

Commentary

Ethics roundtable debate: Withdrawal of tube feeding in a patient with persistent vegetative state where the patient's wishes are unclear and there is family dissension

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Abstract

The decision to withdraw or withhold life supporting treatment in moribund patients is difficult under any circumstances. When the patient becomes incompetent to clarify their wishes regarding continued maintenance in long-term facilities, surrogates sometimes cannot agree, further clouding the issue. We examine a case where the State's interests come into play, forcing a controversial resolution.

Keywords autonomy, ethics, surrogate, withdrawing (life support), withholding (life support)

Introduction

In critical care medicine we use a high-technology care plan to reverse organ system failure. Sometimes, however, organs can only be brought back to nominal function, creating dependence on others to supply sustenance. If these patients had never expressed a clear preference to be allowed to die in such circumstances, then their surrogate's preferences may conflict. We examine the aftermath of a case of a patient in a persistent vegetative state (PVS) whose surrogate conflicts lead to legal complications.

The case

Following an anoxic insult, a 30-year-old female patient resides in a nursing home for 2 years without any evidence of meaningful neurologic recovery. There is some controversy regarding the extent of her brain damage; some doctors have diagnosed her as being in a PVS whereas others disagree. It is agreed that she suffers severe neurologic deficit. At baseline she opens her eyes and appears to track family

members; she smiles but she does not follow commands. She is hemodynamically stable and is sustained by a feeding tube. There is no living will. Both the husband and family state that the patient has never volunteered an opinion regarding end-of-life issues in the past, apart from one occasion when she casually mentioned that she would not ever want to 'live like a vegetable'.

Her husband petitions you to remove the feeding tube and 'let my wife die with dignity'. However, her family says that the patient responds to them and they do not feel she is in any discomfort. The family opposes removal of the feeding tube. The patient's mother appeals to the State to intervene and stop any attempt at removal of life support on humanitarian grounds. The current law of the State she resides in is that there must be 'clear and convincing' evidence of a patient's wishes before life-sustaining treatment (LST) can be removed from that patient.

Would you remove the feeding tube?

Being law abiding and ethical

Malcolm Fisher

This is both a legal and an ethical issue. It is required that doctors obey the law. The law of the State in which this patient's resides is that there must be clear and convincing evidence of the patient's wishes before life support can be removed from that patient. I suspect that in these circumstances the feeding tube may be defined as life support. If we can almost consider patients' wishes in terms of levels of evidence, then we would class the evidence for removal of the feeding tube being in keeping with the woman's wishes as the lowest level of evidence, as opposed to the best evidence, namely an appropriate written directive by a well patient. As with all expressed wishes by whatever means, it is often difficult to determine their relevance to the prevailing situation. Did the patient's casually expressed wish – stated when she was not suffering – disclose her views regarding artificial feeding?

It appears to me from the information given that the feeding tube may not be removed because this would be illegal. If the family agreed, however, then it may be the case that in practice the tube may still be removed on an ethical basis, and the expressed wish be respected.

In my state in Australia, legally the tube could be removed if 'death is imminent'. Death is not imminent in this case, but if there was family consensus that continued tube feeding was against the patient's wishes then the tube could be removed. If there were clearly expressed wishes that the patient would not wish to continue the feeds they would be discontinued. It

is unlikely that the law would have an interest in the absence of conflict.

Our society empowers us to work with families to determine to the best of our ability what the patient's wishes would be, and to act on these wishes to withdraw treatment that the patient would not want. In most circumstances, conflicts between families regarding appropriate treatment are resolved over time. To act supporting the views of one side of a family conflict may be a recipe for disaster.

I have a further problem with removing the tube. An important part of our processes are that the first step is medical consensus. We do not have medical consensus as to the outcome in this case. We are not told whether any of the conflicting doctors' opinions are related to a belief that some unproven or unaccepted therapy (e.g. herbal remedies, coma arousal therapy, or hyperbaric therapy) may be of benefit. In the absence of united medical opinion it is extremely unlikely that the family conflicts will be resolved easily, or that an ethics committee or judge would support withdrawal. Therefore, I would act conservatively and continue to feed, as long as the patient is not suffering, and seek medical consensus before resuming negotiation with the family. If the patient were suffering then it would usually be easier to resolve the family's conflict.

Until and unless there is a clear-cut medical consensus as to outcome, I would continue to feed.

Hong Kong perspective

Tom Buckley

The Professional Code and Conduct of the Medical Council of Hong Kong describes care of the terminally ill [1]. It delineates the ethical principles and communication pathways in making decisions on withholding or withdrawing LST, emphasizes the importance of a proper consensus-building process, and recommends approaches to handle disagreement. The Medical Council Code defines euthanasia as 'direct intentional killing of a person as part of the medical care being offered'. This practice is viewed as being unethical and illegal. The Hospital Authority, which administers all public hospitals in Hong Kong, also supports this view.

The Hospital Authority has produced detailed guidelines on LST in the terminally ill [2]. It has defined LST as all treatments that have the potential to postpone the patient's death, and agrees that it is ethical and legally acceptable to withhold or withdraw LST when a mentally competent and properly informed patient refuses LST and/or the treatment is futile.

In Hong Kong the legal system has minimal impact on medical ethical decision making. There is no legislation regarding patient autonomy or the status of advance directives [3].

Artificial nutrition and hydration are classified as medical treatments and are regarded as being different from the offer of oral food and fluid, which are regarded as basic care. Because of this distinction, the Hospital Authority considers that (other than when death is imminent and inevitable or when it is the clearly expressed wish of a mentally competent patient) withholding or withdrawing artificial nutrition and hydration should be subject to additional safeguards, including in some cases legal review.

When death is not imminent and inevitable, withholding or withdrawal of artificial nutrition and hydration in mentally incompetent patients without valid advance directives requires additional procedural safeguards. Even if requested or supported by the family and there is consensus with the

care team, the proposal requires a formal clinical review by a senior clinician who is not part of the treating team. All such cases also require review by the Hospital Chief Executive, the Hospital Authority Head Office and, in patients in a PVS or a state closely resembling it, a formal declaration from the Court of First Instance.

In the scenario provided there has not been a clear didactic statement regarding the forgoing of LST by the patient. This is the norm in Hong Kong. Moreover, there is a lack of consensus among medical professionals on the degree of neurologic disability, although it is agreed that there is severe neurologic deficit. The polarized views of the husband and parents of the

patient should be resolved by further communication to clarify incorrect or unrealistic information. This may include moderation by a hospital ethics committee in an attempt to reach a consensus. After 2 years of institutionalization, both parties are entrenched in their positions. Under such circumstances application to the Guardianship Board of Hong Kong to appoint a guardian would be undertaken [4].

Assuming the dispute is unresolvable, application to the Court of First Instance would be possible. However, while not attempting to prejudge the Court, it would probably act to preserve life because the patient had not expressed a clear and convincing viewpoint, the family dispute remained unresolved, and medical opinion was divided.

Life support preferences: if you don't talk early you'll lose your voice

David Crippen

Withdrawing life support from patients with unrelenting pain and suffering or who are in a terminal death spiral should be considered humane and beneficent. Withdrawing such treatment from those whose indolence and seeming apathy we do not understand is another problem entirely. The reality is that we have many words to describe how patients in a PVS look, but we do not have any to describe how they feel. Accordingly, as long as the patient does not appear to be in pain or suffering, societal values mandate that we err on the side of giving preservation of life the benefit of the doubt, unless the patient does not want it.

An autonomous citizen may legally and ethically elect to forgo life-sustaining measures by prospective declaration if 'quality of life' (QoL) does not rise to meet their expectation [5]. However, they must make that declaration before they become incompetent. If they become incompetent with no record of their wishes then decision making falls to relatives, and that complicates matters greatly because surrogates do not carry the same weight of authority. When authority becomes diffused, the State develops an interest in the proceedings. The State is charged with protecting its citizens, and there is a thin line between 'quality of life' as measured by an individual and 'quantity of life' as interpreted by the State. The State can and frequently does step in to supersede the wishes of individuals when gray areas occur.

There is no convincing evidence that this patient left any durable record of her wishes not to be maintained in her current condition. The family cannot come to a consensus. There is convincing evidence that this patient responds to her environment and is not in a death spiral or unrelenting suffering. This woman's situation is definitely a gray area that the State has an obligation to consider. The State usually feels an obligation to err on the side of preserving life when the rigorous criteria for withdrawal of life support are not met or there is no durable record of the patient's preferences [6]. Because the evidence of the patient's prospective wishes is arguable, the State has an obligation to argue it and should err on the side of preservation, all other factors being equal.

This unfortunate patient is a poster for prospective durable powers of attorney attesting to their wishes should they unexpectedly become moribund and incompetent. The price paid for this policy is some indolent shells of humanity that may be maintained in a hopeless condition, but it also avoids the pitfalls of individuals assassinating innocents capriciously. It is the lesser of two evils. We have enough problems deciding when to withdraw life support when the indications are much clearer. We are not ready to start burying people that smile at you yet in this country. We should never be ready for that.

Rediscovering dignity

Antonios Liolios

Withdrawal of LST has become a very complex issue because all of the interventions in medicine aim to prolong life, whereas withdrawal ends it. A complicating issue is the young age of the patient.

There is no agreement that she is in PVS, which for the sake of simplicity may be defined as unconsciousness with eyes open. She minimally interacts with her environment but does not follow commands. It is not unreasonable to state that this

patient may be in a minimally conscious state (MCS) – a recently proposed entity. MCS differs from PVS in that it is a condition of severely altered consciousness with minimal but definite behavioral evidence of self or environmental awareness. Although the two groups have not been extensively studied, in an outcome study conducted by Giacino and Kalmar [7], patients in MCS fared better than those in PVS. The differences become progressively more apparent in traumatic brain injury patients and many months after injury.

Furthermore, the patient never expressed any explicit wishes regarding withdrawing LST in situations such as this. A young, healthy woman does not consider end-of-life issues in detail, thus the casual mention attributed to her that she would not like to 'live like a vegetable'. It is unclear exactly what she may have meant by that. Death with 'dignity' is quoted as the reason for the request for removal of the feeding tube but it is hard for me to justify the removal of her feeding tube on the grounds of dignity alone. If anything, she appears to be living in dignity as she is. Withdrawal of LST appears to be more synonymous with euthanasia.

My upbringing colors my practice of medicine. I was born and raised in Greece and I am a Christian Greek Orthodox. This background makes it particularly difficult for me to end a life in most circumstances. Even when a patient is brain dead, extra caution is required. I feel that withdrawal of LST

should be reserved for terminally ill patients or those whose pain and suffering cannot be palliated. If a court ordered me to remove a feeding tube in a patient that I do not feel is in distress, I might refuse on the grounds of personal moral values.

A number of gray areas in this case push me toward preservation of life. Apart from the uncertainty of the patient's wishes, she does not appear to be in pain or distress. She has been repeatedly seen smiling and seemingly interacting with her family. She has not suffered a somatic complication associated with brain injury. There are no decubiti, and no aspiration pneumonitis or severe infections. Her airway is clear and she does not require a tracheostomy. There are people willing and able to provide the necessary supportive care. Accordingly, I would have not removed the feeding tube from this patient.

In the name of the patient

Christine L Scheetz

It is the patient's right to specify her wishes regarding end-of-life care and to have these wishes respected by her health care providers. Given the patient's PVS, her husband, as her legal surrogate, assumes this right and responsibility on her behalf. It may be acknowledged that the patient could emerge from this state at any time; however, the decision to remove the feeding tube must be made on the basis of what realistically can be expected to occur, not the hope of an uncertain or improbable event.

Despite 'appearances' that the patient is responsive, and despite differing opinions regarding the extent of the patient's brain damage, there is agreement that she suffers severe neurologic deficit and has shown no evidence of meaningful recovery of brain function for 2 years. Therefore, there is no reason to believe, with any probability, that this patient will return to a level of cognitive functioning or minimal QoL that she expressed she would want if she were to continue living. The family states that the patient is 'not in any discomfort', and regardless of whether this is true the patient did not state this as a criterion for wanting to continue life in a vegetative state. The only comment anyone can remember the patient making about living in a vegetative state supports her husband's decision to remove the feeding tube, thus allowing the patient to die. Still, the husband likely is not making a decision based solely on this one comment but

rather on a more comprehensive understanding of the patient's values, beliefs, and preferences. As the patient's spouse, he has the legal and ethical responsibility to respect the patient's wishes, and to act as he believes she wants and would have indicated had she stated her preferences before the anoxic injury. There is no evidence that the husband is acting against the patient's previously acknowledged and stated opinion regarding not wanting to live in a vegetative state.

Furthermore, he is following the ethical obligation of the surrogate decision maker in two ways. First, he is following the wishes stated by his wife. Second, because an absolute directive does not exist, he is applying his substituted judgment to make the decision.

The patient had not specified someone other than her husband to make medical decisions on her behalf, and therefore it probably was the patient's understanding that her husband, as legally recognized next of kin, would be making proxy medical decisions for her in the event she was unable to make these decisions for herself. It is the patient's right to have this legally recognized surrogate act on her behalf.

I would recommend that the husband's request to remove the feeding tube be honored.

Standards and evidence are important in choice

Leslie M Whetstone

In the USA competent citizens have the right to choose their own course of treatment, and they do not lose that right once incapacitated [8]. However, in order to retain the right of self-determination, individuals are responsible for making their wishes known prospectively by an advanced directive or a

durable power of attorney. Even with these mechanisms in place, however, some amount of interpretation will probably be necessary. Therefore, communication in conjunction with documentation is key if scenarios such as the one presented are to be avoided.

The fundamental problem in this case is the lack of objective evidence indicating the patient's wishes, compounded by family disagreement. This conflict forces several issues: what level of evidence is required to justify removal of LST, which standard of surrogacy should be applied, and how ought QoL and the preservation of life be balanced?

The standards for surrogacy are different than for autonomous individuals. For a surrogate to authorize removal of LST from a patient in a nonterminal condition, there must be compelling evidence indicative of the patient's wishes. Individual states may also require clear and convincing evidence before LST is removed [9]. Furthermore, there are three standards of surrogacy that may be used when a patient becomes incapacitated: substituted judgment, limited objective standard, and the best interests standard. Because there is no compelling evidence of the patient's wishes, a genuine substituted judgment cannot be made. A limited objective standard of surrogacy cannot be used either because there is dissension among the family, making it difficult to extrapolate what the patient would want.

In this case, it seems appropriate to apply a best interests standard, in which the burdens and benefits of LST are

weighed. This method considers QoL judgments using a 'reasonable person' standard – what a reasonable person would desire in the particular circumstances. It would be disingenuous to suggest that QoL does not factor into LST termination issues. However, it must be clear that QoL judgments should be applied by autonomous individuals who understand all of the factors involved. Society may not impose objective QoL assessments to facilitate removal of LST from individuals perceived as unworthy or useless without risking the welfare of entire populations of disabled or otherwise disenfranchized citizens. The State has an interest in protecting vulnerable parties, and thus its role is often viewed as a parental one, usually favoring the preservation of life unless the continuance of life is viewed as cruel or inhumane.

In a State that requires clear and convincing evidence, unless the family can demonstrate that the patient would refuse such LST or that its maintenance is inhumane, the State has the right to intervene on her behalf to ensure that QoL decisions are not made capriciously. It would seem from her demonstrated interaction with her environment that continued treatment is not inhumane, nor does it foster a life that is overly burdensome. Therefore, LST, in the absence of evidence to the contrary, should be continued.

Wrap up: some concluding thoughts

Anthony L DeWitt

In a perfect world citizens would assume the duty to make provisions for the end of their natural lives by making wills for the disposition of their property, and by making declarations regarding their desires for end-of-life care. The world is a far from perfect place, and a stunning number of people never plan for the end of their lives at any level. Failure to plan for termination of life support, except among the infirm and elderly, is almost universal.

The need for end-of-life planning is most acute among the young, for whom trauma and incapacitation are a frequent consequence of poor lifestyle choices. Because young people often feel immortal, frequently parents and spouses are left to make decisions regarding what should be done, usually at the time of greatest grief and guilt. Human emotions frequently cloud reason, making the health care provider's job that much more difficult because the import of this failure to plan is that health care providers are given a Hobson's choice: get agreement from the family or, barring that, seek approval from the courts for end-of-life decisions.

Common law courts are poor substitutes for family in end-of-life decision making because they do not apply the standards of the family, and instead apply legal standards that are easily manipulated (e.g. see [10]). Although it would unduly tax this article to summarize the standards in all states, some states require clear and convincing evidence of intent whereas others apply more liberal standards to permit termination of

life support. Some states place extraordinary weight on the patient's religious beliefs (e.g. see [11]) whereas other merely consider this a factor. In nearly all states a prior written declaration of intention, as expressed in a written document, are deemed controlling with respect to the intention of the incompetent person [12]. Sadly, these documents may be collaterally attacked by parol evidence demonstrating that the incompetent had a change of mind at some later point. Moreover, although the parent normally has the right to speak for the child, a parent may lose that right in cases of abuse or neglect [13].

A health care provider is frequently on the horns of a dilemma; does the provider rely on the parents' quiet acquiescence to termination of life support (e.g. see [14]) or does the provider wisely seek a court appointed guardian to speak for the incompetent? A health care provider or institution is as likely to be sued for failure to terminate life support as for failure to maintain it (e.g. see [15]). As a result, where there is any disunity among the family or any question as to the proper course of action, the wisest course is to require court involvement so as to protect the physician and providers from claims of improper termination of life support.

A legislative fix is desirable. Ideally, a requirement for graduation from any high school should include a completed health care declaration regarding end-of-life treatment. A mandatory part of every driver's license renewal should be a

demonstration that the driver has a valid end-of-life declaration on file with the Recorder of Deeds. Until such time as these

documents are mandated, courts and providers will continue to incur needless costs and endless delays in rendering LSTs.

Competing interests

ALD is a practising medical negligence attorney who stands to gain from cases involving negligence.

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