Case 8—A Young Woman's Wish to Die

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VH was a 19-year-old woman admitted to the Pediatric Intensive Care Unit (PICU) of a large, tertiary care hospital following a T-bone motor vehicle crash.[1] She was alone in the car. Her injuries included a C-2 C-3 fracture[2] that resulted in quadriplegia. VH was ventilator dependent and had been placed in the PICU for lack of beds in the adult ICU at the time of admission. Upon returning to full consciousness, VH was made aware of the severity of her condition and that she may or may not recover any motor function. This news resulted in profound sadness, and she was evaluated by a psychiatrist for clinically significant depression.

VH was Hindu. She and her family had moved to the United States several years prior to her accident and were settled with the help of her father's brother. The patient's parents were not happy living in the United States, however, and they planned to return to India when their children had completed their educations. The patient herself was a student at the local community college in a physical therapy program. Despite her young age, she was looked to by members of her large, extended family—some of whom were not fluent in English—for guidance in negotiating life in the U.S. Her parents operated an independent grocery store as their primary means of support. They were not wealthy, but they supported themselves. VH's uncle, fluent in English, spoke for the extended family and acted as the intermediary between the family and the hospital.

The family indicated they might not wish to continue life support should VH continue to be paralyzed with little hope of improvement. The uncle stated, "In our culture, the family makes decisions in this kind of situation." He explained that according to their cultural beliefs, suffering could be the result of transgressions committed in a past life. He clarified by saying, "VH might now be atoning for transgressions of a past life and must be allowed to be reborn. Her body is only a garment for her soul, and when the body is broken the soul must be freed to go on to the next life." In the family's view, therefore, this reincarnation into a new existence, a new life, may be a much happier one than the one VH currently had.

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The hospital Risk Manager explained to the uncle and family that the legal age for giving consent in the United States was 18 and that VH would, therefore, be the only one allowed to consent to withdrawal of treatment if her physicians determined she had decision making capacity. The uncle said they wished to be respectful of this, but that they also felt the issue to be a family matter. He also stressed, however, that the family wished to avoid any media or legal involvement, sensitized as they were to the Schiavo case.[3] The patient's physicians strongly urged that no decision be taken until a tracheotomy had been performed to allow continued ventilator support and the patient's current depression be given time to respond to treatment. They felt that once those objectives had been achieved VH would be better able to assess her situation with the help of seasoned medical professionals and family members, take time for careful reflection, and then make her decision. They also encouraged the family to wait (perhaps some months) until VH's prognosis could more adequately be assessed.

An ethics consult was called. The ethics committee strongly supported the recommendations of the physicians and other health care team members, particularly with regard to soliciting the patient's wishes, if at all possible, noting that a competent patient has a right to refuse treatment. The family agreed to wait so that the recommended treatments could be performed, although they demurred on waiting months for further assessments. The uncle stated that while he understood the patient, and not the family, would need to be the one to give consent to any decisions about discontinuing treatment, he said, "VH is a good girl who will do the right thing," reinforcing this with a proud, loving, avuncular smile. The family also indicated through him that VH had begun communicating with them through eye gestures that she did not want to be a "burden on the family," and that she wished to be allowed to die.

The tracheotomy was performed. VH slowly began to form words, though she could not speak aloud. The medical team read her lips for most of their communication with her. The psychiatrist treating her for depression visited daily, as did the licensed clinical social worker assigned to her case. She was also seen daily by the PICU intensivist to keep her up to date about her medical condition and to continue to assess her understanding of her situation. She was given detailed information about options for rehabilitation and financial resources that might be available to her and her family. Her depression abated, and she appeared to have decision-making capacity. VH indicated understanding of her condition and that if taken off the ventilator she would die. She reaffirmed her wish to be allowed to do so and indicated she was unafraid and at peace with that decision.

The ethics committee met again with the uncle and several of VH's family members. "We respect the ethical, legal, and medical positions of the hospital," said VH's uncle, "but our religion and culture are important to us, as is VH." He also emphasized the apparent wishes of the patient herself to stop life support. The ethics committee, believing that VH was making a fully considered and informed decision, recommended to the physicians that the ventilator be withdrawn. The attending physician discussed this with VH and her family, and he reassured everyone that VH would be sedated before the removal of the ventilator and that she would experience no discomfort. The family asked that this be done between 12:00 noon and 1:30 p.m. in accordance with their religious beliefs; they also asked that they be allowed to practice certain religious rituals in the room privately with VH before the ventilator support was discontinued. These requests were granted. The family and VH said their good-byes, and she expired peacefully at 1:20 p.m. with her uncle and several other family members present.

Discussion Questions

1. How can hospitals and physicians in the U.S., where ethical deliberations most commonly focus on the patient-physician dyad, adequately support patients where more family-centered, communal decision making might be preferred?
2. Would it have been helpful in this case to have a chaplain involved? What role can chaplains play in helping hospital personnel and families think through end-of-life issues where religion plays a significant role? How can chaplains serving in hospitals sponsored by a specific religion best be of service to patients of very different religions and cultures, or patients espousing no religious beliefs at all?

A Bioethicist Responds

Full disclosure is in order here once again. This writer was a member of the ethics committee mentioned in the narrative above, and it has to be said that the ethical issues weighed heavily upon all members of the committee at the time. Yet when this case was later brought up for discussion in a university biomedical ethics seminar, the first-blush reaction of the class, virtually year after year, was generally that there were no ethical issues here. If Professor Schenck asked if they were sure that they saw no ethical issues, the response would go something like, "No, once VH was found to have decision making capacity, which she eventually was, it was merely a matter of allowing her to exercise her autonomy. And, the docs and the hospital did allow her to do that, so what's the issue?" Fine, one might say, but Professor Schenck felt there just might be a few more wrinkles to the story, not the least of which was the interesting intersection of two very different cultures, and there was considerable challenge in attempting to enlarge the optic of some students as to what was happening in that regard. Nonetheless, Professor Schenck himself remained puzzled for years, if not to say uncomfortable, about one particular issue in the case until one semester when a number of male and female students of Hindu background enrolled in the seminar. Before further discussion of that, however, some preliminary observations may be useful.

One of the most obvious features to be noted in a wide-angle view of this case, as mentioned above, is the juxtaposition of two very different cultures, the Hindu cultural values and customs of the patient and her family and those of the western hospital and health care team. One might almost suggest a "clash of cultures" here, but that would be too strong a term since no real struggle ensued and a resolution was found to what appeared to be problematic at first. Fortunately for all concerned, this hospital was not only truly dedicated to serving all persons, regardless of race, religion, color, creed or national origin, but it had taken seriously the provisions of the law established in 2000 as the *National Standards for Culturally and Linguistically Appropriate Services in Health Care* (commonly known as CLAS Standards).[4] The physicians and the entire staff were, therefore, fully committed to making every effort to achieve an understanding of VH's feelings, beliefs and wishes, and those of her family, as well as to finding ways to communicate the concerns of the health care team for her and her family, and to communicating the values and ethics of the hospital and the medical team in ways that VH and her family could understand.

Some of the research data reported in recent years on people from the Indian subcontinent regarding their attitudes and beliefs at the end of life might seem surprising to people in the west. Loiselle and Sterling reported on a grassroots cancer care hospice in Bangalore, India, pointing out how the significant rise in late-stage illness diagnoses, such as cancer, is placing enormous demands on palliative care (2012). The primary purpose of their study was to demonstrate the need to develop supportive mechanisms for hospice workers in order to ensure an optimal workplace climate, but it also revealed the increasingly complex cultural, socio-economic and religious contexts of the populations these hospice care workers serve. Briefly put, those in the west should not simply assume that end-of-life issues for persons from the Indian subcontinent will naturally embrace Hindu beliefs; the overall population exceeding one billion persons is far too complex.

The situation for Asian Indians living in the United States could be even more difficult for physicians and others in health care here to understand. Rashmi Gupta's article on Asian Indian American Hindu cultural views related to death and dying presents the results of a qualitative study designed to fill a gap in empirical research on cultural beliefs and meanings of death and pre- and post-death practices in three generations of Hindu Americans in the U.S. (2011). The study revealed the importance for the dying and the family to say their good-byes; the contradictory attitudes regarding expressions of grief that may be found among Hindus; the fact that Hindu culture is group-oriented or collectivist in nature; and Hindu beliefs about the meaning of death as a transition to another life that helps people feel less anxiety about death than would normally be felt by people of many western cultures. Gupta then calls for those in health care in the United States to develop greater cultural awareness of Asian Indian Hindu beliefs and rituals pre- and post-death, as well as a clear recognition that not all Asian Indian American Hindus will respond alike to end-of-life situations.

Somewhat similarly, Sharma and colleagues (2011) reported from their study that first- and second-generation Asian Indians place high value on close parent-child relationships and feel a strong sense of duty to the family. And, they recommended in fact that "When eliciting Asian Indian patient preferences for end-of-life care, clinicians should consider explicitly asking about preferences related to family involvement in care, decision control, and communication; and explore the role of traditional expectations and specific social realities for each patient. By assessing each of these topics and respecting the patient's choice for individual or family-centered decision making, clinicians caring for Asian Indian patients can maintain respect for patient autonomy while also respecting the patient's cultural values" (2011, 316). With the foregoing in mind, it is time to return to a more detailed view of VH's situation and what appeared, at least at one point, to be the troublesome issue of informed consent.

Recalling the case narrative, VH's uncle had said he understood his niece would have to be the one to give consent to any procedures or withdrawal of treatment, but he also knew her to be a "good girl who would do the right thing." One can well imagine the reactions of the members of the ethics committee upon hearing this statement. While no one said anything in direct response to the uncle at the time, committee members expressed their fears and concerns openly amongst themselves once the uncle and other members of the family had left the room. There was some minimal understanding of the nature of *karma*, atonement and reincarnation, but there was also fear that VH might be subject to family coercion out of a sense of obligation to the family, thereby making the issue of informed consent highly problematic. As reported above, however, things eventually worked out to the satisfaction of both parties and VH was made comfortable while she was removed from life support and allowed to die as she had requested.

This leaves the issue temporarily suspended above, the one that had continued to trouble the present writer for some time despite his agreement with the decision to withdraw the ventilator, albeit sadly, and despite his conviction that this was the right decision for VH and an acceptable decision for her American care givers. What still seemed troublesome, nonetheless, was the idea that VH was of majority age, that she apparently played some sort of leadership role in her extended family, but that "the family would make decisions in this kind of situation." It was only when this confusion was expressed years later in class that an 18-year-old Indian-American woman said, "I think I can help you, Dr. Schenck. You see, in my culture, and even though I've spent most of my life in the United States, I won't be considered an adult until sometime in my 20s. And, there's no fixed age when one becomes an adult. I might be considered an adult by my family when I'm 22, or maybe not until I'm 27; it all depends upon when they, as well as I, feel I've really matured. And, in fact, although other people my age, that is 18, are legally adults in the U.S., I'm still a child as far as my family is concerned in Indian culture. So you shouldn't really think that VH's uncle or other family members coerced her into saying she wanted the ventilator withdrawn or that she wanted to die when she really didn't. When her uncle said that 'she was a good girl who would do the right thing' he meant she would do what she really believed was the right thing not only because of her faith but also because the family knew this to be the right thing, and she would have known as well that this was the culturally, ethically appropriate thing to do. After all, serious decisions such as these are made by the family as a whole, not by one individual alone." This eloquent explanation was given by an extraordinarily bright young woman of Indian origin but raised entirely in America, and now in medical school.

And with that, Professor Schenck looked around the room to see heads nodding, several with knowing smiles on their faces, males and females alike, all of them

Asian Indian American Hindus who had been largely educated in the United States, all confirming what their classmate had said. It finally made sense, and the resolution to the case of VH seemed all the more striking, given the potential for problems and misunderstanding.

A Health Communication Scholar Responds

VH's accident, injury, and death were tragedies for her and her family. Some things worked well in this case nonetheless which prevented this sad story from an even more calamitous ending. It can be hard to make sense of a young person dying well before their time, but VH and her family used their religious and cultural resources to create meaning and make decisions that were consistent with their values and beliefs. Ironically, one of the factors that led to VH's peaceful death and good communication between family members and medical staff members was also a troubling one—her uncle acting as the family spokesperson. Having a single point of contact helped this family cope and make decisions, and it undoubtedly helped the medical team to coordinate VH's care, but we are left to wonder how much of a role VH herself played in this sequence of events. Our ethical principles and communication frameworks in medicine are predicated on the assumption that the unit of interest is the patient-physician dyad. Yet we know in practice that this is rarely the case, especially in intensive care units, where teams of hospitalists, physician specialists, nurses, occupational and physical therapists, respiratory technicians, social workers, chaplains and others all play crucial roles. VH was lucky in that in addition to an apparent abundance of good medical care, she also had the loving support of her close family. But how do we know, as we must ascertain given our focus on the patient-physician dyad, that this patient had an opportunity to speak with her attending physician and express her own preferences?

We cannot look inside this patient's psyche and parse how much of her decision to remove herself from life support was based on personal preference, how much was influenced by family pressure, or how much her physicians swayed her opinion one way or another. We do not know much about VH herself, other than her role as navigator for her family members new to the U.S., and her designation as a "good girl." Is this how she saw herself? She was only 19 years old—was she a mature and independent young woman, or still dependent on the ideas and opinions of her family? Did she adhere devoutly to Hindu religious teachings and beliefs, or was she more secular in the beliefs and values that guided her throughout her short life? Does it matter?

VH's family members believed that their religious and cultural perspective led them to conclude that VH should be allowed to let go of her damaged body and await a future reincarnation.[5] Patients who are judged competent are allowed to refuse medical treatment, including life support, under any circumstances. Given VH's young age and high level of family support, we might be tempted, as were some of the doctors involved in her care, to attempt to persuade her and her family to wait longer to decide whether to discontinue life support. We certainly do not want a severely depressed individual to end life supportive treatment before they could make this decision with a clearer head. We do not want to encourage newly injured patients to refuse life support while in the middle of processing the initial shock and despair over their condition. However, imposing an arbitrary waiting or adjustment period before making this decision also imposes challenges.

There is no ethical or legal difference between withholding or never starting life support and withdrawing life support after a trial period. In clinical practice the decision to withdraw life support is often more difficult. Consider the famous case of Donald "Dax" Cowart.[6] Dax was severely injured in a propane gas explosion that killed his father and left him blind and with third-degree burns over much of his body. He attempted to refuse the excruciatingly painful treatments he received, but his mother consented on his behalf despite his protestations and the fact that his some of physicians believed he was competent to make his own decisions. Nearly a year into his treatment, one of Dax's physicians again refused to let him stop treatment, telling him, "you've come this far, why stop now?" This same surgeon convinced Dax to have "just one more surgery" to restore some of the lost function in his hands, and told Dax that once that was done, he would be able to kill himself if he wanted to without a doctor's help. Dax did try to kill himself at least twice—once by trying to step in front of a truck speeding by along the highway at night, and once by taking an intentional overdose of sleeping pills. Neither suicide attempt was successful. Dax has by now been a successful attorney for many years, and describes his life as happy. He still maintains that he should have been allowed to refuse treatment and die from his injuries. He remains personally and professionally committed to the issue of patients' rights.

VH's case reminded me of some interesting parallels to my grandmother's experiences at the end of her life. My grandmother was a devout Catholic her entire life. She never got a driver's license, and after her husband died in his late 60s, she walked to Mass nearly every day, in every season, for nearly 30 years. About a year before her 90th birthday, she was diagnosed with peripheral artery disease and was in danger of losing two of her toes, which distressed her greatly. She was persuaded to undergo femoral-tibial bypass surgery (also known as infra-popliteal reconstruction) to bypass the diseased blood vessels in her lower leg or foot.[7] My grandmother spent several weeks in the hospital and was eventually discharged to a skilled nursing facility. In hindsight, the recovery from amputation of her toes would likely have been easier than the recovery from the bypass surgery. Even though she had the loving support of her two daughters and her extended family, this was still an extremely difficult period of suffering for her. She died a few months after her 90th birthday. At her funeral mass, the priest described her post-surgical suffering and institutionalization as her required time in purgatory. While in line with Catholic teachings about the role of suffering in human life, this explanation of her end-of-life care struck me as cruel and unnecessary.

Religion can be a tremendous resource and a source of meaning, comfort, and strength. Catholicism was a central feature of my grandmother's life, and while the priest's words offered me little consolation, I think my grandmother would have understood his description of her end-of-life journey, and perhaps she would have found succor in his acknowledgement of her suffering. Although we do not know how invested VH was in Hinduism, we can hope that the promise of reincarnation was a source of comfort and hope. It is more difficult to find reassurance, at least to this writer, in the idea that her injury may have resulted from past life transgressions; but perhaps belief in the former requires acceptance of the latter. My grandmother was not what some call a "cafeteria" Catholic, one who picks and chooses only parts of the faith. My grandmother accepted it all, including messages about the necessity of suffering. Perhaps VH was also able to hold both the promise of reincarnation and the sanction of injury for past sins close as she and her family made sense of her situation and grappled with the decision to allow her to die.

Our global and diverse society means that those with varying religious and cultural frames of reference are increasingly part of the fabric of the institutions and norms that make up our American way of life. We need to remain mindful of the ways in which our Judeo-Christian roots have formed and continue to shape our institutional practices, the ways we expect families to behave, our taboos about what we can talk about and how, and the individualism that characterizes our ethical principles and processes. We need to continue to seek ways to talk across our differences and find common ground. At first blush, Hinduism and Catholicism, for example, seem to have little in common. But even a fairly superficial examination reveals that both faith traditions believe in an afterlife (either reincarnation or ascension into heaven), acknowledge suffering as an inherent part of the human condition, recognize the importance of family life, and do not insist that "everything" be done to avoid or forestall death. In VH's case, her family and her medical team were able to reach a respectful compromise. They waited for some time to make decisions, but not too long, consented to some procedures but not to others, and respected VH's autonomy along with her desire to rest it within the bosom of her extended family. Her physicians did not insist on an arbitrary period of adjustment or discharge to a rehabilitation facility. They talked civilly to one another and were able to find a compromise between hospital policy and physician expertise and family culture and religious values. The focus on VH and her well-being, as both a patient and a member of a close family, allowed decisions to be made in a timely way that allowed all to be at peace while still acknowledging the tragic situation at hand.

VH was young, and while that might have meant she had the resilience required to adjust to her new life circumstances as a quadriplegic, it also meant she potentially faced a long lifetime of changed opportunities and expectations. VH made a decision that considered all her options, one that was supported by her extended family and understood by her medical team. Her withdrawal from life support and subsequent death was managed with dignity and acceptance. May she rest in peace until….

Notes

[1] Broadside collisions are described as those in which the side of one vehicle is impacted by the front or rear of another vehicle, forming a "T". In the United States and Canada this collision type is also known as right-angle collision or T-bone

collision. Vehicle damage and occupant injury are likely to be severe, but severity varies based on the part of the vehicle that is struck, safety features present, the speeds of both vehicles, and vehicle weight and construction. In VH's case, her small compact sedan was hit on the driver's side by a much heavier vehicle travelling through a red light at high speed.

[2] The cervical (C) vertebrae are the bones comprising the upper spine or neck. There are seven cervical bones, and if any of these are fractured or severely dislocated, the neck can be described as broken. In some cases, the fractured or dislocated vertebrae can cause compression and damage to the spinal cord resulting in neurological symptoms or paralysis. A fracture of the pars interarticularis on the pedicle of C2 (axis) is often called a "hangman's" fracture. This term was coined by Scheider and colleagues based on the observation that these were the types of fractures seen in hanged criminals; falls and automobile accidents are other common causes. This type of fracture is the most common of all cervical spine fractures and is often caused by extreme hyperextension to the neck when the face forcibly strikes a hard surface. Fractures of the C3 vertebrae, although uncommon, have been linked to a higher mortality rate than other cervical fractures. The phrenic nerve can be damaged in a C3 fracture, resulting in paralysis of the diaphragm, a probable cause of higher mortality.
For more clinical information, see Schneider, R. C., K. E. Livingston, A. J. Cave, A., and G. Hamilton. 1965. "Hangman's" fracture of the cervical spine. *Journal of Neurosurgery* 22: 141–154; and Pull ter Gunne, A., A. Aquarius, and J. Roukema. 2008. Risk factors predicting mortality after blunt traumatic cervical fracture. *Injury,* 39: 1437–1441.

[3] The events of the Schiavo case are likely familiar to most readers of this volume. See Case 9 for a brief review.

[4] See, 65FR80865. (Federal Register/Vol. 65, No. 247/Friday, December 22, 2000/Notices.) The final document consists of fourteen Standards. Interested readers will find terms such as culture, cultural and linguistic competence, culturally and linguistically appropriate services, health care organizations, and patients/consumers defined in the *Preamble*.

[5] Hinduism is a broad-based and doctrinally tolerant religion with hardly any single and exclusive test of orthodoxy; therefore, one must not presume to know what the beliefs and practices of a patient might be from the mere fact of his or her self-identification as Hindu. Hindu medicine is patient-specific, and the ethical course of action is influenced by the individual patient's vocation, age, gender, teleological disposition, and cosmo-temporal placement. (See Sharma, Arvind. 2002). The Hindu tradition: Religious beliefs and healthcare decisions. Part of the "Religious Traditions and Healthcare Decisions" handbook series published by the Park Ridge Center for the Study of Health, Faith, and Ethics.
Joint family systems are prevalent and proxy decision making is eminently acceptable. In particular, women often subordinate their own concerns to that of the

family in the pursuit of their *dharma* (or place in the cosmic order). According to S. Radhakrishnan, "The interests of the individual may be subordinated to those of the family; of the family to those of the county; of the county to those of the region; of the region to those of the nation; and of the nation to those of the larger world." (See Radhakrishnan, Sarvepalli. 1993. *The Hindu view of life.* New Delhi: Indus (first published in 1927), p. 64.)
Handicapped individuals could be viewed as working out their bad *karma* through their present condition. This view could, however, easily lead one into blaming their bad *karma* for their condition. One widely acknowledged ethical stance is to shift the focus to ask "What is our *dharma* (duty), given that the other person's *karma* brought the person to his or her current state?" (See Sharma, Arvind. 1999. Karma was fouled: How Hoddle did no wrong to the disabled. *Hinduism Today*, September 1999, 13).

[6] Much has been written about the case of Dax Cowart. See for example Cowart, D., & Burt, R. (1998). Confronting death: Who chooses? Who controls? A dialogue between Dax Cowart and Robert Burt, *The Hastings Center Report, 28*, 14–24; and Hurst, Ashley R., Dea Mahanes, and Mary Faith Marshall. 2014. Dax's case redux: When comes the end of the day? *Narrative Inquiry in Bioethics* 4: 171–177. Video documentaries about Dax's case are also instructive, see for example, "A Right to Die?: The Dax Cowart Case. An Ethical Case Study on CD-Rom," by David Anderson, Robert Cavalier, and Preston Covey (available on Amazon).

[7] Most of the time, surgery is only done in cases of severe peripheral arterial disease (PAD), such as disabling intermittent claudication; open sores (ulcers that won't heal); or serious skin, bone, and tissue problems (gangrene). Bypass surgery redirects blood through a grafted blood vessel to bypass the blood vessel that is damaged. The grafted blood vessel may be a healthy natural vein or artery, or it may be man-made. The methods of bypass surgery vary depending on the size of the affected artery and where it is located.

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