



Project
MUSE[®]

Today's Research. Tomorrow's Inspiration.

Conflicting Beliefs

Vidya Bhushan Gupta
Debjani Mukherjee

Hastings Center Report, Volume 40, Number 4, July-August 2010,
pp. 14-15 (Article)

Published by The Hastings Center

The image shows a thumbnail of the 'Contents' page from the Hastings Center Report. The page is titled 'Contents' in a red font. It lists several articles with their authors and page numbers. The first article is 'Conflicting Beliefs' by Vidya Bhushan Gupta and Debjani Mukherjee, located on pages 14-15. Other articles listed include 'The Ethics of...' and 'Research at the American...'.



For additional information about this article

<http://muse.jhu.edu/journals/hcr/summary/v040/40.4.gupta.html>

Conflicting Beliefs

Vijay is a forty-eight-year-old man with profound mental retardation and cerebral palsy. He uses a wheelchair, cannot speak or eat by mouth, and requires constant care. He lived in a group home for twenty-eight years.

During the last year, Vijay has required two visits to the emergency room on average per month and has been hospitalized for two hundred days in total. These hospitalizations are the result of a number of painful and dangerous complications related to the gastrostomy tube that provides his nutrition. The last time he was in the hospital, doctors had to give him a peripherally inserted central catheter, or PICC line, to provide nutrition because the gastrostomy tube was no longer effective and Vijay was losing weight. But the PICC line has had its own problems. Shortly after insertion, it became infected, requiring

a prolonged course of antibiotics and Vijay's transfer to a nursing home for care, since the group home does not have the manpower to care for and maintain a PICC line. Vijay's stay at the nursing home lasted two months, and many attempts during this time to return to feeding him through the gastrostomy tube failed.

Vijay has just been rushed to the ER yet again because the PICC line is not flowing. The ER physician wants to change it, but his parents refuse to consent. They consider his care futile at this point and believe he will never resume enteral feeding through the gastrostomy tube. They also consider his care a burden, both to him and to themselves. They tell doctors that the constant surgeries and procedures—along with the pain and suffering they may be causing Vijay—violate his dignity. They also say that dealing with his chronic problems

has made it impossible to pay attention to their own lives and the rest of their family. And finally, his parents are Hindus. They believe that Vijay's body is now trapping his spirit, keeping it from its onward journey. They say Hinduism prohibits unwholesome efforts to prolong life like the repeated surgeries that Vijay has undergone. They tell the ER physician that they will not allow another surgical procedure to adjust or replace Vijay's PICC line, even if doing so means he will starve to death.

Faced with this decision, the ER physician proposes returning Vijay to the nursing home, but the medical director there will not accept him back without a PICC line. He tells the physician that while Vijay's parents may believe his care is futile, he does not think that Vijay meets the usual criteria for withholding life-sustaining treatment—he is not terminal or permanently unconscious, and his recent failure to thrive is not conclusively irreversible. The medical director also believes that the PICC line will probably be a temporary measure, despite a lack of success so far in restoring enteral feeding. And he admits he is afraid that letting Vijay die will make both him and the nursing home vulnerable to accusations of euthanasia and possibly a lawsuit.

How can Vijay's situation be resolved in a way that all parties concerned can accept?

commentary

by Vidya Bhushan Gupta

The primary question here is whether we may consider quality of life when deciding about extraordinary measures to prolong life for individuals with developmental disabilities. And in the absence of a clear definition of—or objective measure for—quality of life,

can the value of a life be assessed subjectively through the meaning it has for family members? And are the family's religious beliefs relevant?

Vijay's family has indicated that their family priest has advised them that withholding artificial nutrition is morally appropriate in Vijay's case. Hindus believe that a person's true self is his soul, which is eternal and transmigrates to another body when its prior one is worn out. Although the body is the vehicle for

discharging karmic obligations, only the spirit unites with God. A Hindu might argue that a body that does not allow the spirit to discharge its karmic duties through desire, ability to reason, ability to feel aversion, pain, pleasure, movement, and awareness of self and others is merely trapping the spirit in its onward journey. But another Hindu might argue against interfering with the karmic retribution the soul may be subject to in this body. If one dies without exhausting

past karma (prarabdha), he will suffer in the next life. Likewise, parents' karma may not be exhausted if their child dies early. Therefore, Hinduism prohibits suicide, particularly if done in a state of passion or depression. On the other hand, Hinduism allows an older person who has fulfilled his life's mission, is totally dependent upon others, or has a terminal illness to take his life by fasting, a practice called prayopvesa. But only a person of sound mind can decide on prayopvesa.

Who has the right to decide on Vijay's behalf? Had Vijay been a typically developing person who grew up in Hindu tradition, he probably would have made decisions similar to his parents. Do his parents then have a right

to make this decision? Because even the theological arguments are not definitive, does the family's subjective opinion have any merit? If a person is defined as one who is born in the human species in a network of social relationships, irrespective of other attributes, then Vijay's parents' argument about the futility of his life has merit because he has ceased to have social relationships. And, following this line of reasoning, since a person's predicament will affect the predicament of everyone in the social network, their perspective is relevant. However, the physicians and other health care workers are not bound by the views and values of Vijay's parents and have a right to follow their own value systems.

Last but not the least, although the issue of cost should not be brought to bear upon these kind of decisions, in these days of escalating health care costs, it seems prudent to point out that taking care of Vijay for one year, including hospitalizations, has likely cost over a million dollars. Rationing may be unacceptable, particularly in the context of disability, but the cost is still daunting.

In this case, transcultural negotiation through the institution's ethics committee to promote a compromise between the physician and Vijay's parents will be the most appropriate course of action. If an agreement is not reached, Vijay could be moved to a facility that is more likely to respect his parents' choices. Judicial intervention should be the last resort.

commentary

by Debjani Mukherjee

The fact that Vijay has profound mental retardation and probably never had the decisional capacity to be involved in his health care decisions is important. But people with disabilities and their surrogates have a right to make decisions that nondisabled people can make. The deterioration in Vijay's health has probably been gradual, and in the last year he has had multiple medical complications that resulted in twenty-four emergency room visits and two hundred days of hospitalization. Many people in his situation would choose to refuse a PICC line. Why is the health care staff so uncomfortable? The disability rights movement has sensitized us to disability stigma and to the biases of health care providers. But there is no reason to suspect that Vijay has not received excellent nursing and medical care, or that his life is less valued.

Of course, I have many questions about Vijay. Knowing his diagnoses and functional capacities tells me little about his wishes, suffering, joys, or pain. Can he communicate nonverbally or through facilitated communication? Does he understand why he is undergoing multiple medical procedures, what

they entail, or what they mean for his quality of life?

Health care providers have been sensitized to the fact that nondisabled family members may not be the best surrogates, but we are given no evidence that Vijay's parents are acting out of disability bias. He has lived in a group home for the past twenty-eight years and there might be others who could inform the decision, but at this point, his parents are his decision-makers. If they were citing only their fatigue as a reason for refusing treatment, and if Vijay's health were not deteriorating, that might be cause for alarm. His parents are concerned about Vijay's suffering and the violation of his dignity. Dignity and nondiscrimination based on disability status are fundamental concepts in human rights.

The fact that Vijay's parents are Hindu is important but primarily because it influences their decisions as surrogates. Hinduism is a heterogeneous and complex set of beliefs and practices, and the concepts of suffering, fate, and the cycle of life and death are relevant for health care decisions. It would be much simpler if we knew that Vijay held the same beliefs as his parents, or that he was capable of having a religious faith from a cognitive standpoint, but Hindus are born into the religion, into families who observe a diverse set of cultural

practices. Hindus typically have a more collectivistic worldview and as such might consider the family's burdens, not just the individual's. There is no reason to believe that if Vijay had capacity, he would disagree with his parents.

"How can Vijay's situation be resolved in a way that all parties concerned can accept?" I think that is the wrong question to ask. Not all parties have an equal stake in this decision. It's Vijay's body and since he doesn't have decision-making capacity, his surrogate should have the greatest say. It is not clear whether his parents are his legally appointed guardians. This is relevant because if they are, then in many states, the physicians could be reassured that they would not be breaking any laws. The moral distress of health care providers is another issue, but one that the institution could address if there was indeed angst about the right thing to do. It is also not clear whether Vijay has a medically qualifying condition based on the facts given. He appears to meet the requirements for palliative care in terms of goals of treatment and multiple ER visits or inpatient hospitalizations over the past six months. A transfer to palliative care, ideally with practitioners who are familiar with mental retardation, could be the best alternative.