

Commentary

Ethics roundtable debate: Child with severe brain damage and an underlying brain tumour

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Abstract

A young person presents with a highly malignant brain tumour with hemiparesis and limited prognosis after resection. She then suffers an iatrogenic cardiac and respiratory arrest that results in profound anoxic encephalopathy. A difference in opinion between the treatment team and the parent is based on a question of futile therapy. Opinions from five intensivists from around the world explore the differences in ethical and legal issues. A Physician-ethicist comments on the various approaches.

Keywords critical care, ethics, medical futility, negotiating, palliative care

Introduction

Jean-Louis Vincent

Intensive care unit (ICU) staff are confronted on an almost daily basis by difficult and emotive ethical issues, but perhaps none more so than when a child is involved. In such situations, although the primary duty of care rests with the child, patient advocates (i.e. the parents or guardian) are more naturally and closely involved than is perhaps the case with adult patients [1]. In all ethical situations, decision making is very subjective and dependent, among other factors, on individual experience and beliefs, and cultural and religious background [2,3].

Although there is now a considerable literature on end-of-life decision making in the adult ICU population, much less has been written about paediatric patients, although many deaths

in paediatric ICUs are now preceded by a decision to forgo or limit life-sustaining therapy [4].

Here we present a case of a child with a short life expectancy who then experiences an iatrogenic episode that leads to irreversible anoxic encephalopathy. The case scenario provokes many questions, in particular related to differences in opinion between staff and parents regarding the value of continuing active care. To explore international differences in the ethical and legal issues involved, intensivists from Russia, Germany, USA, Singapore and Japan were asked how they would approach such a case.

The case

An 11-year-old girl was admitted to the ICU following a partial resection of a highly malignant brain tumour. Prognosis was estimated at less than 1 year. In the days following surgery the patient remained somnolent and hemiparetic, but she followed simple commands on her unaffected side. A tracheotomy and feeding tube were placed on postoperative day 8 with some difficulty because of the patient's body habitus.

The next day the tracheotomy tube was inadvertently dislodged, and reinserting the tracheotomy tube into the trachea proved difficult. The patient experienced a respiratory and cardiac arrest before the tube could be effectively replaced. After resuscitation, the child was found to be in a severe postanoxic coma with decerebrate movements. The electroencephalogram exhibited global reduction in electrical activity, and the evoked potentials were abnormal. A consulted neurologist opined that there was no hope of recovery.

The team concluded that continuing therapy would be futile, and that discontinuation of active treatment should be

presented to the parents as the best option. The father said that he understood the prognosis but he held out hope that the physicians could be wrong and there might be some glimmer of hope. If the patient were maintained then God might decide to intervene. He requested continuation of care indefinitely.

The ICU staff expressed concerns with respect to continuing care. They acknowledged that the child may eventually progress to indolent skilled nursing care but would never be reanimated in the sense that the family desired. They team felt that continued care represented the prolongation of futile therapy for a child whose brain has been lost from severe postanoxic brain damage, and evolution of the brain tumor would prevent any substantial long-term neurological recovery. Furthermore, if a second tracheotomy complication should occur, then repeat correction of tracheotomy function could possibly be seen as battery because the risks clearly exceeded the benefits.

What would you do in this case?

A Russian opinion

Michael Karakozov

Ongoing intensive care is futile and could be construed as battery. Without knowing the child's will and with respect to the father's wishes, however, I would continue life-sustaining treatment contingent on available resources. A qualified psychologist should be involved in talks with the family to relieve suffering and to reinforce the message that continued treatment is futile. Also, the parents could take part in the child's care if so desired.

This approach does not violate Russian law. However, the law presents a contrasting problem. Russian law regarding public health care declares the patient's right (for adults >15 years old) to refuse any kind of treatment; however, it also prohibits withdrawing life support, even if the patient demands it. No one in Russia has the right to withdraw life support (e.g. ventilator support or inotropes) if the withdrawal would quickly lead to cardiac arrest, even if the dying person is to receive optimal palliative care. If the parents were to insist that such therapy be discontinued, then the hospital administration would have the right to appeal to the courts, to 'defend' the rights of the child.

In current Russian medicine there is no clear definition of the term 'end-of-life care'. The lack of research into this issue, together with traditional post-Soviet paternalism and budgetary constraints in the health care system, confound a systematic approach to optimizing the quality of care received by a dying patient. Hospice care is limited, and qualified home care is the exception to the general rule.

The patient's relatives can request to participate in medical conferences with the various specialists involved in the dying patient's care, but traditionally this happens infrequently (relatives do not ask for such participation and doctors do not offer it). A generally inappropriate level of care and often unsatisfactory hospital-family communication can foster distrust between health care providers, patients and relatives. This distrust is even more pronounced when it comes to withholding life-sustaining treatment. Personal communication with intensivists from different Russian regions confirm that the overwhelming majority of parents insist on continuing intensive care for their dying children.

It is clear that none of tradition, modern Russian law, and current practice in the Russian health care system support withholding life support in futile cases. Russian culture at this time is not ready to add this option to existing ones for end-of-life care. Likewise, life support measures cannot currently be withdrawn from dying patients. What this means is that the majority of postoperative patients whose chances of recovery are negligible die in the ICU setting. Only when patients can be weaned from inotropes and mechanical ventilation is a transfer to the general ward considered. Although the usual quality of care on the ward is poor, the level of palliative and nursing care in Russian ICUs is hardly satisfactory. Likewise, good health care options for dying patients in Russia currently do not exist, despite the best efforts of health care providers.

A German opinion

Thomas Marx

In the present case it is the neurologist's opinion that the patient's likely outcome is an apallic (persistent vegetative) state (if not in the short term then in the long term, because of the primary diagnosis). It is not clear whether the termination of active therapy proposed by the ICU staff extends to stopping administration of fluids and nutrition, and controlled ventilation, and opting not to treat complications (i.e. infections, pneumonia). In our practice, withdrawal of fluids or nutrition is seen to be unethical, whereas termination of controlled ventilation can be considered in hopeless cases (it is not indicated whether the patient is breathing spontaneously).

The German juridical/ethical position, as described in the literature and in a lecture by Professor R Merkel (University of Hamburg, Department of Juridical Science, lecture entitled 'Limitations of medical therapy' given at the University of Ulm, Department of Pediatrics, March 2004), emphasizes that conservation of life is of the highest priority. Exceptions to this are as follows [5–8]: in a terminally ill patient who is suffering, treatment with death as a possible side effect is permissible (indirect euthanasia); life support may be terminated in cases where the process of dying has begun and therapy would just extend the dying process (passive euthanasia); and life support may be refused by the conscious patient (the right to live does not mean the duty to suffer).

A patient in an an apallic state may be expected to have no perception of pain, therefore obviating any end-of-life decisions in the present situation based on ending the patient's suffering. An apallic patient does neither suffer anymore nor is in an acute dying process – a process that may be hastened by the development of complications.

Two factors complicate the case: an iatrogenic complication, and at least one of the relatives opposes the decision to end therapy.

My opinion is as follows. The medical staff view the father's position as emotional and based on 'feelings', regarding their own standpoint to be rational, based on experience and therefore superior. I strongly oppose that standpoint. To the staff it should be clear that irrational beliefs also play an important role in their decision making. I have not found any references on the following and would nevertheless like to introduce it into the discussion. From the standpoint of 'irrationality', the ICU staff recommendation to end life support can be viewed within the context of findings in nurses working in geriatric institutions [9]; because the mortality rate of their patients is 100% and they routinely experience the absolute 'futility' of their efforts, these nurses have the highest workload and the greatest percentage of burnout. Ending a patient's therapy is no cure for the ICU team's loss of hope.

Ethically I cannot see any reason to overrule the parent's decision in the present situation. They have probably already given consent for a procedure with a known tragic outcome. Their views must be given careful consideration in all discussions.

Our position would be as follows. We principally aim to gain the consent of a patient's relatives. We would try to wean the patient from the ventilator as soon as possible, discussing with them the consequences of caring for a patient in an apallic state. If new complications occur, then other decisions can be made, possibly with the consent of the parents. This approach allows us to consider the feelings of the family, to give them time to accept the situation and to say their goodbyes, to avoid giving the impression that the patient's case is being fast-tracked, and to have enough time to gain consent.

An American opinion

Scott Gunn

At issue in this case are fundamental questions about clinical decision making at the end of life when interested parties disagree as to the best course of action [10]. Are patients or doctors in the best position to determine the course of treatment? The physician's goals should be to sustain life and relieve suffering. When these goals become mutually exclusive the wishes of the patient should prevail [11]. In general, the principle of patient autonomy remains paramount. However, physicians are not obliged to deliver medical care that, in their best professional judgement, does not have a reasonable chance of benefiting their patients [12]. Disagreements regarding goals of therapy affect patient

care, family satisfaction and the health care team's ability to function.

I would first attempt to delineate what the parents might consider futile care for their child and to define for them what therapies are within acceptable limits for the health care team. Ideally, these discussions should emphasize the shared decision making process between parents and physicians. Realizing that prognostication is an imperfect science, we should use caution when relaying information about prognosis to families. Recent evidence suggests that the strongest predictors of withdrawal of mechanical ventilation

are not prospectively validated severity of illness scores but rather the physician's own predictions about the likelihood of a meaningful recovery [13]. This possible bias could lead to a self-fulfilling prophecy. It is not necessary, and indeed it is unlikely, to have absolute certainty of outcome before withdrawal of life sustaining medical therapy [12]. These issues will most often require more than one discussion with the family. Many families need time to deal with the emotional realities of the imminent loss of a loved one.

If additional discussions are warranted, then I would include extended family members, clergy and other medical consultants. If an ICU support group exists, then the family should be offered an opportunity to meet with parents who have faced similar decisions. If these efforts are unsuccessful

at bringing about a resolution, then the hospital ethics committee should be consulted. A recent randomized trial of ethics consultation in the ICU has found that consultation shortens the duration of life sustaining medical therapies in patients who ultimately have these therapies withdrawn and that most families found the consultation to be helpful [14]. Finally, if the parents maintain their decision to continue life sustaining medical therapy and the health care team feels morally unable to provide it, then transfer to another institution or health care provider (with the family's and accepting institution's approval) may be sought. When the patient's family and physicians cannot be reconciled, however, any appeals to the US judicial system in a prospective manner for arbitration will almost invariably lead to continued care [15].

A Singaporean opinion

Ian KS Tan

I assume the father is the person with parental responsibility, and that the opinion expressed by the ICU staff is unanimous. Given the age and condition of the girl, any opinions expressed by the girl before hospitalization would probably not be meaningful.

There is not a lot more that can be done for this unfortunate girl. 'Active' treatment revolves around provision of artificial nutrition and hydration, and routine nursing (suctioning, turning, and bladder and bowel care). Death was predicted to occur in 'less than a year' from the 'highly malignant brain tumour', and death or poor neurological outcome from the cardiac arrest is also predicted [16,17]. Care decisions therefore determine different ways of dying. The father may feel that 'If the patient were maintained then God might decide to intervene', but divine intervention can occur after death too and should not impact on the question of continuing care.

Although under common law I am not required to provide care that is counter to the best interests of the patient [18], and it is the treating doctor – with advice from the rest of the health care team – who decides on treatment [19], discontinuing care creates conflict. Furthermore, withdrawing therapy should not routinely involve hospital administrators or hospital ethics committees, who have no better understanding of the situation than do doctors who are familiar with the patient's illness and who are in close contact with the relatives. Only where adversarial relationships and lack of trust has occurred is recourse to committees and the authority of the courts required.

Establishing commonality of purpose is important. I would explain to the father that relief of pain and suffering is the chief goal of care. It is very unusual that this would be rejected. When trust is established, then scenarios can be discussed in which care can be viewed in the light of not prolonging pain and suffering, rather than one in which the body is maintained for the purpose of divine intervention. Examples could include the treatment of recurrent infections and bedsores, which would be inevitable despite 'active care' of the highest quality. Antibiotic treatment or continued nutrition could then be construed as contributing to continued recurrent suffering.

I would not immediately withdraw artificial nutrition, hydration and routine nursing care. I would encourage the nurses to teach the father how to perform nursing care. If the father desires to 'maintain' the girl, then this request would generally not be refused. Participation and involvement contributes to the idea that all parties work together rather than in an adversarial manner.

Given time, the prognosis and the futility of active intervention for complications, and possibly the futility of even routine care will become apparent to the father. Given time, the patient will die too. It is unimportant what decisions are made, or which party 'wins' in the decision making process, and when. It is important that the patient be accorded every dignity, that pain and suffering be minimized, and that human relationships are maintained.

A Japanese opinion

Satoru Hashimoto

I should like to view this scenario from my practice as a full-time intensivists in Japan. I can recall several similar cases,

each with its own unique character and many factors that led to somewhat different conclusions. First, I cannot ignore the

difference in ethnic background. Cultural differences in Far Eastern countries such as Japan, Korea and China are important in understanding decisions to withhold or withdraw care at the end of life. Do-not-resuscitate orders are still rare in these cultures [20]. Japan, although wealthy and developed, has had very few cadaveric heart or liver transplants since the 1997 law allowing organ harvesting after brain death. Since then, only 30 brain-dead donors have been reported. Whereas, about 2000 living-related liver transplants have been carried out in the same period. Since then, only 20 adult heart transplantations have been performed. Diagnosing brain death in patients under 15 years old is not yet legal. There are many Asian parties who oppose the concept of brain death as a criterion for end-of-life. In Japan it is interesting to note that, even if family members pursue a miracle, then their attitudes suggest that this is rarely for religious reasons. The national insurance system will allow us to give almost limitless life support, sometimes costing more than US\$100,000 a month, with almost no expense to the family.

We should bear in mind that there are many disabled children and adults who need comprehensive chronic medical care but are still cherished by their families. If there is a chance that the child might survive, even in a decerebrate

form and for a limited time, and the family has the slightest hope, then I would not insist on withdrawing any ongoing active therapy. In my view, this care is not futile. Reasonable recommendations on limiting care might vary between different countries, but I might even suggest to the father that a second tracheostomy be done by an expert laryngologist to secure her life, even though it could result in a persistent tracheocutaneous fistula. On the other hand, I probably would not resort to extracorporeal membrane oxygenation or other aggressive cardiac life support. I would not withdraw mechanical ventilation or nutritional support.

We are not ready yet to give up on this patient. I believe that it is imperative to educate the family on the risks and benefits of proposed therapies in order to prepare for the next choice. The team decision making process involves educating the family as to the most effective and ethical decisions. Then, I would wait until the father inevitably accepts his daughter's predicted death – it is only a matter of time. It is in the best interests of the patient and our health care system that we exercise patience. Of course, I am aware that there might be a malpractice lawsuit for the first dislodgement of the tracheal tube, but that is beside the point. I think it is senseless to discuss futility in this case at this point. I would continue to treat the patient until the family accepts the situation.

Discussion

Dan Thompson

An ill child frequently elicits many emotions both by family and staff. A child has not lived long enough to have an opinion on end-of-life issues, and we depend on surrogates who, like those of us who are parents, are always hopeful that things will turn out all right for our children. Sometimes we can appear to think in what some may consider an irrational manner. When an iatrogenic complication happens, we tend to feel a special responsibility that is different than if the problem occurred by more natural means. Is this less irrational than the thinking of the father?

In Western thought we tend to think of autonomy as paramount and group justice secondary. With a child, the individual's autonomy is expressed by the parents. We do not know whether there is another parent. How parents interact is very culture dependant, as is the staff response [21].

Three issues arise from the various perspectives. Futility is a difficult and very value laden concept, and probably does not have a significant role to play here [22]. There needs to be a transition from cure to comfort in the care of this individual. During this transition it must be recognized that different cultures will have different issues with the process. Legal issues may predominate, as in the Russian or New York or Missouri State perspectives, as may religious and ethnic issues, as discussed in the Japanese position and by Fisher

[21]. The range of capabilities of the local system may make both issues either easier or more difficult.

We should recognize that we care for both patients and families. It is easy to forget that for families the dying process, which is so familiar to us, is a new experience, especially when it involves children. We need to provide support for families during surrogate decision making, even when we do not agree with the results [23]. Consensus building and allowing the father to learn what it means to provide every day care may allow him to put the realities of his 'waiting for a miracle' into prospective. These efforts may also be therapeutic, and he may come to understand the present situation of his child.

As medical care providers, we not only preserve life as we know and accept it, but at the same time do not want to do things that we find morally inappropriate. In their positions described above, each writer respected the right of the father in this situation. We understand that there is a limit to what we can do. Frequently, those who we care for or their families have unrealistic goals that result in conflict. Did the father understand the child's prognosis or was he just waiting for an unlikely event to happen? Even a paternalistic view was moderated with the concept of consensus building [24,25]: 'Mediating differences about treatment decisions is the most

important conflict resolution tool available to physicians.¹ It is of prime importance to remember that resolution involves support of the staff as well as family.

Consensus building with mediation may allow a reasoned approach to the problem. Although some feel that outside help may be problematic, others feel that outside help may be valuable. I suggest that mediation with outside help may be important for all [26].

Follow up

After the tracheotomy tube was replaced, the young patient was transferred for a few days to the floor and from there to a chronic care facility, where she died a few weeks later. As expected, she never regained consciousness. Her parents were globally satisfied with her care in these last weeks of her life.

Competing interests

None declared.

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