

Hospice Care for Patients Who Choose to Hasten Death by Voluntarily Stopping Eating and Drinking

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Some hospice and palliative care organizations are considering the merits of creating written policies to guide clinicians' responses to patient requests for information and support for a voluntarily stopping eating and drinking (VSED)–related hastened death. How hospice clinicians understand the meaning of a request to hasten dying and the legality and morality of the VSED option will determine their responses. Some may view a plan to intentionally hasten dying by fasting as an act of suicide that should be discouraged; others may regard VSED as an ethically appropriate decision to forego an unwanted life-prolonging measure. A discussion of the ethical and legal pros and cons of this option will be presented within the context of a case of a patient who requested hospice support for her decision to VSED. This case will illustrate a range of beliefs among team members and the potential benefit of having a written policy to help mediate interteam conflict.

voluntarily stopping eating and drinking (VSED). Given the diversity of views about the morality and/or legality of VSED, hospice and palliative care organizations will be challenged to respond in an organizationally coherent and clinically consistent fashion in the absence of clear written procedures and guidelines. A case study is presented of a patient who was neither imminently dying nor experiencing great physical pain when she requested hospice support for her decision to forego food and fluid as a means to hasten her death.

THE CASE

Marilyn was an experienced hospice nurse who recently joined the staff of a home hospice agency in a large Northeastern city. As she traveled to the senior living facility where E.M. was a resident, she reviewed what she knew about her 83-year-old patient. E.M. was independent, resilient, and rather set in "her way" of doing things. She had been successfully treated for both breast and lung cancer while still in her 60s and had a hip replaced when she was 75 years old. She quickly recovered after each medical intervention and resumed her active life in the Southern city, where she lived with her husband. With this history, she was shocked when her oncologist informed her there was no recommended treatment for the pelvic tumor that had metastasized throughout her abdomen. She promptly sought additional opinions, but the prognosis was confirmed, and hospice was recommended because it was thought she would die within the year. She rejected the hospice suggestion and continued to manage well for the next 2 years—until her husband died unexpectedly. She grew weaker, and her physical symptoms became harder to ignore. Her only child insisted she move back to the Northeast so he and his wife could more easily supervise her health care needs. She resisted as long as she could—she had never been close to her son, but ultimately recognized that she could no longer manage her own care. Her son moved her into a luxurious senior living facility and arranged for hospice support.

Marilyn had been seeing E.M. for about 6 weeks and recalled that although her pain was well managed with small doses of opiates, she was experiencing increasing difficulties

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Even with the best of palliative care, terminally ill patients with advanced disease occasionally think about dying and may wish for death to come sooner. It is also not uncommon for some patients to ask a trusted clinician for help in hastening death. How hospice team members understand the meaning of the request and the nature of the assistance they are asked to provide will determine how they respond. Although hospice clinicians frequently encounter patients who stop eating and drinking as a natural consequence of advanced disease, until recently, it was less common to meet patients who intentionally chose to fast in order to hasten their dying. As an increasing number of such cases are described in professional and lay literature, hospice clinicians will likely encounter more requests for information and support for

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with elimination. The possibility of bowel obstruction was a concern to Marilyn, but E.M. was far more worried about having an “accident”—a humiliating possibility that caused her to stay in her apartment to be close to her own bathroom. She ate little, lost weight and strength, and had to use a motorized scooter when she wished to socialize with other residents.

E.M. had strong opinions and felt comfortable sharing them with Marilyn. She did not enjoy visits from the hospice social worker and asked her to stop calling, but looked forward to seeing David, the hospice team’s spiritual counselor. She told Marilyn that although she was not a religious person, she enjoyed their wide-ranging discussions, in part because David was an attentive and nonjudgmental listener, and he had a great sense of humor. She told him that she was exploring the possibility of foregoing food and fluid in order to hasten her death and was pleased that he responded as Marilyn had—without shock or dismay, but by asking thoughtful questions.

E.M. told them she had lived a good life, achieved all that she had hoped to accomplish, and was now ready to die—without fear or regret. She concluded that the burdens of living consistently outweighed the benefits. She knew she was dying but was frustrated by the slow pace; she wanted to speed up the process without having to involve her son in her plans. She had heard about the VSED option from other residents who had watched the peaceful death of a resident who suffered from amyotrophic lateral sclerosis. That man began to fast once his symptoms became intolerable; it seemed like a good option for her to investigate. She had questions about the process and particularly wanted to know whether it would be painful, and how long it would take to die. She also wanted to be sure the hospice team would support her decision if she decided to proceed. This was to be the focus of Marilyn’s visit today.

In Marilyn’s previous hospice position in another state, she had worked with several patients who had chosen to forego food and fluid, so she felt well prepared to discuss the pros and cons of this option with E.M., to ensure that she had a realistic understanding of the process and all alternatives and to answer any questions she might have. There was a potential problem. David told Marilyn there might be resistance from other team members or hospice management regarding the choice to fast—particularly as E.M. was not in great pain and not close to death. It was thought she might otherwise live with her disease for months.

As a consequence of these concerns, the question for next week’s team meeting was to discuss whether intentionally hastening death by fasting should be supported as an appropriate (ethical and legal) palliative/hospice option—or whether it would be viewed as an act of suicide that was unethical and illegal to support. Marilyn was very conscious of her current “new employee” status and did not want to create problems for herself or her colleagues.

Yet she also felt strongly that hospice patients should have all their questions answered and be helped to make informed decisions that reflected their values and wishes, and they should expect continued palliative support even when their choice was to (legally) hasten their dying.

Marilyn’s meeting with E.M. was productive. She told her that most patients who chose to intentionally fast found the discomfort associated with VSED could be readily managed by good bedside care. Patients require comforting physical support, for example, offering to provide lotion baths and helping with position changes, as well as continuous empathic support for the patient and family members throughout the process. Although few patients complained of hunger or physical pain, the experience of a dry mouth and feeling of thirst commonly occurred and could usually be relieved by good oral care. Depending on the patient’s physical condition and preexisting disease state, death generally occurred within 2 weeks after initiating the fast. The process required a patient who was determined and resolved to hasten dying. Although E.M. was eager to begin, Marilyn recommended that she first discuss her decision with her son and the other members of the hospice team so she would have their support throughout the process.

The next hospice team meeting revealed divergent views about the morality and legality of the VSED option. Whereas some believed that a core principle of hospice care involved supporting autonomous and informed choices that permit patients to die “on their own terms,” others were concerned about the legality of VSED. They wondered whether providing supportive care during this dying process would involve them in assisting a suicide, which was illegal in their state. Still others strongly held that intentionally hastening death was contrary to the hospice philosophy of care and believed E.M. should be told that her plan to hasten/cause death by dehydration could not be supported. At the end of this contentious discussion, it was agreed they needed more information and guidance. They decided the case should be presented to the hospice’s ethics committee, while other members of the hospice team would meet E.M. to further explore her wishes as well as her understanding of consequences and alternatives to her apparent choice. They also wanted to meet with her family to explore her son’s views about her choice.

The next week, a meeting was held with E.M. and her son; Marilyn, the hospice nurse manager, and the social worker were also present. Although E.M. had previously informed her son of her plan to VSED, he expressed dismay and opposition to her choice. He was particularly concerned about the possibility that, as the primary beneficiary of her estate, he would be held legally liable if he supported or encouraged her decision to fast. He thought her choice was illegal and that her caregivers and family had a duty to see that she ate.

The social worker also expressed reservations about E.M.'s choice; she was concerned about the possibility of untreated depression, impulsivity, and suicidal ideation. She thought all potential mental disorders that could compromise decision making should be thoroughly explored. The nurse manager was anxious about the possibility that VSED would be painful and involve months of suffering. She acknowledged that she had never known a patient to make such a choice and wondered whether there were "unmet needs" that, if addressed, would cause E.M. to change her mind about her desire for a hastened death. Marilyn said little, and E.M. seemed quite unmoved by these expressions of concern about the choice she had made.

The hospice ethics committee reviewed clinical and legal opinions in the palliative and hospice care literature and was soon persuaded that VSED was a legal option that could be chosen by decisionally capable, terminally ill, and suffering persons.¹⁻³ This information was shared with the son and the hospice team members.

In their ethical analysis of the hospice role in VSED deaths, the committee considered positions in support and opposition to making this option available to their patients. (A fuller exploration of those positions will be presented in the following discussion.) At the end of their deliberations, they concluded that hospice clinicians could ethically counsel "appropriate" patients about the VSED option and provide support throughout the ensuing dying process. (By *appropriate* they meant patients who were decisionally capable, experiencing intolerable suffering that could not otherwise be relieved, and who made a voluntary and resolute choice to hasten their dying.) The committee also made specific reference to the organization's policy regarding conscientious objection, which would provide a mechanism to support clinicians who were morally opposed to supporting patients who chose this option to hasten their dying process. The committee members also noted the absence of written organizational policies and guidelines regarding VSED and recommended that such guidelines be developed.

Meanwhile, E.M. proceeded with her plan to achieve her end-of-life goals. She hired several residential aides who would provide care when she became bedbound. She continued to meet regularly with David and Marilyn. She agreed to be evaluated by an experienced psychologist to ensure that she was not suffering from any affective disorder that could compromise her ability to make an informed decision. She readily passed that assessment. Once it became clear to all members of the hospice team that VSED was a legal option and that E.M. was decisionally capable and suffering in ways she found intolerable, they agreed to provide support to her and her son. He was reassured to learn that his mother was making a legal choice and in time came to understand her reasons for doing so, although he remained sad that she was "choosing" to die sooner than

her disease dictated. He began meeting with the social worker for bereavement support.

On the day she had chosen, E.M. began her fast. She remained alert and oriented for the first 5 days of fasting and denied experiencing any significant discomfort. She invited the hospice team's nurse manager to visit, remembering her worry about the possibility of unacceptable suffering associated with VSED. E.M. slipped into a coma at the end of the fifth day of her fast and died peacefully 4 days later, with her son at her bedside.

DISCUSSION

There is broad agreement about how palliative care clinicians ought to respond to patients who request assistance in dying. They are taught to systematically explore the reasons behind the request, to identify and intensify efforts to relieve pain and suffering, to consult specialists in the relief of psychological or spiritual anguish as needed, and to commit to nonabandonment and the identification of mutually acceptable solutions to the patient's suffering.⁴⁻⁶ When unacceptable suffering persists despite all efforts, most palliative care clinicians agree that decisionally capable patients who request assistance in dying should be informed about all legal options that permit a hastened death.^{2,4,6} Those options include forgoing or withdrawing life-sustaining interventions, VSED, and sedation to unconsciousness for relief of intractable suffering.^{2,7}

In most cases when hospice patients request assistance in dying, the underlying source(s) of suffering that prompts the request can be ameliorated by the provision of comprehensive palliative care. When suffering cannot be relieved in a manner that is satisfactory to the patient, the option to VSED as a means to shorten life may present a welcome strategy. It remains the case that few of those who are informed of this option decide to pursue it. Sometimes, the patient's request for assistance seems more a momentary or fleeting wish for death and does not proceed to the level of enduring and determined desire necessary to intentionally hasten dying. In other cases, the patient's knowledge that he/she has "a way out" seems to provide relief from feelings of desperation and entrapment. Patients' awareness of their continuing ability to control this important aspect of life can in itself be therapeutic.⁸

More than a decade ago, when palliative care clinicians first began discussing VSED as one of the "palliative options of last resort," they acknowledged that the legal precedents guiding this option were less developed than those supporting the refusal of other life sustaining interventions such as ventilators and feeding tubes.³ However, in the intervening years, a growing number of legal scholars and palliative care clinicians have concluded that VSED is a legally acceptable option.^{1,4,9} Yet, even when clinicians agree about the legality of this option, questions may persist



for some providers about the morality and professional advisability of supporting the practice. Clinicians' concerns about this option may arise from a number of sources.

Clinicians' Concerns

When a terminally ill patient chooses to forgo further use of life-sustaining interventions in order to hasten or cause death, there is a legal and ethical consensus regarding the cause of death. It is agreed that the underlying disease that necessitated use of the life-sustaining measure causes death, not the decision and subsequent removal of the life-sustaining intervention. Discontinuing unwanted treatment allows the patient to die "naturally" of the underlying disease; such decisions are routinely made by terminally ill patients and/or their families and are supported by hospice and palliative care clinicians.

However, when a patient chooses to forgo food and fluid, some argue that the patient has introduced the cause of death—specifically, dehydration—and such a choice may seem closer to an unethical act of suicide. Some clinicians believe that any act that intentionally hastens or causes death is always morally wrong, even when taken to escape intolerable suffering.^{10,11} Those holding this view may also believe that informing a patient of the VSED option would also be morally wrong because by doing so the clinician might influence the patient to choose this immoral option, and providing this information would be condoning and cooperating in wrongdoing.¹¹

It is established professional practice that clinicians are not required to act against their own strongly held moral or religious beliefs, yet it is also the case that health care professionals are obliged to inform their patients about all legally available treatment options. In the face of such moral conflict, a clinician who is morally opposed to a particular practice is expected to refer the patient to another who will provide information and support for all legal medical options before withdrawing from the case.¹²

Other clinicians who have not witnessed a VSED death may fear that if they inform an already suffering patient about this option, they might indirectly encourage a dying process that is unduly painful, prolonged, and "inhumane." Such fears are not supported by clinical reality. Several small empirical studies and an increasing number of anecdotal reports suggest that VSED provides most patients with a peaceful and gentle death that is generally well tolerated and occurs within 2 weeks of beginning the fast.^{8,9}

Additional Clinician Responses

When hospice patients ask their professional caregivers for help in hastening death, clinicians often experience a "storm" of emotions that may include guilt, shock, self-doubt, failure, sadness, and self-blame.⁴ Such feelings may influence the clinician's response to the request and adversely influence the patient's care.¹³ When hospice pa-

tients specifically ask their nurse or social worker to help them die sooner, some clinicians may feel they have failed their patient by not adequately managing their symptoms of suffering. Hospice clinicians rightly view themselves as experts in symptom management—throughout the whole of the dying process. The clinical goal is to help the patient experience a "good" death that occurs naturally. When patients ask for information and/or support for hastening death, some simply say, "I can't help you with that,"¹⁴ which effectively stops further communication and eliminates an important opportunity for the nurse to acknowledge the patient's distress, explore the meaning of the desire for a hastened death, and refocus efforts to relieve his/her suffering. Some of the reluctance to enter into an exploration of the request may be driven by fear and misunderstanding about whether legal or ethical liability attaches to a discussion about options that permit patient-controlled dying.

The Patient's Perspective

Patients who live with an incurable and progressive disease often have to accept many losses. Their lives may be filled with pain, physical limitations, dependency on others, and a decreasing ability to engage in activities that once were a source of joy and satisfaction. Some people can accept such limitations with grace and good will, but for others, the inability to have a voice that is heard or to make a choice about dying that is respected is an intolerable affront to their personhood. Many in this group want to know that there are still options and choices available to them during this time. Only the person living with the terminal illness can know when the burdens outweigh the benefits of continuing to live, when suffering becomes unbearable, and when the time has arrived to explore whether and how to hasten dying.

It is important to again note that more people will seek information about VSED than will pursue this means to hasten dying. Nonetheless, those who learn about VSED may feel empowered by the knowledge that they can choose this option without seeking a physician's written order or anyone's permission. Because VSED is a legal option, it can be openly discussed in a thoughtful manner with loved ones and caregivers. Discussions and consideration of this choice further patient autonomy because control remains with the patient throughout the process—whether and when to begin the fast and whether to continue to fast each day until consciousness is lost.

The Ethics Committee's Deliberations

The ethics committee was composed of approximately 20 persons with a variety of professional backgrounds including advanced practice and registered nurses, physicians, chaplains, administrators, attorneys, social workers, and a philosopher/bioethicist. After thoroughly reviewing the available literature (and there was not a great deal of material), they invited clinical experts with VSED experience

to present their views to the committee. Marilyn was one of the experts invited to address the committee. The committee considered ethical positions in support and opposition to including VSED as a sanctioned option within the hospice organization.

Ethical Support for VSED

The hospice philosophy of care emphasizes patient- and family-centered care that seeks to optimize quality of life by preventing and treating suffering throughout the whole of the dying process, while facilitating patient autonomy, access to information, and personal choice. Consistent with this philosophy is the duty to relieve suffering, which is understood to include threats to personal integrity and wholeness and loss of control and dignity.

Hospice clinicians demonstrate respect for autonomous choice and personal integrity when they provide VSED information to decisionally capable patients who seek professional advice about patient-controlled dying to escape intolerable suffering. They demonstrate fidelity and promise nonabandonment when they assure patients and families that intensive symptom management will continue regardless of what decision is made. The committee noted that while most professional codes of ethics prohibit health care professionals from intentionally acting to hasten or cause death, VSED is patient directed and controlled, rather than clinician imposed.

Ethical Concerns About VSED

It was noted that another traditional hospice value was the commitment to neither hasten nor prolong dying. Thus, participating in support of an act to intentionally hasten death could be viewed as inconsistent with the value that supports finding and creating meaning during all phases of the dying process. Similarly, questions of proportionality could be raised when relief of suffering occurs at the expense of shortening the dying process.¹⁵ Some members of the ethics committee continued to be concerned about the possibility that dying of dehydration would involve an intolerable amount of suffering; they feared that discussing this option with already suffering patients and families might seem contrary to their obligation to relieve suffering and not cause more suffering.

The ethics committee members also acknowledged that when family members or clinicians disagreed with a VSED decision, the experience of watching the patient die in this manner could be a source of significant suffering for those family members and/or clinicians. Thus, if VSED was chosen, patients and families would need ongoing emotional, spiritual, and physical support throughout the dying process, and clinicians might also need such support from colleagues. This hospice had a conscientious objection policy that identified and supported a process for those with moral objections to VSED to withdraw from the patient's team,

while another clinician without such objections would join to provide ongoing support.

Other aspects of E.M.'s case were examined for their ethical relevance—for example, the fact that she was neither imminently dying nor suffering unmanaged physical pain was considered. They noted that in Quill and Byock's³ guidelines for VSED, the prognosis for death was “weeks to months,” and patient characteristics included “persistent, unrelenting, otherwise unrelievable symptoms that are unacceptable to the patient...”^{3(p414)} These experts noted that when the patient was not imminently dying, clinicians should seek a second opinion from specialists skilled in the assessment of depression and spiritual suffering who could facilitate the clarification of motives and alternatives with the patient, family, and professional caregivers. The committee believed that such considerations ought to be included in the development of written guidelines and procedures regarding VSED for the hospice.

Conclusions of the Ethics Committee

After considering the prospective benefits and concerns about informing patients about this option, the committee concluded that, on balance, providing comprehensive information about VSED permits a patient to make an informed decision that reflects their personal values and wishes. The decision to stop eating and drinking was thought to be consistent with the ethical and legal right to forego unwanted life-prolonging measures.^{2,3} And finally, it was thought that educating patients and families about “what to expect” as VSED progresses, providing support as the patient dies, and providing the family with bereavement care after death were actions consistent with the hospice value of patient- and family-centered care.

Their final report highlighted their concern about the absence of organizational procedures and guidelines to provide direction to clinicians, patients, family members, and the hospice organization when future cases of requests for VSED support occurred. They recommended that a subcommittee be created to develop a written VSED policy. Marilyn was invited to become a member of that subcommittee, and she was pleased to do so.

CONCLUSION

Increasing numbers of patients across the country are exploring and sometimes choosing VSED to escape intolerable suffering. A growing number of hospices, in noting this change, are recognizing the need for written policies and procedures to guide clinicians' responses to such requests.¹⁶ Although it is likely that not all hospices will choose to sanction this option within their organizations, having a clear written policy will enable clinicians to respond in a cohesive fashion to patient requests for this information. As more stories of family experiences following a loved



one's choice to VSED are published in professional and lay journals, future hospice patients may wish to know whether their local hospice has a VSED policy in order to make an informed choice about whether to begin a relationship with a particular hospice. Although VSED will not be an appropriate option for all hospice patients, given the opportunity to consider this option in discussions with family members and caregivers, some hospice patients may feel empowered by the knowledge that they can, if they choose, indirectly control the timing of death.

In the present case, E.M. was able to proceed with her plan to hasten her death despite the initial reservations by some members of her hospice team and her son. Once they recognized that she had made a well-informed and determined decision to proceed, and they understood they would assume no legal risk in supporting her choice, her death was peaceful and dignified, and the process was instructive for all those involved.

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