Tube-feeding patients in PVS[1]

James E. Read

Introduction

In 1990, 26-year old Terri Schiavo suffered cardiac arrest. Circulation of life-sustaining oxygen to all parts of her body, including her brain, ceased. By the time her heart was started again, she had suffered catastrophic and medically irreversible brain damage.

According to the expert judgment of neurologists who examined her, Terri Schiavo entered into a 'persistent (or permanent) vegetative state'. 'PVS' describes 'the behaviour of people who have profound cortical brain damage. Although they display a sleep-awake pattern, they respond to stimuli only reflexly and with no evidence of cognitive function….Because the brain-stem is intact, there is spontaneous respiration and heartbeat….However, there is no known intellectual activity, no rational response, no sentience, no cognitive function. The condition has been summed-up vividly as "awake but not aware"'.[2] So writes Dr. Andrew Fergusson, a Christian physician who disagreed with the 1992 court-approved withdrawal of 'tube-feeding' from Tony Bland, a young British man injured when he was crushed in an overcrowded stand at Hillsborough football stadium in April 1989.[3]

Because of Terri Schiavo's unconsciousness, food in the mouth could well have been 'aspirated', going into the lungs rather than the digestive tract, causing infection and perhaps death. So, she was 'tube-fed'. In Terri Schiavo's case this meant performing a small operation on her abdomen and the permanent implantation of a plastic tube through which pureed food and fluid was delivered for over fourteen years.

The opinions expressed in this article are those of the author and do not necessarily reflect the views of The Salvation Army.

447 WEBB PLACE • WINNIPEG, MANITOBA • CANADA R3B 2P2 • PHONE: (204) 957-2412 • FAX: (204) 957-2418
EMAIL: ETHICS_CENTRE@CAN.SALVATIONARMY.ORG
Website: www.salvationarmyethics.org

Although there were *many* factors that contributed to their long-term survival (things such as attentive care of their skin), the public debate in both Bland's and Schiavo's cases focused on the issue of 'tube-feeding' or 'artificial nutrition and hydration'. The key question was whether it is morally permissible for 'tube-feeding' to be discontinued on anyone who is in the kind of condition Tony Bland was in by 1992 or Terri Schiavo was in by 2005.

Contrary to a number of people (some of them Christian thinkers I admire), I believe it is. What follows is an attempt to sketch some of the arguments that separate us, and an implicit invitation for others to join a conversation that will lead us into further truth. For manageability's sake, I will highlight just four alternatives and then set out my own thoughts.

Four approaches

First, there are those for whom the answer hinges on the patient's 'autonomous wishes'. According to this way of thinking, if persons in full possession of their reasoning powers declare that they would not want to be 'tube-fed' if they were ever permanently unconscious, then it would be a violation of their moral rights if others imposed tube-feeding on them. That's why many people think Terri Schiavo's case would have been much less complicated if she had left a 'living will' or 'advance directive'.

Second, there are those who think the question of what Terri wanted is morally secondary or irrelevant. For them the fundamental moral issue is that human life is 'sacred', that it is given by God and may only be ended by God. The human responsibility is to protect, preserve and prolong life.

According to the Orthodox Jewish bioethicist Benjamin Freedman, 'In spite of scanty Biblical warrant, a clear norm was established in Judaism that persons are obliged to preserve and protect their lives'. Freedman shows how traditional Jewish ethics ranks the obligation to preserve life above the principle of patient autonomy:

447 WEBB PLACE • WINNIPEG, MANITOBA • CANADA R3B 2P2 • PHONE: (204) 957-2412 • FAX: (204) 957-2418
EMAIL: ETHICS_CENTRE@CAN.SALVATIONARMY.ORG
Website: www.salvationarmyethics.org

> The central principle underlying the concept of informed consent is the value of autonomy. However, the power of this value is limited according to the view of *halakha*. In the *halakhic* understanding, there is a duty upon the physician to heal, and a duty upon the ill person to be healed, and therefore the entire value foundation underlying the principle of informed consent is almost totally nullified. … The ill person who refuses treatment in case of danger is coerced, and [his express refusal] is not accepted; all that is needed to save life is done, even against the ill person's will.[4]

Third, there are those who believe that the critical factor is the relative benefits and burdens of 'tube- feeding'. One of the standard questions in medical ethics is whether a particular treatment would be in the best interests of a particular patient. If treatment would provide no benefit, or would be harmful or burdensome to the patient, or is outweighed by greater goods with which it is interfering, that is a reason for forgoing or discontinuing the treatment, even if by so doing, the patient's death ensues. Some (more utilitarian in their thinking) have argued that we ought not only to balance the benefits and burdens to the PVS patient but also include the benefits and burdens imposed on others.

A fourth perspective argues that there is something special about 'feeding' that means that we shouldn't evaluate it on the same basis as other medical treatments. This claim is at the heart of the very influential 'papal allocution' issued by Pope John Paul II in March 2004. He said: 'The sick person in a vegetative state…has a right to basic health care (nutrition, hydration, cleanliness, warmth, etc.) and to the prevention of complications related to his confinement to bed….The obligation to provide the "normal care due to the sick in such cases"…includes, in fact, the use of nutrition and hydration'.[5]

An Integrated Alternative

My view draws on but differs from all of these.

I grant that 'autonomy' is a factor. It certainly matters what Terri Schiavo said about continuing to tube-feed her; but that alone should not be determinative. The courts

The opinions expressed in this article are those of the author and do not necessarily reflect the views of The Salvation Army.

447 WEBB PLACE • WINNIPEG, MANITOBA • CANADA R3B 2P2 • PHONE: (204) 957-2412 • FAX: (204) 957-2418
EMAIL: ETHICS_CENTRE@CAN.SALVATIONARMY.ORG
Website: www.salvationarmyethics.org

(stretching a point, I think) determined that Schiavo had voiced a conviction about these matters[6], but how many 26-year olds are likely to have done so?

I also grant that the sanctity of human life is a factor. It matters to me that we treat embodied human life as a divine gift whose value is not determined by how intelligent or how healthy or how productive it is. Human lives are not to be abandoned because we think them of insufficient quality. At the same time, I do not believe that Christian ethics obligates us to do everything possible to maintain and prolong human life. As great a gift as life is, it is permissible to set limits on the lengths to which we go to preserve it. It is permissible – indeed it is in some instances mandatory – to set other goods or other duties above the prolongation of life.
I think this is a critical point in Christian ethics. We know that Jesus did not make the prolongation of his life or the lives of others around him his highest goal.

As for the question of benefits and burdens, we ask: by 2005 was 'tube-feeding' continuing to benefit Terri? Was it doing her any good? Was it, on the contrary, 'medically futile'?

When I looked at the internet video of Terri, I admit that it appeared as if she was looking at her mother. It was eerie. I defer to the experts in neurology, however, when they say that the best evidence they have is that such phenomena are attributable to the autonomic nervous system whose control centre is the brain stem, not the brain cortex (the physical infrastructure that supports bodily consciousness in human beings). Because of the destruction of her cortex, Terri was not aware of herself or her surroundings. She could not feel the warmth of her room or feel the nurses' touch when she was being washed. She could get no satisfaction from the food put into her stomach, and she could feel no thirst if her body was not 'hydrated'. She could not be happy that people were continuing to be at her side. On the other side, she could not experience suffering either. In the days between the discontinuation of her 'tube-feeding' and her death, she felt no pain.

The opinions expressed in this article are those of the author and do not necessarily reflect the views of The Salvation Army.

447 WEBB PLACE • WINNIPEG, MANITOBA • CANADA R3B 2P2 • PHONE: (204) 957-2412 • FAX: (204) 957-2418
EMAIL: ETHICS_CENTRE@CAN.SALVATIONARMY.ORG
Website: www.salvationarmyethics.org

What fifteen years of 'tube-feeding' did was to keep Terri Schiavo alive. In that sense it was not futile. But did it benefit her? Did it do Terri any good?

What you say about this may depend on what you think about some other possibilities that could have happened to Terri Schiavo. Suppose she had developed a serious bacterial pneumonia (as could happen to people who are permanently bedridden and 'tube-fed'). Would the administration of antibiotics have been obligatory? They would likely have cured the pneumonia; and if not given, the pneumonia could have become fatal. In that sense antibiotics would not be futile. But if Terri's doctor recommended not treating the pneumonia, would the doctor be guilty of harming the patient? Or suppose that Terri developed breast cancer that had advanced by the time it was detected. If that happened to you or me, surgery or chemotherapy or radiation therapy would be the order of the day, since it would not be in our interests to let us die of a cancer for which there is a highly effective treatment. But would surgery on Terri be called for? Would it be in her best interests just as it would be in ours?

My sense of it is that Terri would not be benefited by antibiotics or cancer treatment. How then, is discontinuing 'tube-feeding' different? From the standpoint of patient benefit, I cannot see that it is.

Which brings us to an idea that may be inside that papal allocution[7]. I have been struck by the number of people who fear that a dying relative might 'starve' to death. Specialists in palliative care do (as they must) explain how appetite often abates as a person enters a dying phase or how giving food or fluids to the person dying of cancer might actually make them feel much worse. In the case of a patient who, like Terri Schiavo, is irreversibly unconscious, nurses and doctors explain that their loved one will not be able to eat or drink and will feel no effects from being tube-fed. Still families can have a hard time simply acceding to what is said.

The opinions expressed in this article are those of the author and do not necessarily reflect the views of The Salvation Army.

447 WEBB PLACE • WINNIPEG, MANITOBA • CANADA R3B 2P2 • PHONE: (204) 957-2412 • FAX: (204) 957-2418
EMAIL: ETHICS_CENTRE@CAN.SALVATIONARMY.ORG
Website: www.salvationarmyethics.org

I believe this may be because of the significance that providing food and water has in human community. It's not just about the physical benefits, but about the grace, the hospitality and human caring that is incarnated in 'table fellowship'. Christians of all people should understand this.

The point can be made equally well using an example other than feeding. Suppose someone had proposed to leave Terri Schiavo naked in her bed on the grounds that, being unconscious, she wouldn't be embarrassed by her nakedness and putting a hospital gown on her yields no benefit. I hope we'd be scandalized! Some things are things to which one has a right on the basis of human dignity. As the example shows one can be disrespected and excluded from the circle of care even if one doesn't know this is happening, and even if one lacks the capacity to know it is happening.

I think this is an ethically intriguing line of argumentation. But does it prove what the Pope thought it proved regarding people in 'PVS'? Does respect for human dignity (as well as human well-being) actually support a decision to keep tube-feeding someone who is permanently and irreversibly unconscious and has been that way for over a decade? Which of us would say, 'If I happen to suffer an accident like Terri Schiavo's and am rendered completely and irreversibly unaware of myself, my surroundings and any capacity for pain or pleasure, I would like to be tube-fed indefinitely'? I know I wouldn't say that. Not only do I find myself wondering, 'what good would it do me?' but I find myself recoiling at the prospect of being made to linger in this state year after year. I can't see how that would show my family's care or how that would constitute a medical attendant's respect.

Conclusion

Without persistent medical intervention to hold back the effects of her heart failure, Terri Schiavo would have died. 'Tube-feeding' her kept her alive, but unable to appreciate or in any subjective way derive any benefit from it. Continuing to suspend

The opinions expressed in this article are those of the author and do not necessarily reflect the views of The Salvation Army.

447 WEBB PLACE • WINNIPEG, MANITOBA • CANADA R3B 2P2 • PHONE: (204) 957-2412 • FAX: (204) 957-2418
EMAIL: ETHICS_CENTRE@CAN.SALVATIONARMY.ORG
Website: www.salvationarmyethics.org

her in this liminal condition for fourteen years distorted respect and care. It was not wrong to discontinue the feeding and let her die, I believe.

My greatest fear in saying this is that it will expose others who are disabled, poor, weak and already easily-overlooked to even greater vulnerability and social disregard. Christians need to decide not only with themselves in mind, but also bearing in mind the character of the community in which they live and die. My hope is that we don't really have to make it one or the other.[8]

End notes

[1] This is a revised version of an article that first appeared in *Horizons* (July-August, 2005), a publication of The Salvation Army, Canada & Bermuda Territory.

[2] Andrew Fergusson, 'Should tube-feeding be withdrawn in PVS?—a brief review of the issues'. This is chapter 6 of the euthanasia booklet published by the Christian Medical Fellowship and available on-line at cmf.org.uk.

[3] Airedale NHS Trust v. Bland (4 Feb 1993). [1993] 2 WLR 316

[4] Benjamin Freedman, *Duty and Healing: Foundations of a Jewish Bioethic* (London: Routledge, 1999). It should also be noted that Freedman himself argues against this view as a strictly observant Orthodox rabbi.

[5] Pope John Paul II, 'Care for patients in a "permanent" vegetative state', *Origins* 33 (April 8, 2004): 737; 739-40.

[6] In re Schiavo 90-2908GD-003 (Fla Cir Ct, Pinellas Co., 11 Feb 2000); cited in JE Perry, LR Churchill, and HS Kirshner, 'The Terri Schiavo case: legal, ethical and medical perspectives', *Annals of Internal Medicine 2005*; 143: 744-748.

[7] I say 'may be' because the issues surrounding this allocution continue to be hotly contested in Catholic circles. While the literature is vast, a selection has been compiled in Christopher Tollefsen, *Artificial Nutrition and Hydration: The New Catholic Debate* (Springer, 2007).

[8] Interested readers are encouraged to explore the Center for Bioethics and Human Dignity on-line collection of articles advancing Christian perspectives on this and many other issues at cbhd.org.

For further reading

Kilner, John F. "Reflecting on the Death and Life of Terri Schiavo" (on-line article) access at cbhd.org/resources/endoflife/Kilner_2005-03-31.htm

The opinions expressed in this article are those of the author and do not necessarily reflect the views of The Salvation Army.

447 WEBB PLACE • WINNIPEG, MANITOBA • CANADA R3B 2P2 • PHONE: (204) 957-2412 • FAX: (204) 957-2418
EMAIL: ETHICS_CENTRE@CAN.SALVATIONARMY.ORG
Website: www.salvationarmyethics.org

Lynn, Joanne (ed.) By no extraordinary means: the choice to forgo life-sustaining food and water. Bloomington: Indiana University Press, 1986.
Meilaender, Gilbert. "On removing food and water"against the stream," Hastings Center Report, v.14, 14 December 1984.
Tollefsen, Christopher. Artificial Nutrition and Hydration: the New Catholic Debate (forthcoming) Springer, 2007.
Wheeler, Sondra Ely. Stewards of Life: Bioethics and Pastoral Care. Nashville: Abingdon Press, 1996.

Published by the Kirby Laing Institute for Christian Ethics, Cambridge
(http://www.tyndale.cam.ac.uk/KLICE/) in
Ethics in Context, Summer 2007

Dr. James E. Read (Ph.D., UCLA) is Executive Director of The Salvation Army Ethics Centre, Winnipeg, Canada, and Associate Professor of Philosophy and Ethics, William and Catherine Booth College.

The opinions expressed in this article are those of the author and do not necessarily reflect the views of The Salvation Army.

447 WEBB PLACE • WINNIPEG, MANITOBA • CANADA R3B 2P2 • PHONE: (204) 957-2412 • FAX: (204) 957-2418
EMAIL: ETHICS_CENTRE@CAN.SALVATIONARMY.ORG
Website: www.salvationarmyethics.org