



# Patient and Family Requests for Hastened Death

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**Patient and family requests for hastened death, upsetting as they are to the treating team, are usually a way for patients and their families to express their need for an increase in the intensity of communication, improved symptom control, or acknowledgment of an existential or spiritual crisis. Rarely do they represent the need for patients to control the time, place, and manner of their death. Using a hypothetical case study, this paper reviews the unspoken concerns underlying these requests; characteristics of patients**

**who request a hastened death, and when and why they make the request; the Oregon Death with Dignity Act and its implementation since its passage in 1997; the effect these requests have on clinicians, their common reactions, and suggestions for self-care after such requests; techniques for responding to the requests and keeping the dialogue open with the patient and family; and the legal and ethical options available to clinicians outside of Oregon.**

## The Challenge

Dr. V, a 55-year-old sociology professor living in Vermont, has had multiple myeloma for 6 years. She has been married for 30 years, with 2 children, aged 25 and 20. Dr. V had an initial remission, relapsed after transplant, and was unresponsive to investigational agents. She had a terrifying delirium from high-dose corticosteroids. Four weeks ago, she was admitted for sepsis, dehydration, and oliguric renal failure, and has been on thrice weekly dialysis for 3 weeks. She and her family have learned to work out disagreements about therapy with the help of their hematology team, therapists, and their rabbi.

This morning, when you meet with her and her family, she tells you she wants to discontinue dialysis. She recounts her amazement at the journey her family has been on together, their growth in understanding and love for each other, and she assures you they are at peace. She is not depressed, but she knows that after she stops dialysis, she will only deteriorate. She does not want to “watch herself die.” Her family is tearful, but says that they are all in agreement with whatever she wants. She is hoping you can end her life as quickly as possible.

What is she really asking for? What underlies the request? How do you feel about her request? What are your legal and ethical options? What do you want to do?

## Unspoken Concerns

Patient and family requests for hastened death are not uncommon among patients with advanced malignancies.<sup>1</sup> In a survey of 441 oncology nurses, 30% had received requests for assisted suicide.<sup>2</sup> Block and Billings, in their classic 1994 paper, detail the unmet needs that underlie those requests (Table 1), which are discussed briefly below.<sup>3</sup>

Some patients ask for hastened death because they need more communication with their team,<sup>3,4</sup> more information about their options or prognosis, or reassurance that the team will be there for them to the end, whether or not they continue to take antineoplastic therapy. Other patients want better symptom relief, especially for pain or its related disorder, depression. Patients who express hopelessness, worth-

**Table 1. Elements of requests for hastened death.<sup>3</sup>**

|  |
|--|
| Need for more physician attention                  |
| Information  |
| Symptom control                                    |
| Non-abandonment                                    |
| Inadequately controlled physical symptoms          |
| Pain   |
| Dyspnea  |
| Nausea   |
| Psychological disorders                            |
| Depression   |
| Anxiety  |
| Grief  |
| Delirium   |
| “Chemical coper”                                   |
| Personality disorder                               |
| Fears of future suffering                          |
| Strained relationship with family                  |
| Overwhelmed caregiver                              |
| Failure to meet basic physical and emotional needs |
| Fear that family will fail them                    |
| Concern over being a burden                        |
| Dysfunctional family                               |
| Personal values                                    |
| Suffering ennobles                                 |
| Self-reliance and control                          |

lessness, feelings of guilt or being a burden are likely to be depressed,<sup>5</sup> and benefit from referrals to psychologists, social workers, or psychiatrists. These clinicians can also prescribe antidepressants such as methylphenidate, which is effective in as little as a week, or a selective serotonin reuptake inhibitor (e.g., citalopram or escitalopram), which is often effective within a month.<sup>5</sup>

Some requests for hastened death arise from patients who either have inadequate family support or who do not want to take the chance of asking for support, for fear that their family will let them down.<sup>3</sup> Requests also arise from patients who feel they are a financial, physical, or emotional burden on their caregivers.<sup>3</sup> Social workers can often provide the resources or clarify the reality of the social support available, and so alleviate the patient distress.

Some of the most difficult requests come from patients without these other problems, but who need control, are reluctant to trust others, and cannot tolerate the thought of being dependent.<sup>1,3</sup> Oregon data indicate that patients requesting assisted suicide have, from the start, been involved with choices about their care; they also want choice in where and when they die.<sup>6-9</sup>

### Reports of Desire for Hastened Death

Ambulatory cancer patients with advanced gastrointestinal or lung malignancies and a good performance status (Karnovsky 70 or better) rarely have a desire for hastened death.<sup>10</sup> Of the 329 patients studied, over 35% expected to suffer “a great deal from physical problems in the future because of their illness.” There was a 23% prevalence of depression and hopelessness, a 50% prevalence of drowsiness or pain, and a 72.4% prevalence of lack of energy, but only 1.5% had high scores, and only 8.3% had mildly elevated scores on the Schedule of Attitudes Towards Hastened Death.<sup>11</sup> Studies of inpatients with cancer also found only a 2% desire for hastened death,<sup>12</sup> which increased to 7% to 9% for those with advanced disease.<sup>12,13</sup>

A Canadian investigation of 379 terminally ill cancer

patients receiving palliative care found that 62.8% felt euthanasia and/or PAS should be legal, 39.8% believed they might make a future request, but only 5.8% (22 patients) would ask for it right away.<sup>14</sup> But of inpatients in palliative care units, unequivocal and persistent desire for hastened death rose to 17%.<sup>15</sup>

Depression was the key factor predicting desire for hastened death among patients in palliative care units,<sup>15</sup> cancer patients,<sup>13,16,17</sup> and patients deciding to discontinue dialysis.<sup>18</sup> Also prevalent were moderate to severe pain,<sup>15</sup> low physical function, distress from all symptoms, feeling oneself to be a burden to others, poor support from family or friends,<sup>13,19</sup> or loss of dignity.<sup>20</sup> A 2006 systematic review confirmed that physical factors were less influential than social, psychological, and existential factors in a patient’s desire for hastened death.<sup>21</sup> Patients who had good quality social and family supports,<sup>15</sup> or spiritual well-being and an ability to find meaning in life were less likely to desire a hastened death.<sup>22</sup>

### Oregon Death with Dignity Act

Passed in 1997, the Oregon Death with Dignity Act made Physician-Assisted Suicide legal in Oregon.<sup>23</sup> The Act permits physicians to prescribe what they know to be a lethal prescription of *oral* medications; patients take the medications where and when they choose. These deaths, however, are not considered “suicide,” and the state, as well as the American Academy of Hospice and Palliative Medicine (AAHPM), use the term: “physician-assisted death.”<sup>24</sup> The principles elucidated by Quill et al before the law came into being are useful guides for all clinicians who receive requests for hastened death (Table 2).<sup>25</sup>

The key components of the Act are listed in Table 3.<sup>26</sup> As of 2006, there have been 292 patient deaths in Oregon under the Act, and in 2006, physician-assisted death accounted for about 1 in 1000 deaths in Oregon. The proportion of patients asking for and using the prescriptions has been stable (i.e., about two-thirds die from the taking the medication, and the remainder from other causes).<sup>24</sup> The patients “tended to be white, relatively educated, insured, and enrolled in hospice; they also tended to be at least as motivated by concern about losing autonomy, dignity, and control over their bodily functions as by any suffering from immediate intractable physical symptoms.”<sup>24</sup>

As might be expected, the most common concerns of Oregon patients who asked for prescriptions were loss of autonomy or of bodily functions, and decreasing ability to participate in the activities that mattered to them. The specific reasons they chose to die varied with their proximity to death.<sup>9</sup> The few patients interviewed who had more than 6 months to live had suffered for years with severe pain or disability, and saw themselves entering an intolerable, relentless downhill course. Those with 1 to 6 months to live were concerned that their anticipated increase in mental or

**Table 2. Clinical criteria for physician-assisted suicide.**<sup>25</sup>

- Meaningful doctor-patient relationship
- Physician appreciation for and understanding of patient’s values, beliefs, and who the decision will impact
- Evaluation for reversible or treatable medical, psychological, spiritual or social causes of distress
  - Psychiatric consultation required
  - Palliative care consultation strongly suggested
- Repeated requests over time
- Inform family/support system members of the request
  - “Does the patient’s wish seem consistent with his or her longstanding values? What are family members’ reasons for opposing the decision?”<sup>3</sup>

**Table 3. Key components of Oregon Death with Dignity Act.<sup>26</sup>**

1. Oregonians are allowed to end their own lives by taking medications prescribed by their physician expressly for this purpose. Their physician must be licensed to practice medicine by the Board of Medical Examiners for the State of Oregon.
2. Physician and health system participation is voluntary.
  - a. Physicians employed by Catholic hospitals or the Veterans Administration do not participate, if this a term of their employment.
3. The participating physician determines if the patient is:
  - a. 18 years or older
  - b. Current Oregon resident
    - i. e.g., Driver's license; lease agreement or property ownership; voter registration; tax return
    - ii. No minimum residency requirement
  - c. Capable of making and communicating health care decisions
  - d. Expected to die in 6 months or less
4. To obtain a prescription:
  - a. The patient must make two oral requests, separated by at least 15 days and provide a written request to the physician, signed in the presence of two witnesses, one of whom is not related to the patient. Surrogates cannot make these requests.
  - b. The patient's physician and a consulting physician must determine whether the patient is capable of making and communicating healthcare decisions for him/herself
    - i. If either physician believes the patient is impaired by a psychiatric or psychological disorder, they must refer the patient for a psychiatric evaluation
  - c. The patient's physician must inform the patient of feasible alternatives to the Act (including "comfort care, hospice care, and pain control")
  - d. The patient's physician must request, but cannot require, the patient to notify the next-of-kin of the request for the prescription
  - e. The physician chooses which medication to prescribe (usually an oral barbiturate)
  - f. Individual insurers determine whether the costs of the visit and medication are covered. Federal funding cannot be used for these services, but Oregon Medicaid funds can.
  - g. The physician is not required to be present, but may be present when the lethal dose is taken, as long as he or she doesn't administer it
5. Patients may rescind the request at any time and in any manner; the physician will offer the patient an opportunity to rescind the request at the end of the initial 15-day waiting period (i.e. following the initial request).
6. Oregon law specifies that "participation in the Act is not suicide," so participation should not affect insurance benefits that pertain to suicide.
7. Reporting
  - a. Physicians report the prescriptions to the Department of Human Services, Vital Records. The pharmacist must be informed of the medication's planned use.
  - b. The Department cross-checks death certificates with the names of the patients, but does not "record them" in any manner; physician's code is recorded. No names of physicians or patients are shared with the public or media.
  - c. All source documentation is destroyed about one year after the annual report is published

physical disability would make them unable to stay in control of the time and manner of their death, or render them unable to take the medications. Patients with about a month to live felt they were not dying "fast enough." They anticipated only further deterioration and significant future suffering. Patients who hastened their deaths in the last week had usually suffered some new physical problem (such as new-onset rectal bleeding, diarrhea, or vomiting) that led them to feel that they "couldn't do it anymore."

In part from fear of a "slippery slope" to euthanasia, no other state has legalized physician-assisted death. In the Netherlands, where physician-assisted death and euthanasia have been practiced for 17 years and have been legal since 2002, there has been no increase in the use of either of these modalities, while palliative and hospice care have increased.<sup>24</sup> And among the states, Oregon leads the nation in per capita opioid prescriptions, rates of referral to hospice, home deaths, physician palliative care education, and a statewide approach to advance directives ("Physician Orders for Life-Sustaining Treatment"<sup>24</sup>).

### Effect on the Clinician

Being asked to hasten death, "often elicits a storm of feelings in the physician,"<sup>23</sup> and physicians are rarely taught how to recognize or manage such feelings. We may avoid the subject, feel guilty or depressed about forcing patients to continue an unwanted existence, or feel we should comply.<sup>3,5</sup> Nurses, too, suffer intense distress from these requests.<sup>1</sup> Nurses' reactions include anxiety, shock, and self-doubt as well as conflicts over how to meet the family's request while upholding their professional values. Although at some level physicians understand that they will not cure most patients with cancer or even prolong their lives as long as they would wish, physicians still feel responsible for failing to arrest the disease. A request for hastened death can trigger even stronger clinician feelings of failure, sadness and self-blame.

These requests may be so painful that physicians cannot "hear" them and find themselves continuing the conversation without acknowledging them. Physicians may withdraw emotionally from the patient and family, telling themselves it is because they have "nothing left to offer" but, in reality, it is because these patients trigger such powerful feelings of inadequacy. The truth, of course, is that physicians always have something to offer, especially to dying patients: their ongoing commitment to their welfare and that of their families, maximizing the quality of their remaining life, and helping them bring that life to a peaceful, dignified end.

### Addressing Requests for Hastened Death

First, physicians must acknowledge that they heard the request, repeating the patients' words to verify their understanding: "You have 'had enough, and life just isn't worth living any more?'"<sup>2,27</sup> Next, clarify the underlying causes

of the request, as you would a complaint of pain or dyspnea. “We haven’t talked about this before. Tell me more.”<sup>22,27</sup> Most patients are ambivalent about the request and are actually just hoping for a resolution of one or more of the concerns listed in **Table 1**. Tulskey et al suggest asking, “What is the worst part of your condition right now for you?”<sup>28</sup> You might add: “What would make life worth living? What can we do to help?”

Though a request for hastened death does not in itself imply a lack of decision-making capacity,<sup>28</sup> a formal assessment is needed. Also evaluate for depression, risk of suicide, and whether they have a plan. Questions offered by Block and Billings<sup>3</sup> in this regard are: “In your worst moments, do you find yourself wishing that death would come soon? Does it ever approach the point where you think about killing yourself or asking someone to help you?” Obtain an immediate psychiatric consultation for anyone with a plan. For other patients, referrals to a palliative care team, social worker or psychologist, or, for patients with spiritual or existential concerns, a chaplain may help. And make a plan for a follow-up visit or phone call.

But if the patient or family push for a commitment that now, or at a time of their choosing, you will help them die, you need to explore your own values and feelings. What makes sense for this patient, and what feels right for you? Can you continue to provide pain or anti-anxiety medications that this patient might use in other ways? What assurances or circumstances would help you to do so? Even if you would never accede to the request, to diminish the patient’s sense of isolation keep the dialogue going. Reiterate your commitment to ongoing discussions about their concerns, to care for them whether under active treatment or not, and to seek solutions together to problems arise. That reassurance alone is often helpful. You might ask: “How can I help you, short of ending your life, to get through this terrible time?”<sup>3</sup>

For those patients for whom the control of the time and place of their death are the core concerns, a discussion of their other options may be needed. Patients have a legal right to stop eating and drinking, or to stop artificial nutrition or hydration.<sup>29-31</sup> You can assure them that your care for them and their family would continue should they choose that path.

But also recognize the emotional impact on you of such a request. Find time later that day to discuss this disturbing request with colleagues, who may have had similar requests that they were reticent to share with anyone. It will allow you to “unpack” your feelings, make a better plan for that patient, and be more “present” for your other patients that day. Ask yourself: “Do I feel guilty? Shocked? Angry? (I can’t believe they expect me to hasten his death!) Sad? Why do I feel that way? How will this request change my relationship with him and his family?”<sup>3</sup>

### What Can We Offer Dr. V?

When the Supreme Court denied the constitutional right to assisted suicide in *Vacco vs Quill* (1996), it upheld the right to palliative care.<sup>23</sup> The American Board of Medical Specialties’ recognition in 2006 of Hospice and Palliative Medicine as a subspecialty and the expected growth of palliative care programs in the community, in academic medical centers and with hospice programs should make expert palliative care available to the vast majority of patients and their families. Palliative home care, and, when possible, hospice programs will meet most patients’ physical, social, psychological and spiritual needs. The palliative care team can also help the hematology team and the inpatient staff to cope with the personal distress caused by caring for their suffering patients and their families.

Unfortunately, hospice programs will remain a resource not accessed by hematology patients unless the funding paradigm changes. The current Medicare Hospice regulations, and the similarities in the hospice benefits provided by private insurance companies, make it difficult for patients with cytopenias from hematologic disorders to enroll in hospice programs. Of over 4000 patients admitted to a Boston hospice program over the past 4 years, < 1% had a hematologic disorder as the terminal diagnosis (J. Nowak, personal communication). Hospice programs are required to pay for all the palliative treatments (e.g., medications, transfusions, radiation or chemotherapy, enteral or parenteral nutrition) related to the terminal diagnosis, to provide a skilled team of caregivers (nurses, nursing aides, social workers, chaplains, volunteers, and a medical director), and all durable medical equipment and oxygen. For this care they receive about \$135 for each day the patient is enrolled. Some insurance carriers will “carve out” the palliative transfusions and antimicrobial medications needed for the comfort of patients with persistent cytopenias, but until more universal coverage for these is available, patients and families may be best served by collaborations among their hematology team, the palliative care team, and a Bridge to Hospice or home nursing service.

But Dr. V did not want comfort care. She requested a hastened death. Is that a reasonable request? Is it legal? Ethical? The Supreme Court upheld in *Quinlan* (1976) and in *Cruzan* (1990) that patients have the right to refuse all life-sustaining therapies, including intubation, dialysis, nutrition and hydration.<sup>31-33</sup> Dr. V, therefore, is legally and ethically entitled to refuse dialysis and to refuse artificial hydration, but she fears she will be unable to tolerate the existential crisis of watching herself die and the delirium that may accompany her choice. Is it so different, then, to accede to her request and to end her life directly, or to provide physician-assisted death, the means by which she can quickly end a life that all agree is coming to an end when she stops dialysis? Is a hastened death for Dr. V not a compassionate response that honors her self-determination,

her right to a dignified death and avoidance of suffering?

I would answer, “No,” to these rhetorical questions. Euthanasia, the committing of an action with the intent to end the patient’s life, is illegal in all 50 United States. Physician-assisted death is legal only in Oregon, and it remains very controversial in the United States. It is officially opposed by the American Medical Association, the American Nursing Association,<sup>1</sup> and the American College of Physicians.<sup>34</sup>

The Oncology Nursing Society and the AAHPM have taken a position of “studied neutrality.”<sup>35</sup> As the AAHPM position statement says: “Despite all potential alternatives, some patients may persist in their request specifically for physician-assisted death. The AAHPM recognizes that deep disagreement persists regarding the morality of physician-assisted death. Sincere, compassionate, morally conscientious individuals stand on either side of this debate. AAHPM takes a position of ‘studied neutrality’ on the subject of whether physician-assisted death should be legally regulated or prohibited, believing its members should instead continue to strive to find the proper response to those patients whose suffering becomes intolerable despite the best possible palliative care.”<sup>36</sup>

What then are the physician’s legal and ethical options in caring for Dr. V? Titrating medications to effect, even if the medications cause sedation, is not euthanasia or physician-assisted death.<sup>30</sup> Patients with a refractory delirium, for example, may require the sedating antipsychotic, chlorpromazine; those with severe dyspnea may need benzodiazepines and opioids. The sedation is an expected side effect of the medications and is minimized as much as possible. This option was offered to Dr. V, but the prospect of her potentially re-experiencing delirium was unacceptable.

Palliative sedation to unconsciousness is also a legal and ethical option for patients like Dr. V, who have an advanced, terminal illness and whose suffering is refractory to all other measures. The physician uses rapidly sedating medications (midazolam, propofol, pentobarbital) that are titrated until the patient is unconscious.<sup>37</sup> Palliative sedation to unconsciousness is rarely needed, but when it is, nurses and families find it comforting to know that physicians can relieve the otherwise intractable suffering. And it was in part because of the availability of palliative sedation that the Court decided against the right to assisted-suicide. As Justice O’Connor stated in her brief: “The parties and *amici* agree that in these States a patient who is suffering from a terminal illness and who is experiencing great pain has no legal barriers to obtaining medication, from qualified physicians, to alleviate that suffering, even to the point of causing unconsciousness and hastening death...”<sup>23</sup>

Does sedation itself hasten death? No. But if dehydration is the expected mode of death, voluntary cessation of hydration may hasten it.<sup>29,31,38,39</sup> The vast majority of patients who need palliative sedation to unconsciousness (or their surrogates) decide not to use artificial hydration, which

only prolongs the dying. If we assure patients that we will sedate them, if needed, to ease their suffering, are we helping them make a choice that may hasten their death?

If so, palliative sedation to unconsciousness still seems to be an ethical choice. It is consistent with the doctrine of double-effect.<sup>32</sup> To meet that standard, the act must in itself be ethically good or neutral, the physician must intend a good effect, the good effect may not be produced by a bad action, and the physician must be willing to accept that the action may have unintended consequences that shorten life. Palliative sedation to unconsciousness is a good act, in that it relieves intractable suffering; it is done with the intent to relieve intractable suffering; it does not in itself produce a bad effect (i.e., hasten death); and it has no unintended consequences that would hasten death. And the patient (or surrogate) has chosen, within their ethical and legal rights, to forgo the life-sustaining therapies of hydration and nutrition.

## Epilogue

Dr. V’s hematologist asked both the ethics and palliative care teams to consult. The palliative care team asked that Dr. V again meet with her therapist and her rabbi. After a day of extensive conversations all agreed that Dr. V had the legal and ethical right to refuse dialysis, and that without it, she would die in a matter of days. It was also clear that she might become delirious, a condition that was unacceptable to her. She was made DNR/DNI, and her care was now focused on intensive comfort measures. She was offered care at home in a hospice program or in an inpatient hospice facility, but the hospice program was clear that they would not acquiesce to her request for a hastened death. The palliative care team discussed with the hematology team and the ethics team the nature of the suffering that Dr. V was experiencing, and whether the solution of palliative sedation to unconsciousness was proportionate. They reached a consensus that it was, and then explained the process of palliative sedation to unconsciousness to Dr. V and her family, and the nurses caring for her, informing her that she could receive it at home with a hospice program, in an inpatient hospice facility, or in the hospital, which had a specific policy and guideline for the procedure. She chose to remain an inpatient, and about an hour after the palliative care team implemented the sedation guideline, she was asleep. She remained asleep, apparently comfortable, breathing at 10-12 per minute, until her death 3 days later. When contacted for bereavement care, her family was very grateful to the hematology team for the care shown to Dr. V, and the respect shown for her choices and maintaining her dignity.

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