Parents generally have the right to make medical decisions for their children. This right can be challenged when the parents’ decision seems to go against the child’s interests. The toughest such decisions are for a child who will survive with physical and neurocognitive impairments. We discuss a case of a 5-year-old boy who suffered a spinal injury as a result of a motor vehicle accident and whose father requests discontinuation of life support. Many experts recommend a “trial of therapy” to clarify both prognosis and quality of life. The key ethical question, then, is not whether to postpone a decision to forego mechanical ventilation. Instead, the key question is how long to wait. Parents should be allowed time to see what life will be like for themselves and for their child. Most of the time, life turns out better than they might have imagined. Comments are provided by 2 pediatric intensivists, Drs William Novotny and Ronald Perkin of East Carolina University, and by a specialist in rehabilitation, Dr Debjani Mukherjee of the Rehabilitation Institute of Chicago. Pediatrics 2014;134:593–597

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Dr Novotny reviewed the available literature and helped discuss the ethical dilemmas that confronted both the parents and health care providers who sought to act justly and responsibly in the care of this young boy; Dr Perkin framed and discussed the ethical problems for the medical ethics committee, staff, and parents; contributed valuable literature; and provided thoughtful analysis as he helped to construct the manuscript; Drs Mukherjee and Lantos helped conceptualize the project, contributed to the manuscript, and reviewed the final manuscript; and all authors approved the final manuscript as submitted.

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In the PICU, family-centered care strives to include parents and other significant family members in decision-making. The family’s input becomes especially pertinent when we face decisions about limiting life-sustaining treatment. The toughest such decisions are the ones that involve physical disabilities and uncertain prognosis for cognitive outcomes. In this “ethics rounds,” we present a case of 5-year-old boy who suffered a spinal injury as a result of a motor vehicle accident and whose father requests discontinuation of life support. Comments are provided by 2 pediatric intensivists, Drs William Novotny and Ronald Perkin of East Carolina University, and by a specialist in rehabilitation, Dr Debjani Mukherjee of the Rehabilitation Institute of Chicago.

THE CASE

A healthy 5-year-old white boy was an unrestrained passenger involved in a head-on motor vehicle collision that occurred when the driver, his mother, crossed the midline of the road. Emergency medical services found him ejected from the vehicle and in cardiopulmonary arrest. Return of spontaneous circulation occurred after 7 minutes of resuscitative efforts. At arrival to the emergency department he was apneic and unresponsive. Intubation was accomplished and mechanical ventilation continued. An MRI of the head and cervical spine revealed extensive craniocervical dissociation with marked widening of the distance between the skull base and C1 and between C1 and C2. Low and high attenuation within the spinal cord indicated cord injury with hemorrhage and edema. At the time of presentation parents were informed that high cervical spinal cord injury and severe anoxic brain injury were likely consequences of the accident. Three days after the injury the father approached 1 of the pediatric intensivists to seek a prognosis regarding his son’s brain and spinal cord injuries. After being told that significant motor injury would likely persist, the father asked if it would be permissible to discontinue mechanical ventilation and allow his son to die. He was told that it was very early in the postinjury course but that an ethics committee meeting would be convened to address this question. Fortunately, the mother had suffered no substantial physical injury. She spent much time at her son’s bedside grieving but expressed no opinion regarding the withdrawal of life support.

Question: Would it be ethically permissible to withdraw life support in this child, at 4 days after the occurrence of traumatic quadriplegia, if both mother and father agreed that would be the appropriate thing to do?

RESPONSE OF DR S WILLIAM E. NOVOTNY AND RONALD M. PERKIN

Competent adults have the right to make end-of-life treatment decisions for themselves. Children, and other patients who lack decisional capacity, necessarily rely on others to make such decisions for them. The 5-year-old child presented here likely has no realistic concept of death. He would be incapable of choosing or refusing life-sustaining treatment of himself. Parents have the legal duty to provide necessary medical care to their minor children. A failure to provide care exposes the parent to prosecution for neglect, manslaughter, or murder. This concern makes parental end-of-life decisions all the more complicated. Five considerations have been advanced to assess the continuance of life-sustaining treatments in children: (1) the amount of suffering and the potential for relief, (2) the severity of dysfunction and the potential for restoration of function, (3) the expected duration of life, (4) the potential for personal satisfaction and enjoyment of life, and (5) the possibility of developing a capacity for self-determination.

The first 2 issues were assessed by the father to weigh heavily in the direction of continued suffering and poor chance to restore function. On the other hand, this child would have been expected to live for many years if he was provided mechanical ventilation and treatment of intercurrent infections. The last 2 issues were unknowns because a thorough assessment of the mental capacity of this child was not possible.

Because of the development of advanced technologies, life-sustaining treatments frequently support life in severely ill children who in earlier times would have died. As a result, parents of children are frequently presented with the problem of when to forego life-sustaining treatment. When the 5 considerations noted above all lead in the same direction, then the decisions are straightforward. When, as in this case, those considerations point toward differing conclusions, the decisions are controversial. For the clinicians, this was a controversial case.

In cases such as this, the ethics committee should consider the father’s request to maximize his son’s long-term best goals while avoiding pain and suffering. The ethics committee may come to accept that it is ethically permissible to allow the parents to discontinue mechanical ventilation, even though physicians are morally entrusted to support the rights of the individual patient.

The ethics committee should address 3 issues of particular interest:

1. Is there a difference between withholding and withdrawing life-sustaining treatment?
2. When, if ever, is withdrawal of life-sustaining treatment equivalent to euthanasia?
3. Is withdrawal of life-sustaining treatment in a case such as this an indication of unjust discrimination on the basis of disability? Miller et al. proposed that there is no difference between withdrawing life-sustaining treatment and either assisted suicide or active euthanasia. They concluded that euthanasia should be legal in the same circumstances in which it is legal to withdraw life-sustaining treatment. Legally, however, there is a distinction. Although some states have legalized assisted suicide for competent adults, no jurisdiction in the United States permits assisted suicide or euthanasia for children. All, however, allow the withdrawal of life-sustaining treatment under some circumstances. The key question, then, is whether this case is one in which such withdrawal is ethically defensible.

Is there a difference between decisions to withhold or withdraw life-saving therapy? Most philosophers and legal scholars say no. Many clinicians may prefer to withhold rather than withdraw therapies. Adults with high cervical-level quadriplegia have the moral and legal right to refuse treatment. Even with adults, the capacity to make the decisions “early on” may be compromised by metabolic derangements, medications, depression, the ICU environment, and head trauma–related cognitive impairments. Furthermore, the prognosis is usually not precise in the first days after an injury. Intensivists and rehabilitation specialists frequently recommend waiting for weeks or months after an injury before making a decision to withdraw life-sustaining treatment.

Parents considering the option of withdrawal of ventilator support should also have a time period to assess a child in a supportive setting as he or she acclimates to his or her physical limitations.

Impairments related to spinal cord injury may not affect the eventual sense of well-being. The patient’s quality of life depends on the quality of physical therapy and on available environmental adaptations.

In this case, cardiopulmonary resuscitation and early stabilization had been accomplished when the father initially began to explore his responsibility to make medical decisions on the basis of what he perceived to be in his son’s best interests. The father initiated this discussion. The hospital staff did not attempt to persuade or coerce him. The father felt that vital social and cognitive dimensions of existence would be critically diminished for his son.

The ethics committee, in cases such as this one, should consider that the parents may be permitted to determine the best course for their son but only after a postinjury rehabilitation period, which would allow a better assessment of psychological, social, and spiritual issues.

RESPONSE OF DR DEBJANI MUKHERJEE

With only the information in the case description, it would not be ethically permissible to withdraw life support for this child at this point in time. If I were considering this case in practice, I would ask more questions, try to understand the context, and find out more about why the father was asking for withdrawal, and I would interview the health care team about the medical uncertainties and their perspectives on the case. These questions are key because health care providers’ views can often impact the way that information is interpreted and presented.

I have been working in rehabilitation on and off since 1991. I have seen many cases of traumatic quadriplegia in which people thrive after an injury such as this. And I mean thrive, not just suffer and live despite of their injury. Would this fact make a difference to this boy’s parents? It might. I don’t know enough about them or their values, priorities, and family obligations or their cultural and spiritual background to say. Those are important considerations because, although I am committed to the best interests of pediatric patients, I am also committed to cultural diversity and to honoring individual differences and preferences. I would try to approach this case with an open idea about why the request was being made now.

My main question is whether these parents have understood the relevant information and truly appreciated the facts of the situation. In other words, I would want to know that their refusal of medical treatment was an informed refusal. What is the relevant information and what are the risks and benefits of making or of not making this decision at this point in time? I would tell the parents that many children adjust to severe disabilities, especially when their injuries impact motor functioning. I would tell them that their son’s ability to follow commands on day 3 indicates that his prognosis is likely better than first feared. I would discuss the plasticity of the brain and what we know about novel therapies. Others could speak to the difficulties and missed opportunities and struggles this 5-year-old would face. There will be obvious major impacts on the lives of both the young boy and his family.

There are at least 2 risks to consider: the risk of making an irrevocable decision to withdraw life support and the risk of not having options to withdraw life support at a later point in the boy’s recovery. Does one outweigh the other? His parents are probably legally competent, but I would wonder if they are thinking clearly. I would worry that they are exhausted, depleted, overwhelmed, and possibly guilty. More importantly, 5
days ago they had a healthy 5-year-old
and they have since dealt with a seri-
cous car accident and various medical
professionals with incomplete and un-
known answers to tough questions.
How does a family member make such
a serious decision when still in shock
and attempting to process everything
that has happened?

I would suggest a time-limited trial to
this family and to the boy’s health care
team. I first learned about time-limited
trials when I was in graduate school. I
was investigating the “aftermath” of a
decision about life-support with-
drawal after severe traumatic brain
injury. Many on the health care team
reported that, from their perspective,
the withdrawal decision had been
rushed and medical uncertainties had
been framed as medical facts. Now as
the director of an ethics program at a
rehabilitation hospital and a licensed
clinical psychologist, I have become
convincing that time-limited trials are
a good way of acknowledging the fol-
lowing important features of this situ-
ation: (1) this is a very difficult situation,
(2) there is significant vari-
ability in clinical and social outcomes,
(3) we don’t yet know enough to give
a definitive prognosis in this case, and
(4) withdrawal of life-sustaining treat-
ment is a final decision; it does not al-
low for adjustment to disability or
adjustment of the family to the enor-
mity of what has just happened.

How do such trials work? The family
and the health care team would agree on
a time frame for assessing clinical
progress. After an agreed-upon in-
terval, they would revisit the issue of
withdrawing life support. A time-limited
trial would require the health care team
continue to accompany and engage
with this family and to consider the
withdrawal request again if the request
persisted. In the meantime, the team
would have more medical information,
and clearer prognostic indicators, and
the family would have had time to
process, at least to some extent, the
ramifications of life-altering car accident.
So, is it ever ethically permissible to
withdraw life support on a young boy
who has a traumatic injury? Yes, just not
in this case, at least not yet.

JOHN D. LANTOS COMMENTS

A recent review from the Hospital for
Sick Children in Toronto illustrates how
the use of long-term home ventilation
for children has grown. In 1991, they had
2 patients at home on ventilators.
Twenty years later, in 2011, they had 156
children living at home on ventilators.12
In all such cases, clinicians and
parents face decisions about whether
to continue or forego life support.
Writing about spinal muscular atrophy,
Hardart and Truog13 noted, “The ulti-
mate determination of a given child’s
best interests must be the upshot of
dynamic interchange between the
physician and the family. . . . The physi-
cian must try to present a realistic
concept of the long term implications
of chronic ventilation and the financial,
emotional, social, and medical burdens
it entails. Perhaps the greatest chal-
lenge in preparing families to live with
their ultimate decision is anticipating
what each family would consider ade-
quate quality of life for their child.”

Most intensivists and rehabilitation
specialists understand that decisions
to withdraw life support should not be
made quickly. Battaglia et al14 argue
that a time-limited trial of life-
sustaining treatment allows for more
informed decisions. They write, “A time-
limited trial (TLT) allows opportunity
for (1) patient reflection, (2) family in-
put, (3) adaptation to a ‘new normal,’
(4) palliation of symptoms and suffer-
ing, (5) building trust, (6) goals setting,
(7) evaluation of trends and progress,
(8) recruiting community resources,
and (9) rehabilitation and functional
improvement. During TLT, if functional,
emotional, and social barriers are
minimized, then a patient’s joy and
purpose for living may be restored and
unnecessary hastening of death can
potentially be avoided.”

The key ethical question, then, is not
whether to postpone a decision to
forego mechanical ventilation for a few
weeks or months. Instead, the key
question is how long to delay. Patterson
et al9 warn that “acquiescing in a dev-
astated patient’s wish to die is re-
spectful neither of the patient nor of
the subtleties of the principle of au-
tonomy, particularly in a society with
1 pervasive negative bias about dis-
ability.” Ross15 also advocates time-
limited trials, but notes, “Physicians
and their patients ought to pursue
meaningful dialogue over a period of
time. . . . After that interval, a physician
who overrides the patient’s decision is
disrespectful of the patient’s auton-
omy.” Even when the patient is not the
decision-maker, the same consid-
erations apply. Decisions about life
support should be delayed until
parents see what life will be like for
themselves and for their child. Most of
the time, life turns out better than they
might have imagined.16

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**DOING NOTHING:** “My Dad just can’t relax” said my eldest son to our dinner guest the other night. By “relax” he meant “just do nothing” or “hang out.” He and his friend laughed, but I wondered if I was an aberration. Do most people really enjoy doing nothing? It turns out that doing nothing is not nearly as popular as suspected.

As reported in The Wall Street Journal (Life & Culture: July 18, 2014), scientists showed over a series of experiments that most people asked to do absolutely nothing for 6 to 15 minutes disliked the experience. In the first set of experiments, more than half of college students – asked to sit in a plain room and simply think – disliked the experience. Their dislike was not related to happy or unhappy thoughts, nor was the environment the cause. When students were asked to sit in their own home and just think, even more disliked the experience, and almost one-third cheated (for example, by using a cell phone).

It’s not just young adults who dislike being alone with their thoughts. The same results were seen in a group of middle adults (mean age 48 years) recruited from a church group and a farmers’ market.

To determine just how much people dislike doing nothing, researchers gave students a small electric shock and asked if the students would be willing to pay five dollars to avoid another shock. Students who reported they would pay to prevent another shock were put into a room and asked to do nothing. However, they were also given a button that stimulated the same electric shock they said they would pay to avoid. Amazingly, 12 of 18 men and 6 of 24 women voluntarily shocked themselves, suggesting that they preferred negative stimulation more than no stimulation.

My son is correct that I do not simply “hang out” very often. However, I am pretty sure that I would not choose an electric shock over doing nothing. After all, I think it is fun to daydream about what I would do if I were a master chef or riding in the Tour de France.

*Noted by WVR, MD*
Mechanical Ventilation for a Child With Quadriplegia
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