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Care versus Treatment at the End of Life for Profoundly Disabled Persons

Jeffrey P. Spike

ABSTRACT

Individuals who are profoundly mentally handicapped do not have the capacity to make their own decisions and also do not have a past record of decisions, from when they had capacity, to guide us in making decisions for them. They represent a difficult group, ethically, for surrogate decision making. Here I propose some guidelines, distinguishing between these patients and patients in a persistent vegetative state (PVS). As the life span of patients becomes shorter, or their level of consciousness becomes permanently impaired, the presumption for comfort care should become an imperative, and the standard of evidence to justify any invasive intervention should become higher. For members of this population, who have no more ability to refuse treatment than to consent to it, protection of the vulnerable must mean allowing a peaceful death as well as a comfortable life. Reasonable legal safeguards are also proposed to allow improved end-of-life decisions to be made for this population.

Cases involving patients who never had capacity are among the most difficult any clinician or ethicist will encounter. This case by Arvind Venkat, MD, provides a perfect illustration.¹ It is filled with important clinical details

and solid ethical and legal analysis. Yet for all of the information provided, it lacks some very important information, clinically and ethically.

Paramount are the cognitive level and level of consciousness of Mr. M after his acute anoxic and hypoxic events. From the case description, this 45-year-old man had profound intellectual disability before these events. If he had an IQ of 25 prior to an unknown period of asystole, followed by an extended period of hypoxia, did he ever regain consciousness? Under normal circumstances, any person who is deprived of oxygen for more than five minutes will suffer permanent brain damage. By the time Mr. M got his vital signs back, he may have been much more profoundly brain damaged than prior to the event. He may well have been left in a vegetative state (and after a month may have been diagnosed as being in a PVS). This diagnosis is an ethically relevant factor in decision making.

The other primary concern for Venkat, on my reading, is when (or whether) palliative care is the best available option. There may be an unspoken bias against palliative care among some caregivers, but palliative care should not be considered a last resort. It should be on every list of reasonable options when life-sustaining medical treatment is under consideration.

The development of palliative care services is one of the most important medical advances of the past decade, and it is unfortunate that it

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is still resisted in some hospitals as “giving up.” In contrast, I would advocate that every patient who dies without palliative care represents a failure of optimal care. We should all, once we accept our mortality, hope to have palliative care for most or all of the final year of our life (including home hospice when possible). To put off that decision too long is only to deny ourselves a better quality of life than was possible. With these two preliminary observations, there are further ethical considerations.

SURROGATES AND GUARDIANS

Substituted judgment cannot be used. For a patient who once had capacity, those who know the patient best can be asked what they think the patient would want. This presumes these intimates knew the patient’s most strongly held values—core beliefs used to make important medical (or nonmedical) decisions. For example, if a patient clearly went to great lengths to avoid surgery, or even invasive tests, a responsible surrogate will make different decisions, based on substituted judgment from these values, than from those of a patient who had many surgeries in the past. But when a patient has never been capable of making choices, such guideposts are not available. The usual advice is to use the “best interest” standard when substituted judgment is impossible. The problem in Mr. M’s case is that different people might think different things are in his best interest.

The healthcare system tends to overestimate the prognosis of many patients, as here. This should not be considered “harmless,” for it can (and often does) lead to the infliction of unnecessary harm when the mission is simplistically thought to be “cure at any price” or “any chance is better than none.” Decisions for profoundly mentally handicapped (hereafter MRDD²) patients might often be best handled by geriatricians or specialists in patients with developmental disabilities, and not physicians who primarily care for non-MRDD patients. Whatever clinician it is, he or she should always consult with a palliative care team. If we can get this profoundly MRDD population to die in the care of a hospice or palliative care team, they would avoid the over treatment that unfortunately has

become almost the “last rites” in our culture. If a patient with capacity chooses to try every possible option, perhaps out of denial, that is his or her right. But we do not have the right to subject a patient without capacity to end-of-life care that is contraindicated.

Mr. M, who was severely debilitated, may have come to the end of his natural life, physiologically, and that may be why he required more hospitalizations in the final year. In that case, his sister may well have had a more accurate medical understanding of his condition than the facility administrator. Although it isn’t clear, the facility director may not be its medical director, and his or her medical knowledge may be limited. Furthermore, in my years as an ethics consultant, I have observed many cases when a physician or surgeon was in greater denial about the impending death of a patient than the family. This might have been such a case.

That no guardian was named is unfortunately very common, and little can be safely inferred from it. For many parents it costs too much money to go to court. In many other cases, a failure to appoint a guardian may be psychologically driven: assigning a guardian involves an acceptance of one’s own inevitable death, something many prefer to not face. Hence many defer important decisions like wills, as well as living wills, as well as assignment of guardianship for institutionalized family members.

The lack of an appointed guardian leads to the subtle and controversial question about the burden of proof. Who should be the *presumed* decision maker, and who should be left the secondary responsibility of reviewing the resulting decisions for being reasonable and acceptable? In this case, I would definitely infer that Mr. M’s sister was the right primary surrogate, and review by the medical director of the facility (not the administrator) and the ethics committee of the hospital would be good safeguards to include in either institutional policy or state regulation for the developmentally disabled. His sister should be able to choose from among *all* of the reasonable medical options; in other words, she should be able to choose as long as the option she chooses is reasonable (and we should not raise the bar from reasonable to medically optimal, which risks substituting our

medical judgment for hers). The policy should be clear that the review process is not an open invitation to second-guess a surrogate's decisions or ascribe bad motives; only egregious and indefensible choices should be questioned.

QUALITY OF LIFE CONSIDERATIONS

Before this hospitalization, it is reported that Mr. M was capable of experiencing pain, and one would hope he was also capable of experiencing pleasure, or happiness. But if the anoxic event left him permanently unconscious, then he could not experience pain or happiness. If a person cannot experience any pleasure, then there is no benefit to experience from continued life. Hence, an ethical resolution of this case must include a request for a better description of what Mr. M was capable of before, especially what seemed to give him pleasure. Was he ambulatory before the respiratory event? Did he sit in a TV room and watch TV, even if he didn't really understand it? Did he enjoy music, or find it soothing? Did he respond to familiar people with a smile? Did he enjoy a hug ever?

If the answer to any of these questions is yes, then what was Mr. M's state like in comparison afterwards? Would he be able to enjoy any of these things ever again? Would he ever again smile at familiar faces or voices? If the answer is no to these questions, then Mr. M's quality of life had been seriously affected, and to deny the importance of that fact is to ignore the value he gained from his own life; which is to say, this denies that Mr. M's life had value to him and uses Mr. M in only an instrumental way, treating him as a means to our medical ends, rather than as a person with inherent (internal, self-contained) value.

If, on the other hand, Mr. M was never able to enjoy anything in his life, but only to experience pain, then the primary principle to consider in this case is nonmaleficence. In my reading of that principle, avoiding over treatment is vital, and performing invasive medical and surgical interventions with low probability of success is to be avoided in favor of comfort measures. The pearl, "Don't just do something, stand there," comes to mind. (In other words, it can be hard to resist the temptation to do some-

thing—*anything*—so you feel like you tried, but "just" doing something for the sake of doing something can make things worse.)

INVASIVE MEDICAL AND SURGICAL INTERVENTIONS AS HARMS

For patients who end up in a PVS from any cause, the involvement of palliative care should be the norm. Palliative care will be best at ascertaining if the patient can experience pain, and if so, how to treat it. And, in case there might be some residual level of consciousness, the team's experience with managing symptoms of dehydration can be vitally important. But turning over care to a new team with different goals of treatment can be hard, especially for those who have been involved in providing treatment to the patient before a PVS. But this is a problem that members of the treatment team must overcome, and it does not give them the right to impose treatment on a patient.

Surgery will usually be unjustifiable; even so-called palliative surgery would rarely (if ever) be indicated. However, relieving a pneumothorax or free air with a chest tube would be acceptable if Mr. M could still experience pain; for example, if he might be in a minimally conscious state (MCS) rather than a PVS. It is still hard to diagnose MCS, and a patient might have intermittent low levels of consciousness sufficient to justify providing analgesics.

The outcome of this case is not surprising. Nor is it a terrible outcome, given the situation. It is more comfortable and less painful to die from hypotension with no surgery than from complications after surgery. This may sound harsh, but it is not meant to be. Once death is accepted as an outcome, ethicists ought to try to intervene to prevent the medical system from harming the profoundly mentally handicapped, even when it is motivated by good intentions.

For patients who are conscious with profound MRDD, their disability means they cannot understand why we do anything to them that is unpleasant, painful, or frightening. They literally cannot tell us from a kidnapper who tortures them. For these patients, a life of 45 mostly painless (and occasionally pleasant or happy) years is to be preferred to a life of 45

mostly painless years followed by a very frightening and uncomfortable year (for example, on a ventilator requiring frequent suctioning).

In terms of health law, this is the *Saikewicz* exception to life-sustaining interventions.³ *Saikewicz* is a legal case in which the court was asked to decide what to do for a man in his later years who had never been competent. Its decision was that the added pain that Mr. Saikewicz would have from not understanding what was being done to him should be taken into account. This is based on the inference that pain is a psychological state as much as a physiological state, and hence one would experience more pain due to not understanding its cause or appreciating any future benefit than one might achieve later as a consequence of enduring the pain.

Nonmaleficence directs that we not cause fear or suffering—not just pain. If patients cannot understand the reason we do something to them, then perhaps we should refrain from doing it, even though it is medically indicated and we would do it for patients who could understand the reason. This adjustment of justifiable intervention according to patients' level of understanding is ethically justified, especially when the benefits of treatment are limited. A month of discomfort could be justified by a high likelihood of gaining many years of improved life, but a month of pain and fear cannot be justified by only that month of further life.

Norman Cantor has written extensively on the legal issues involved with treatment of never-competent persons.⁴ His suggestion is that we use the criterion of "preserving human dignity" as a guide. Similarly, I use the language of "The Belmont Report" (since it is so familiar) and call it "respect for persons."⁵ When patients have capacity, this is the same as autonomy; but when patients lack capacity, the principle of respect for persons requires treating patients with respect, being gentle when you touch them, showing concern and compassion, keeping them comfortable, giving them as much privacy as possible, using minimum restraints, allowing them activities that bring them pleasure or happiness (such as feeding them favorite foods if they are able to swallow), and so on.

Another important difference to which we must attend is the difference between mental

and physical disability. Because they share the term "disability" (and used to share the term "retardation"), and because ethics tells us to avoid discrimination against people with a disability (and to try to ameliorate the effects) it is easy to think medical ethics has similar responsibilities to both groups. But that is wrong, and may lead us to cause unnecessary suffering.

The patient's best interest is the goal. For the physically disabled, we must be careful not to under treat; for the mentally disabled, we must be careful not to over treat.

DISABILITY AND CONSCIOUSNESS

This raises a final question: Is a PVS a disability, or is it something worse, such as the loss of being a person, or the loss of having a *life in a biographical sense*? A complete analysis must distinguish between them, and explain that we owe much more to the profoundly MRDD patients who have consciousness but never had capacity than to PVS patients. But the "much more" is more emotional and social support to improve their quality of life, and preventive care such as turning them in bed to prevent bedsores, not more invasive medical interventions.

Although the outcome is not stated, it is likely from the events described in this case that Mr. M changed from being disabled to being comatose or vegetative, and thus, what was the best course to follow changed. If this is accurate, then much of the discontent of Mr. M's caregivers might be understood as a failure to understand or accept the importance of Mr. M's new condition to his new treatment plan.

ETHICS CONSULTATION AND THE LAW

Lastly, it is clear that this case caused much discussion and more than a little discord, and left a strong enough feeling of dissatisfaction that the hospital plans to take the next case to court to establish a better precedent. However, this could be a mistake, as invoking a state agency is not a neutral or harmless decision.

The relationship between a good ethics consultation service and the law is complex and interesting, and not much discussed. Sometimes ethics uses the law to accomplish its goals, by

either providing expertise or by recommending the involvement of a state agency, but more often its primary value is to *avoid* recourse to the law. Deciding which course to take is an important part of the role of ethics consultation. As I wrote in an earlier article:

Occasionally . . . the circumstances of a case raise questions about the wisdom or necessity of invoking the law. The presence of a law that protects vulnerable persons should not compel a bureaucratic impulse to implicate the law in every case that involves a protected person. Rather, health care providers must judge when the law applies. Although laws authorize “necessary” medical treatment of minors and mentally disabled persons, it is the caregivers who must first decide whether a treatment is “necessary.” Ethics consultation can help clinicians in this process by clarifying the ethical relevance of clinical information.

. . . the process of ethics consultation focused the facility director’s attention on balancing the benefits and burdens . . . of treatment and the clinical view . . . that the burdens outweighed the benefits. Legal risks to the institution are not part of the patient’s benefits and burdens ratio.

However, once a case is brought to a state agency for a decision, the tendency is for an available treatment to be deemed necessary, especially if it extends the life of a patient. Yet other factors besides length of life should be considered. It must be remembered that “erring on the side of life” is sometimes an error. Hence, going to court is not a neutral act to choose; it is not something that can sometimes help and never hurt. Sometimes, [going to court] is uncalled for, sometimes it is a factual mistake, and sometimes it is a moral mistake.⁶

Some scenarios are so common that all clinicians are, or should be, prepared to deal with them. A good example of such an ethical issue is helping a patient make decisions about likely future problems by executing an advance directive and selecting a surrogate decision maker. In any busy practice, this would come up daily, or at least weekly. But there are some scenarios

that are so rare they are, in effect, one of a kind, *sui generis*. One cannot be prepared for something one has never seen before. These situations are so rare or so dependent on exigencies that it would be an unjustifiable use of time to prepare all trainees to deal with them (and perhaps impossible if each case is *sui generis*).

This case is somewhere in between, neither common but also not so rare that we should be unprepared when it happens. At the very least, any clinical ethicist should be familiar with these issues and prepared to deal with them. Certainly an ethicist for a hospital with a contract that results in 300 admissions a year from a long-term care facility for MRDD patients ought to be fully prepared. If some of the problems hinted at in this case were due to a lack of preparation, then part of the solution is for the hospital to hire or train an ethicist who is better prepared to handle such cases. If the current ethicists are all volunteers with little or no training, then the hospital ought to correct that deficiency by hiring a well-trained ethicist. Having a contract with a long-term care facility for the MRDD patients ethically requires this, in order to improve end-of-life care for their residents and to avoid unnecessary resort to the courts.

NOTES

1. A. Venkat, “Surrogate Medical Decision Making on Behalf of the Never-Competent, Profoundly Intellectually Disabled Patient,” in this issue of *JCE*.

2. MRDD is an acronym for mental retardation and developmental disabilities.

3. *Superintendent of Belchertown v. Saikewicz* 1977, 373 Mass 728, 370 NE 2d 417.

4. N.L. Cantor, “The bane of surrogate decision-making: Defining the best interests of never competent persons,” *Journal of Legal Medicine* 26, no. 2 (June 2005): 155-205; N.L. Cantor, *Making Medical Decisions for the Profoundly Mentally Disabled* (Cambridge, Mass.: MIT Press, 2005).

5. “The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research,” 18 April 1979, <http://ohsr.od.nih.gov/guidelines/belmont.html>, accessed 27 January 2012.

6. J. Spike and J. Greenlaw, “Case Consultation: When to Invoke State Agencies to Treat: The Cases of a Minor and a Mentally Disabled Adult,” *Journal of Law, Medicine & Ethics* 24, no. 1 (March 1996): 65-9, 69.