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Please Do Whatever It Takes to End Our Daughter's Suffering!

Stéphan Clément de Cléty, MD,^a Marie Friedel, RN, PNP, MSc,^b A.A. Eduard Verhagen, MD, JD, PhD,^c John D. Lantos, MD,^d Brian S. Carter, MD^d

What is the best way to care for a child with severe neurologic impairment who seems to be dying and is in intractable pain? Can we give sedation as we remove life support? Is it ethically permissible to hasten death? In the United States, 5 states have legalized assisted suicide (although only for competent adults). In Belgium and the Netherlands, euthanasia is legal for children under some circumstances. We present a case in which parents and doctors face difficult decisions about palliative care. Experts from Belgium, the Netherlands, and the United States then discuss how they would respond to such a case.

abstract

Medical technology allows us to sustain the lives of people with profound neurologic impairment. In some cases, survivors experience intractable pain or discomfort. In such cases, family members and doctors may agree that continued use of life-sustaining interventions (LSI) is no longer appropriate. Then another series of decisions follows. What is the best way to care for a child as he or she is dying? In the United States, 5 states have legalized assisted suicide (although only for competent adults). In Belgium and the Netherlands, euthanasia is legal for children under some circumstances. We present a case in which a critically ill child has apparent intractable pain. We asked experts from the United States, Belgium, and the Netherlands to discuss how they would respond to such a case.

THE CASE

A 12-year-old child with anoxic encephalopathy after a near-drowning event at age 2 years develops viral meningitis and is rehospitalized in the PICU. After 21 days, she remains on assisted ventilation via

her tracheostomy; her parents are concerned that she is not responsive and has not returned to baseline. She has daily episodes of agitation, hyperpyrexia, hypertension, hypoxemia, and dystonia, and she appears to be in pain to both her parents and the ICU team. In addition, she has new-onset seizure activity. None of these signs improve after a medically induced state of deep sedation is lifted.

Her parents approach the PICU team after daily rounds and state, "This is unbearable to watch and endure after the past 10 years of caring for her. If she cannot be made comfortable, and you cannot make her pain go away, what can you do?" The team asks about her baseline status. "She needs suctioning of her tracheostomy every 1 to 2 hours, she smiles and responds to our voices and our gentle touch; she likes music." The PICU team remarks that her chest film is clear, her oxygen requirement is nil, and her apparent seizures are controlled, but her respiratory drive is poor and her electroencephalogram demonstrates persistent electrographic seizure activity. Her agitation, seizures, and respiratory insufficiency appear to require deep sedation. The neurologist

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suggests that her prognosis for recovery to her baseline is bleak.

Out of seeming desperation, her parents ask, "We want you to whatever you can to stop her suffering, even if it means shortening her life." How do you respond to their request?

STÉPHAN CLÉMENT DE CLÉTY, MD, AND MARIE FRIEDEL, RN, PNP, MSC (BELGIUM) COMMENT:

This case is common in PICUs. The response of the team will be influenced by many factors and requires a multidisciplinary approach. One might think that this approach would be different in Belgium, a country that recently legalized self-requested euthanasia for children. The debates on euthanasia were intense and remain so even 2 years after the bill has been affirmed because the sense of the law and its objectives are not clearly understood.¹

1. Self-Requested Euthanasia and End-of-Life Decisions in Belgium

Under the terms of the Belgian law, euthanasia is a procedure through which a physician intentionally puts an end to the life of a patient at the patient's request. This was legalized for adults in 2002 and for minors in 2014.

The law decriminalizes euthanasia under well-defined conditions, some of them specific to minors.² For minors, the patient must have an accidental or pathologic terminal disease with death expected within a short period of time. Psychiatric disorders are excluded. Constant, unbearable, refractory physical pain must be present. The child must be conscious and his or her request voluntary, repeated, and finally written. Therefore, the law does not apply to newborns and is thus different from the Groningen Protocol for newborn euthanasia in the Netherlands. The law does not permit euthanasia for patients

who are mentally handicapped or comatose. It excludes proxy requests. The child must be endowed with a capacity of discernment; he or she must be able to understand all the information his or her situation requires and then be able to make a decision, knowing all the consequences this decision will lead to. An external child psychiatrist or psychologist must assess the discernment capacity. The written consent of each parent must be obtained in all cases.

The clinical case presented here does not meet any of the conditions requested by the Belgian law. This young girl is unconscious, mainly because of her underlying neurologic disease but also because of the deep sedation her condition requires. She cannot express her will, does not meet criteria for discernment, and never requested euthanasia. Even if the parents formulate such request, it could not legally be followed in Belgium today. Any administration of drugs that have a primary goal to end life would be considered as a homicide in this case.

2. Palliative Analgesia-Sedation and Euthanasia

According to the parents and the PICU team, the child is suffering. The parents clearly ask to stop her suffering, "even if it means shortening her life." They probably know the side effects of medications and are perhaps considering their potential double effect: deep sedation is already required for their daughter; it might be increased if needed without becoming euthanasia.

As several authors have emphasized, major differences exist between palliative analgesia-sedation and euthanasia.^{3,4} The first objective of palliative analgesia-sedation is to relieve suffering, whereas that of euthanasia is to end life in a short period of time. The frontier between both may be tenuous in selected cases.⁵ Nevertheless, we disagree

with Inghelbrecht et al, who argued that if the consequences are equal, the intention and the way to achieve death seem unimportant.⁶ Their study does not reflect the point of view of all Belgian PICU teams.

The young patient in question requires intensive care but also, maybe now more than ever, palliative care. Her pain should be relieved. The best quality of life should be offered to the child. The parents should be included in all decisions. The doctors should have expertise in the use of medications, know the side effects, and react promptly in case of complication. They can also withdraw or withhold treatments when these are judged futile.

Palliative analgesia-sedation is a way to ease suffering while respecting the main ethical principles, often called the "double effect." We agree with Billings et al when they wrote that "the rule of the double effect should not pre-empt additional moral reflection or serve as the final word on justifying palliative sedation and related acts."^{7, p 172}

3. Proposed Management of This 12-year-old Girl

Despite deep sedation, the child's suffering is still significant according to her parents. They also suffer: they see their daughter and know that she probably will never recover to baseline; they realize that respiratory support is mandatory. Even if the child had a tracheostomy after her near drowning, they might find that this support interferes with their daughter's quality of life and perhaps that of the entire family.

After hearing the parents' request, we would organize a follow-up multidisciplinary meeting. The team should think through all management options and present them to the parents during this discussion. The team must also explain to the parents why they have adopted 1 well-defined care plan. The parents should not carry the weight of the final

decision alone, but must participate in the debate knowing the team's opinion. Time is frequently needed before a final decision could be made.

The care plan we would propose for this girl consists of several components. Antiepileptic treatment should be adapted to control clinical seizures with the intent to switch to oral drugs as soon as possible. The sedation should be optimized, but adequate dosage could significantly vary with time.⁸ A complete weaning from respiratory support should be considered if the neurologic evolution remains worrisome and the child is unable to breath independently. This support could be seen as an artificial way to prolong life and could be withdrawn after the parents agree. If the patient's comfort is ensured, this procedure is respectful of the child. In parallel, psychological, social, and spiritual support must be provided to parents and close family. Staff support also should not be neglected.⁹

PICU teams frequently hear the question the parents of this girl asked. They know that sometimes the limits of curative care are reached and that the death of a child could be a relief for the patient and her family.

A.A. EDUARD VERHAGEN, MD, JD, PHD (NETHERLANDS) COMMENTS:

This child has a life-threatening, complex, chronic condition requiring optimal palliative care. The parental despair is understandable, considering the persistence of the symptoms despite treatment interventions and the bleak prognosis. So is their request to stop her suffering.

Before any recommendation is made, we need to first clarify what the parents believe constitutes the child's suffering. They may focus on the persistent seizures despite deep sedation and the severe symptoms when the sedation is lifted. They may conclude that any prolongation of life,

even under sedation, carries a high risk of continued suffering, which they believe should be avoided.

Alternatively, the parent's notion of suffering may be caused primarily by the perceived "hopelessness" of the child's situation, the current poor quality of life, the lack of prospects for improvements, or by a combination of all of these factors. In this case, the parents would reason that even if their child could survive this episode, she would be left with an unacceptably low quality of life, now and in the future. In the first scenario, improved symptom management would address their concerns; it would not do so in the second scenario.

In addition, the parents' current and future suffering as a result of their inability to protect their child may influence their decision to accept, or even embrace, shortening of life as a result of intensified symptom management. Aside from the ethical and legal value of these considerations, they need to be specifically addressed by the team to prevent unrelieved psychological pain in bereaved parents.

Furthermore, to arrive at a careful response to the parents' request, more knowledge from the doctors and nurses would be helpful. How does the PICU team assess the presence and the level of suffering of the child? The nurses who care for the child on a daily basis would know the patient and parents well enough to have an idea about what the suffering means to the patient and the parents and how they could be supported in dealing with it. Have possibilities of caring for the child at home been discussed? The physicians, too, will have formed an opinion about the symptoms and their relationship to suffering. Are there reasonable medical interventions that could work? How did they include quality-of-life considerations in

their decision-making and in the discussions with the parents?

If all agree that provision of optimal palliative care is the decision that best serves the patient's interests, then the key question is which treatments will alleviate her suffering.¹⁰

Alleviation of physical suffering in this case requires deep sedation. If the PICU team confirms that the child is suffering and improvement of the condition is unlikely, foregoing the sedation is unethical and unjustifiable. However, given the patient's poor prognosis and the unlikelihood of achieving an acceptable quality of life, prolongation of deep sedation for a longer period of time is also hard to justify because it lacks a reasonable medical end goal. In fact, justification of the use of artificial ventilation and other medical interventions that prolong the child's life is equally problematic. If I were the patient's pediatrician, I would therefore be comfortable with the parent's request to withdraw all LSI.¹¹

Withdrawal of LSI would certainly lead to death in this patient, but the dying process might take several hours or even days. This creates new dilemmas.¹² Clearly, a prolonged dying period with potential additional suffering is contrary to what the parents want and not in the child's best interest. As a consequence, I would respond by discussing the following alternative scenarios with the parents.

A first scenario would be to withdraw LSI and have analgesic and sedative medication ready for immediate use if symptoms become detectable. This strategy is aimed at treating additional suffering, even if the dying process takes longer than expected. At the same time, the extra medication might further diminish the child's respiratory drive and hasten death.

A second scenario would be withdrawal of LSI with an increase of comfort care shortly before withdrawal. The goal of the increase is to prevent additional dyspnea experienced by the child as controlled ventilation is removed. The side effect of the increased medication may well be shortening of life. In both scenarios, the potential hastening of death would be ethically and legally acceptable in most hospitals and units and justified by the double-effect principle¹³ or by including them in the definition of “good” palliative care.¹⁴

A third scenario, which may only be an option in the Netherlands, would be to actively end the life with lethal medication. This is often referred to in the literature as “pediatric euthanasia.”¹⁵ In the Netherlands, children with decisional capacity of 12 years and older and adults can request euthanasia.¹⁶ Parents of newborns up to 12 months of age can also request neonatal euthanasia, which can be granted under strict conditions.¹⁷ For children without decisional capacity of 1 year and older, as in this case, no special regulation has been established, and ending the life of those children is a criminal offense. However, even in these circumstances, euthanasia is permissible if there is intractable suffering that cannot reasonably be alleviated. Successful appeal to this legal exception requires (1) agreement of the doctors, nurses, and parents about the presence of hopeless and unbearable suffering and (2) careful documentation of the consultation and consent.

Legally, these actions are different in most countries. For many people, there may also be an emotional difference. Ethically, however, there is not much difference between withdrawing life support that will lead to a certain death, and a planned death after euthanasia. I would try to understand which options the parents would prefer, and I would

support them in either scenario, as long as it is their choice.

**BRIAN S. CARTER, MD (USA)
COMMENTS:**

This case involves a child with a complex and multilayered history. It can well be imagined that her first 2 years of life were joyous and provided the typical experiences that all parents anticipate. When that was interrupted by the near-drowning event, her parents most certainly traveled a daunting path. The tasks of parenting had to be seen in a new and different light, with very different expectations.¹⁸

After many years, they face another crisis. This family has been tried and tested. They have likely been the “good” parents depicted by recent investigators.¹⁹ They ought to be characterized as “resilient” parents as well.²⁰

In the current crisis, they have seen their daughter’s health status decline. She is gravely ill. Her physicians have responded with excellent critical care support in the PICU. Recovery is unlikely. New complications reflect the severity of her illness and pathology within her central nervous system. Her basal respiratory drive is inadequate, and her distressing symptoms require deep sedation to control. Hearing that the likelihood of recovery is low, her parents may question their daughter’s future quality of life. They desperately inquire about relief of her suffering. What are her physicians to do?

This situation is not new to medicine or to pediatrics. Twenty years ago, Fleischman and others addressed such situations. They wrote, “When cure or restoration of function is no longer possible or reasonable, promotion of comfort becomes the primary goal of management. Optimal use of pain medication and compassionate concern for the physical, psychological, and spiritual well-being of the child and family

should be the primary focus of the professionals caring for the dying child.”²¹

It would be helpful for her doctors to directly address her prognosis for survival. This is difficult. She could survive, but it is unlikely.²²

In situations in which symptom management requires deep sedation, arousal or awakening may be distressing to many involved with the patient. Although her parents might consider it to be of some value to lighten the sedation, allowing her to “wake up,” they may regret such an attempt if it were impossible due to her illness severity (rather than her sedation) or she became unstable. Similarly, her care team may respond to the idea of such an event with mixed feelings. I believe that such an attempt at arousal/awakening is not in the best interests of this severely impaired and critically dying child. It might just add to everyone’s suffering.

In the current condition, I would acknowledge and validate the parents’ grief and suffering. I might say, “I wish things were different. After such a long time of phenomenal devotion to your daughter, this must be very disheartening.” I would certainly acknowledge that they have been loving, supportive, and good people as they cared for their daughter over the previous 10 years. In trying to determine what is the best thing to do moving forward, I would offer an ability to keep her comfortable using palliative sedation. It is apparent from their imploring question that this is of utmost importance to them, as it is most parents in similar circumstances.^{23,24}

Although tragic circumstances currently prevail, they should be reminded of their shared joys with their daughter and be provided time and opportunity to continue in their love and provision of comfort and care; be allowed the privacy and respect they are due as a family;

and, as much as they are able and desirous, exercise “normal” parental responsibility by contributing to the decisions about what happens to their child, perhaps in the creation of the setting, timing, or means for accomplishing a peaceful death for her that is in line with their cultural, religious, or other stated family values and traditions. Evidence suggests that parents can, in fact, handle such propositions, and desire to be helped in doing so.^{25,26}

If these parents are informed that their daughter’s suffering cannot be alleviated in any manner other than deep sedation, I believe that they could be accompanied on the path toward redirecting care toward a compassionate life support withdrawal. With assistance they may be able to prepare to say good-bye, order priorities for the remaining time that they have, and communicate their desire for their daughter’s level of consciousness or sedation at such a time.²⁷

**JOHN D. LANTOS, MD (USA)
COMMENTS:**

It is hard to know how best to care for loved ones who are dying. It is hard even to know whether and when they are dying. All we can do is work together, as doctors and parents, to make the best possible decision, given the clinical uncertainties, the ethical ambiguities, the legal particularities, the emotional agonies, and the spiritual implications. In this article, experts working in countries with different cultures and different legal systems end up agreeing about almost everything. Communication is essential. Shared decision-making is crucial. The child’s interests are paramount. The differences between the recommended approaches are subtle. Withdrawal of life support requires palliative sedation. Palliative sedation can look a lot like euthanasia. The boundaries and

barriers between 1 set of end-of-life practices and another are there to call our attention to the dangers of making such decisions too casually or thoughtlessly. As we develop the legal and ethical systems to help doctors and families with such decisions, we should continue to strive for meticulous attention to the interests of our patients, transparency about our practices, and honesty with ourselves about our distinctions, our methods, and our goals.

ABBREVIATION

LSI: life-sustaining interventions

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