How should a Catholic hospice respond to patients who choose to voluntarily stop eating and drinking in order to hasten death?

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The practice of voluntarily stopping eating and drinking (VSED) in order to hasten death poses a unique problem for the Catholic hospice. Hospice staff may be confronted with patients already on their service who decide to pursue this option for ending their lives. Patients not on hospice service who are contemplating VSED are often advised to contact hospice for symptom palliation associated with the process of VSED. Intentionally hastening death not only violates the sanctity of human life and the Ethical and Religious Directives the Catholic hospice is bound to uphold, but it also runs counter to the general philosophy that hospice neither hastens nor postpones death. At the same time, hospice programs have a strong philosophy of nonabandonment of patients. This article will analyze the ethical issues from the perspective of the Catholic tradition and suggest strategies for the Catholic hospice to respond to this group of patients.

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Imagine yourself as the director of a Catholic hospice program receiving a telephone call from your intake social worker. The social worker tells you that there is a concern about a new client on the program whose case history is as follows:

Ms. V is a 76-year-old retired bank teller who has end-stage chronic obstructive pulmonary disease. After three hospitalizations in the last eight months, each requiring several days on a ventilator, Ms. V has decided that she does not want to be intubated in the future and she asked her doctor to sign a do not resuscitate order for her. Ms. V's breathing requires home oxygen therapy for most of the day and her other medical issues include

some mild hypertension and chronic pain from osteoarthritis of her hip. Her main complaint, however, is fatigue. Her primary care physician believes that depression is a major contributor to her fatigue and prescribed an antidepressant for her. The patient is married and she and her husband have no children. They both decided long ago that they did not wish to die by a lingering, debilitating death, and if that became a reality, they would choose to die "by their own hand." Feeling more debilitated and fatigued by her chronic diseases and recent hospitalizations, the patient and her husband sought a "coach" from Compassion and Choices (an aid in dying organization). Their coach instructed them on the

protocol for “voluntarily stopping eating and drinking” in order to hasten death (VSED) and encouraged them to contact hospice for the palliation of symptoms which sometimes accompany VSED if they chose to do that. At the hospice intake interview, the patient and her husband tell the hospice social worker that the patient intends to hasten her death by refusing all food and fluids. At this point, the social worker phoned her manager stating her discomfort with the patient’s request for hospice services. It was unclear whether the patient’s medical conditions really required the symptom management of hospice nor was it clear that her prognosis had progressed from chronic to terminal except for her voluntary decision to stop eating and drinking.

A key issue for the hospice in this situation is whether accepting a patient who is choosing VSED constitutes cooperation with suicide. Since the hospice knows the patient’s intention, denying the patient’s enrollment in hospice could potentially leave a dying person without the palliation, spiritual, and bereavement support they might badly need. Conversely, accepting this patient would seem to contradict the very nature of hospice care and the mission of hospice organizations. Careful exploration of these issues is essential to the ongoing development of hospice programs and the future articulation of their mission. Hospice programs, in particular Catholic hospice programs, must remain steadfast in the philosophy that they do not hasten death by any method including VSED. The Catholic tradition views life as a precious gift from God and recognizes that human beings do not have absolute power over when life begins and ends but do have an obligation to preserve the dignity of human life. This obligation precludes participation in suicide or euthanasia (United States Conference of Catholic Bishops 2009, Part V,

Introduction). Responding to patient requests for symptom palliation related to VSED will require clear communication, expert assessment, establishment of a mutual understanding with regard to what services can be provided, and the formation of a relationship in which the patient does not feel abandoned. These issues are made even more difficult because clinicians, aid in dying advocates and lawyers all seem to have slightly different conceptualizations of the practice of VSED to hasten death. Additionally, the estimated number of deaths actually attributable to VSED alone is difficult to quantify though it is thought to be increasing. A recent review article estimated that 2.1 percent of deaths in the Netherlands (approximately 2,800/year) occur as a result of VSED (Ivanovic, Busche, and Fringer 2014, 13). Pitre (2009) documented legislative efforts in California to require physicians and other healthcare providers to inform patients of their “legal options including VSED” as end-of-life treatment (Pitre 2009, 390–407). Local and national media stories, often promoted by Compassion and Choices, are easily retrievable on the internet (Gross 2012). Clearly, this little discussed, decades old practice is quietly making its way into mainstream health care.

DEFINITION OF VOLUNTARILY STOPPING EATING AND DRINKING

For decades clinicians and others involved in end-of-life care have debated the merits of what is currently known as voluntarily stopping eating and drinking. Definitions of VSED differ, however, in subtle but important ways. For example, Quill and Byock (2000) have claimed that VSED is a “palliative option of last resort” for “competent, terminally ill patients who are suffering intolerably in spite of intensive

efforts to palliate and who desire a hastened death” (pp. 408–414). By contrast, Judith Schwartz, a clinical coordinator for Compassion and Choices talks about VSED as a “legal end of life option that might hasten dying for someone who is not terminally ill or in the last days of life.” She speaks about VSED as a legal choice for people who want to take control of their dying regardless of whether they are terminal (Schwarz 2009, 52–61).

Common to both definitions is the notion of intentionally hastening death. However, the Compassion and Choices approach includes a broader spectrum of patients going beyond those who are terminally ill. Far from being a last resort, VSED, according to Compassion and Choices, is particularly appealing to the elderly and chronically ill who are isolated and alone and who have “lost the ability to read or watch TV” or to pursue other enjoyable activities (Schwarz 2010, 3). While Quill and Byock describe VSED as applying to a small percentage of patients, Compassion and Choices (2011) has sponsored a national campaign to promote VSED as an end-of-life option which can be utilized by anyone to “bring peace at life’s end anywhere.” For the purposes of this discussion, VSED is understood as any intentional effort to hasten death by refusing food and fluids regardless of whether or not the patient is terminal.

Is VSED SUICIDE?

Controversy exists regarding whether or not VSED ought to be considered suicide. Here both the legal and ethical questions remain unsettled. Clearly the intentional nature and ultimate outcome of death would understandably suggest the practice is consistent with common dictionary definitions of suicide, i.e., “an act or instance of taking one’s own life voluntarily and

intentionally” (Merriam Webster 2014). Additionally, the Centers for Disease Control (2013) label as suicide “any self directed, injurious behavior with any intent to die as a result of the behavior.” Legal analysts point out that there are few judicial decisions regarding VSED and though the practice has some “earmarks of suicide,” courts will likely not intervene to force suffering patients to receive nutrition against their will (Cantor 2006, 101–125). Still, the issue is important from a legal perspective for caregivers and providers who could be implicated in assisting suicide if VSED were considered as such. In New York, for example, a state where physician-assisted suicide is prohibited, promoting a suicide attempt is a Class E felony and assisting another to commit suicide is considered manslaughter in the second degree (New York State Penal Code 120.30, 125.15 2014).

From an ethical perspective, it may be very difficult to discern whether an instance of VSED ought to be considered suicide. Imminently dying patients may not have the energy or interest in eating or drinking as their bodies physiologically shut down. Most commentators are careful to distinguish patients choosing VSED from dying patients who experience a natural loss of appetite and interest in food (Quill and Byock 2000, 408–414). Most also exclude those patients for whom eating and drinking has become burdensome hence their refusal of food and fluids is seen as refusing a disproportionate measure to remain alive (Jansen 2004, 61–74). Still others, like Ms. V, are clearly intending to hasten their deaths.

Some have argued that VSED is the right of a competent patient to be respected as a legitimate expression of autonomy. Quill and Byock point out that some physicians may not have an ethical issue with VSED as long as it is clearly the terminal patient’s choice in the face of

unrelenting suffering. They are careful to note that depression should be ruled out in patients who request VSED and that symptoms be reviewed in the event that they may respond to some untried method of palliation (Quill and Byock 2000, 408–414). Recall that Ms. V had just started treatment for depression but the duration of her treatment was too short to assess effectiveness before Ms. V began fasting.

There are providers and ethicists who view all efforts to intentionally hasten death as suicide and many of those who view suicide and/or assisting suicide to be ethically impermissible. (Jansen and Sulmasy 2002, 845–849). From the perspective of Catholic tradition for example, the matter is clear. The 1980 Declaration on Euthanasia states,

Intentionally causing one's own death, or suicide, is therefore equally as wrong as murder. . . . By euthanasia is understood an action or an omission which of itself or by intention causes death, in order that all suffering may in this way be eliminated. . . . Furthermore, no one is permitted to ask for this act of killing, either for himself or herself or for another person entrusted to his or her care, nor can he or she consent to it, either explicitly or implicitly, nor can any authority legitimately recommend or permit such an action. (Congregation for the Doctrine of the Faith 1980, Sec I, II)

The central question for these providers is what, if any, involvement with patients who choose VSED in order to hasten their death is appropriate. It is often a difficult moral question for providers who personally do not believe in hastening death but who also do not wish to abandon their patient.

Perhaps the most difficult issue left under-explored in the quest for universal agreement as to whether VSED is properly considered suicide is the underlying reason these patients are requesting death

in the first place. There has been little research in this area but most studies cite the main reasons for patients choosing VSED are “readiness to die, life perceived as being pointless, poor quality of life, a desire to die at home and the wish to control the circumstances of death” (Ivanovic, Busche, and Fringer 2014). Intractable pain and suffering does not appear as one of the main reasons though the paucity of articles and studies does not rule this out as significant or perhaps buried in the category of “poor quality of life.”

THE DILEMMA FOR HOSPICE

Hospice providers face a similar dilemma. Most hospice providers adopt the philosophy of the National Hospice and Palliative Care Association which says, “Hospice affirms life and neither hastens nor postpones death” (National Hospice and Palliative Care Organization 2010). Bruce White, the director of the Alden March Bioethics Institute states it more emphatically. In a newspaper article about VSED, Dr. White said,

Suicide is a lose-lose situation for hospice. They have a reputation . . . that they support people in their last days of life. If people feel that hospice is . . . hastening their death, hospice will never recover from that. (Crowley 2011, A8)

Aid in dying advocates promise patients that “when coordinated with hospice care, the process of VSED is peaceful and the patient does not suffer from hunger or thirst” (Schwarz 2007, 4). In other words, the expert symptom management provided by hospice is needed to address the discomfort or delirium which may occur with VSED. So hospice caregivers are caught in an uncomfortable tension between continuing services knowing the patient’s

intention is to voluntarily stop eating and drinking or declining services to a patient who is actively dying. Not all caregivers are comfortable with this level of involvement in a patient's intentional death. Rady and Verheijde (2012), commenting on the use of sedation with VSED, put it bluntly,

the use of sedatives with voluntarily refusing food and fluids is commensurate with euthanasia ... owing to the absence of empirical evidence for the efficacy of continuous deep sedation in managing distress, it may be argued that voluntarily refusing food and fluids with sedation may represent a cruel and inhumane method of terminating life. (pp. 510–512)

Jansen (2004) reflects the complexity for hospice when she notes,

VSED raises difficult moral questions about the extent to which physicians can permissibly collaborate with moral wrongdoing (or with what they perceive to be moral wrongdoing) as well as the nature and limits of the authority they exercise over terminally ill patients. ... While we might wish otherwise, in orchestrating care at the end of life, there is no moral safe harbor. (pp. 61–74)

The increasing effort to promote VSED is also a dilemma for Catholic health care. In the *Ethical and Religious Directives for Catholic Health Care Services*, euthanasia and assisted suicide are specifically prohibited. Directive 60 states plainly, "Catholic health care institutions may never condone or participate in euthanasia or assisted suicide in any way." This would seem to exclude Catholic health care from engaging with patients who express an active intention to end their lives regardless of the means they choose to use. However, the rest of directive 60 states,

Dying patients who request euthanasia should receive loving care, psychological and spiritual support, and appropriate

remedies for pain and other symptoms so that they can live with dignity until the time of natural death. (United States Conference of Catholic Bishops 2009)

Psychological and spiritual support and effective remedies for pain and other symptoms are the hallmarks of hospice care. How does the Catholic hospice or healthcare facility reconcile the obligation to oppose euthanasia, suicide or assisted suicide with the Christian mandate to care for the dying? More broadly, how does the Catholic community witness to the dignity of human life specifically during the challenging times of aging, disability, and dying in a culture that is being characterized by an ideology that promotes absolute human autonomy over decisions about when life begins and when it should end?

THE RESPONSE OF THE CATHOLIC HOSPICE

Catholic health care needs a thoughtfully considered and carefully articulated approach. All patients should be advised prior to the initiation of services that no form of euthanasia or suicide or assisted suicide including VSED will be supported or facilitated. Non-dying patients who request hospice services only to support VSED should be counseled that the Catholic hospice may not participate in their endeavor. The patient should be offered evaluation for depression and assessment for pain, discomfort, nausea, or other distress which may be amenable to medical care. However, the Catholic hospice should decline to enter into an agreement to provide palliation for symptoms brought about *solely* by VSED as that agreement could constitute facilitation or represent tacit approval of the patient's intention.

On the other hand, dying patients who are receiving hospice services or who

would otherwise qualify for hospice care should not be abandoned because they express an intention to hasten their death. Here the Catholic hospice has the opportunity to present a life giving alternative to a patient's desire for an expedient death. By continuing to reassure patients that pain and other uncomfortable symptoms are manageable and by expert assessment and intervention for possible depression, hospice care providers bear witness to the inherent dignity of the individual's life.

With regard to VSED, all hospice care providers (i.e., faith based and others) would be well advised to refuse to sanction or facilitate the refusal or withholding of food and fluids from a patient for the purpose of hastening death. The care team or the care plan should not express "support for the patient's choice." Instead, the plan of care should remain consistent with the philosophy of hospice—neither hastening nor preventing death. The opportunity to offer food and fluids if requested and as tolerated by the patient may occur if the hospice remains involved. Though she is an advocate for patients who choose physician assisted suicide, Linda Ganzini (2010) observes that, "hospice is the single most effective means of allowing patients to reconsider physician assisted death, not by taking the issue head on, but by slowly chipping away at the patient's fears of dependence and care." Certainly, the same dynamic could occur with patients considering VSED. No patient can be forced to take food or fluids and no patient should be urged to eat if eating causes distress. If the patient capable of eating persists in refusing food and fluids, the presence of the hospice provider can also serve as a protection for the patient by assessing that the patient is not being forced or coerced against their will. By not abandoning the patient, the hospice caregiver retains the potential

for reinforcing that no matter how limited or debilitated, the patient's life has value and there exists a viable option for supporting that life until the patient's natural death.

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