her family physician. The note read as follows: "Can't we get this over with? I am grateful for your care, but I am too tired to go on with this any longer."

Requests for hastened death or physician-assisted suicide are very troubling and emotionally challenging for physicians. It is often tempting to give the quick answer "I can't do that for you because it is illegal" and change the subject. The request for hastened death is a topic that typically upsets patients' families and friends; it makes them fearful and they avoid discussing it. However, entering into discussion with patients can lead to better understanding of their situations and often the prevention of suffering.

An occasional request to die or an expression of the readiness to die can be quite common in those with advanced illness and will fluctuate over time. A persisting desire for assisted death is relatively uncommon, and although 10% to 20% of patients might consider it, a smaller number will actually pursue it with their doctors.

A systematic review of the literature on desire for hastened death1 categorized the factors associated with patients' requests by the following circumstances:

- 1) expressions of feelings and current reactions to their circumstances (fears regarding death and loss of control);
- 2) communication of distress and suffering, or a communication of exploring ways to relieve the distress;
- 3) seeking information about suicide or euthanasia as a response to 1 or 2; and
- 4) specifically seeking health professional assistance with hastened death or acknowledging an intent to commit suicide.

Several studies have looked at the relationship between depression and desire for hastened death and have found that a much higher rate of depression exists among those requesting hastened death than among those with terminal illnesses who do not request hastened death. In general, the issues of psychosocial distress, such as being a burden, lack of social support, spiritual distress, and poor quality of life, seem to be the main factors.2 Newer studies suggest that a request for hastened death can be predicted more by an individual's psychosocial traits and beliefs than by disease severity or symptomatic distress.3

Assessment

Any approach to assessing the patient will require time. If you do not have the time when the patient makes the request then you need to acknowledge the suffering, validate the importance of discussing this at length, and plan a time to discuss it as soon as possible.

Many times patients will make statements or requests about hastened death using euphemisms, so it is essential to clarify what they are actually requesting or stating. With Margery's statement ("Can't we get this over with?"), it is not unrealistic to think that she was requesting that the visit end rather than her life.

Acknowledging the suffering of the individual can be done in a way that invites further explanation. Try a reply such as the following: "Usually when people say this they are suffering a lot. Tell me more about what is making you feel this way." Inviting patients to elaborate is often all that is necessary to reveal their concerns.

Often multiple issues cause suffering. To explore all the issues it is helpful to have a "suffering checklist," which you can mentally tick off while listening to the person.

Ask patients about symptom distress if they do not volunteer the information, as they might assume that some

symptoms cannot be controlled. Inadequate physical symptom control is often an issue, and patients should be asked about the common symptoms of pain, dyspnea, nausea, fatigue, constipation, insomnia, itch, and other symptoms particular to their conditions.

Include questions about anxiety and depression, as both symptoms are common in advanced illness. In a study of 189 patients with advanced disease, the will to live was significantly correlated with anxiety and depression (*P*<.001) rather than physical symptoms.⁴ Patients are often anxious about the process of dying, particularly if they have illnesses they feel will result in choking, suffocating, or intractable pain. A previous experience with another's dying might add to the anxiety.

Depression is common in terminal illness, and the physical symptoms of depression will often overlap with the symptoms of advanced illness; however, the psychological symptoms such as anhedonia, hopelessness, and low mood will still be present. Patients often assume that being depressed is part of terminal illness rather than a complication that can be treated.

Existential suffering is often the most difficult yet the most common cause of the pervasive desire for hastened death. Being a burden to others, loss of control over the circumstances of death, perceived loss of dignity, and lack of meaning to life are the main concerns. Often these concerns will need further discussions with family members and ongoing listening to and support of the patient. Chochinov⁵ wrote an excellent article on existential issues at the end of life and a method for preserving and promoting dignity.

After acknowledging Margery's suffering, her family physician paid close attention as Margery wrote about her issues. Despite already being on an opioid, she was somewhat short of breath, which always made her fearful of choking or suffocating in her last minutes.

She was otherwise comfortable and did not have any symptoms of anxiety or depression. She did not think she was a burden to her daughters and believed they were coping well with her illness.

How to approach the request for hastened death

The physician needs to accomplish several tasks in dealing with a request for hastened death:

- Be certain about what the patient is asking.
- Acknowledge the suffering of the patient.
- · Listen actively to what the patient is communicating, both verbally and nonverbally.
- · Assess the patient for physical, psychosocial, and spiritual suffering.
- Make a care plan with the patient.

BOTTOM LINE

- Requests for hastened death can be quite common among those with advanced illnesses. These requests are very emotionally challenging for physicians.
- There are often multiple issues that cause patients' suffering. Take the time to learn more about each issue, and you will understand their situation and know how to address the issues.
- Depression is more common in those who request hastened death, so ensure that questions about mood are included in the assessment.

POINTS SAILLANTS

- Il n'est pas rare de se voir demander une mort précipitée à un stade avancé de la maladie. Ces demandes sont très difficiles sur le plan émotionnel pour les médecins.
- La souffrance des patients est souvent attribuable à de multiples problèmes. Prenez le temps d'en savoir plus sur chacun de ces problèmes pour bien comprendre leur situation et savoir comment y réagir.
- · La dépression est plus courante chez ceux qui demandent une mort précipitée. Assurez-vous de poser des questions au sujet de leurs émotions dans votre évaluation.

Margery's main issue was that her life no longer had meaning. Linda expressed that she believed her mother's life still had enormous meaning for her and her sister, and that there was still much she wanted to reminisce about and share with her. This gave Margery a sense of meaning and she no longer requested hastened death. She died peacefully several weeks later, the night after a family party when old pictures and videos of their life together had been shared.

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Competing interests

None declared

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