

Judging the Quality of Mercy: Drawing a Line Between Palliation and Euthanasia

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ABBREVIATION

PAS—physician-assisted suicide

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abstract

Clinicians frequently worry that medications used to treat pain and suffering at the end of life might also hasten death. Intentionally hastening death, or euthanasia, is neither legal nor ethically appropriate in children. In this article, we explore some of the historical and legal background regarding appropriate end-of-life care and outline what distinguishes it from euthanasia. Good principles include clarity of goals and assessments, titration of medications to effect, and open communication. When used appropriately, medications to treat symptoms should rarely hasten death significantly. Medications and interventions that are not justifiable are also discussed, as are the implications of palliative sedation and withholding fluids or nutrition. It is imperative that clinicians know how to justify and use such medications to adequately treat suffering at the end of life within a relevant clinical and legal framework. *Pediatrics* 2014;133:S31–S36

Prologue

The young parents sit in a room with multiple medical teams: neurologists, geneticists, and intensivists. They had been worried for more than one year that their 7-year-old son did not seem to keep up with other children; many months ago, he began to show progressive difficulty with his balance and seemed to be speaking even less than before. They sought second opinions when the seizures began. He is now having several seizures every hour, causing respiratory failure that requires him to be supported with mechanical ventilation in the ICU. They have journeyed through 3 hospitals and met innumerable physicians to arrive at this day.

There is an answer, but the news is not good. A retinal examination and genetic testing have confirmed the diagnosis: neuronal ceroid lipofuscinosis. At this stage of disease, there is no treatment that can reverse the progressive deterioration.

The parents and the medical team make the difficult decision to discontinue the ventilator and focus solely on keeping the child comfortable. His parents have seen that he gets agitated at times and are concerned that he will struggle or be in pain when the ventilator is removed. He has not been awake and aware of his surroundings for weeks, although he grimaces, stiffens, and coughs against the ventilator when any interventions cause discomfort. They ask if he can be taken to the operating room and "put under" so that it will all go quickly.

Providing compassionate, appropriate care to any patient at the end of life requires navigating complex situations. To do so skillfully requires an understanding of ethical norms and controversies, pharmacologic and nonpharmacologic tools for symptom management, and the risks and benefits of medical technology. Equally important, one must know how to discuss all of these issues with a patient and family while continuing to support them through what is likely one of the most stressful times of their lives. Additional complexities arise when the patient is a child because it is often true that a child is unable to state his or her own wishes in such a situation, and the surrogate decision-makers are frequently

unprepared for the possibility that a child might die.

Most deaths in the United States today are preceded by a decision to limit the use of medical technologies. This fact is certainly true for patients who decide to stay at home rather than be admitted to the hospital near the time of death, and it is also true for both adult and child patients in ICUs, where more patients now die after decisions to withhold or withdraw technology than die of failed cardiopulmonary resuscitation.^{1,2} Such decisions are typically made when cure or survival with a good quality of life is no longer possible, and the goals of care therefore shift to focus on the comfort of the patient, palliation of symptoms, and psychosocial support of the patient and family. Even in cases in which medical technology is limited or discontinued, there are circumstances such as in the aforementioned case in which the line between controlling symptoms that occur after technology is discontinued and expediting death is unclear.

Managing pain, dyspnea, or agitation associated with a terminal illness usually requires the use of medications such as opioids that may have undesired respiratory or cardiovascular adverse effects. Many clinicians are therefore concerned that administering the medications may hasten death. Is the family in the opening vignette asking for an appropriate intervention to ensure that their child does not suffer? Or would a management plan that included a general anesthetic in the operating room cross a line into unacceptable territory? In this article, we explore the historical and legal background, ethical debate, and clinical reasoning informing what differentiates palliation from euthanasia. In the process, we hope to provide some insight on distinguishing between what is and what is not acceptable practice. Throughout, palliation is defined as symptom-directed therapy aimed at improving quality of life,

usually without curative intent. Euthanasia is defined as administration of medications to a patient with the intent of causing death.

HISTORICAL OVERVIEW

Advances in medical technology over the last century have led to medical care that can be life-saving but in some cases can also merely prolong the dying process. Several well-known legal cases relate to whether terminally ill patients have a right to control the timing and manner of their death, with judicial opinions in these cases commenting on what therapies are acceptable at the end of life. Although none of the examples or legal cases described here concern pediatric patients, many of the principles delineated still apply.

In 1988, an essay published in the *Journal of the American Medical Association* (titled "A piece of my mind. It's over, Debbie") sparked controversy and public debate when an anonymous author, apparently a resident physician, described meeting a patient at night: a young woman in severe pain from intractably progressive, disseminated cancer.³ The resident gave her a dose of morphine that was "enough," followed immediately by her death. Some letter writers responded by calling for the author of the essay to be prosecuted for murder, while others lamented the poor treatment of pain at the end of life, lack of good options for patients, and importance of an open public debate.^{4,5} The controversy highlights that the medication used could be administered either to treat suffering or to hasten death, that there can be ambiguity regarding which result a physician intends, and that opinions regarding what treatment is appropriate diverge widely based on personal background and cultural beliefs.

In 1997, 2 cases brought before the Supreme Court of the United States

(*Washington v. Glucksberg* and *Vacco v. Quill*) addressed whether adult patients have a constitutional right to ask for assistance in dying from a physician (defined as physician-assisted suicide [PAS] when a patient is provided with the means to end his or her own life, rather than euthanasia). The courts ruled that states were not obligated to allow PAS but were also not prevented from legalizing it in their regulation of medical practice, as some states have since done.⁶ No state has legalized such a practice in children. In her opinion on the case, Justice Sandra Day O'Connor stated that "a patient who is suffering from a terminal illness and who is experiencing great pain has no legal barriers to obtaining medication, from qualified physicians, to alleviate that suffering, even to the point of causing unconsciousness and hastening death."⁷

Justice O'Connor's statement perfectly summarizes one of the basic tenets of palliative care; if a patient is suffering, it is appropriate to treat that suffering, and clinicians do not need to fear that there are legal risks in doing so. That it may be acceptable to hasten death is justified by the principle of double effect, which states that an undesired effect (death) may be accepted if the desired effect (relief of suffering) is what is intended, as long as the undesired effect is not the means of achieving the desired effect and the good of the desired effect outweighs the bad of the undesired effect. Thus, it would be acceptable if medications used to treat suffering led to the death of a patient who is imminently dying but not of a patient who might otherwise live for years more.

DO PHYSICIANS HASTEN DEATH?

More than one-half of oncologists have received requests for assistance in dying,⁸ and almost 15% reported having

participated in euthanasia or PAS.⁹ However, even after legalization of PAS in Oregon, only 7% of physicians reported having written prescriptions for lethal drugs.¹⁰ Interestingly, physicians with more training in end-of-life care were less likely to report having assisted adult patients with dying.⁹

Respondents in such surveys, however, may not have understood what was being asked. In a large, multicenter European study, many physicians who reported having "shortened the dying process" had administered standard doses of medications to patients who died no more quickly than patients for whom that intent had not been stated.^{11,12} Several studies in adult and neonatal patients that did not ask about intent examined whether higher medication doses at the time of withdrawal of technological support are associated with a more rapid death, and found little relationship.^{13–18} In fact, 1 study found that higher sedative doses were associated with longer survival.¹⁹

HOW CAN ONE TELL THE DIFFERENCE BETWEEN TREATING SUFFERING AND HASTENING DEATH?

Palliation and euthanasia have some of the same goals. Both are ultimately spurred by the desire to relieve suffering. In palliation, the primary goal is to treat pain and symptoms, with an understanding that there is some chance that death may happen more quickly. With euthanasia, ending life is the means of ending suffering. In theory, the distinction should be clear. But in clinical practice, it can be harder to differentiate. Whether a physician intends to treat suffering or hasten death when medications are administered can be difficult to discern.^{11,20,21} Actions are easy to assess; intentions are not.²² Were the doses prescribed ones that made sense in the given clinical situation? Were they

titrated appropriately (even if to high levels) based on the patient's reports or clinical signs of discomfort, pain, or agitation?^{23,24} Was it clear from the documentation why more medication was needed?

Some medications would clearly cross the line. Giving a dose of a neuromuscular blocking agent or potassium chloride at the time of ventilator withdrawal would do nothing to treat suffering; the only plausible intent would be to cause death. Although some feel that neuromuscular blocking agents may make the patient appear more "peaceful," the opposite may be the case because these agents make it impossible for the clinician to detect patient awareness or dyspnea. Professional organizations have advised against the use of such medications in almost all end-of-life circumstances.^{25,26}

Another way that palliation differs from euthanasia is in the degree of control over the timing and the outcome. Appropriate palliation often requires letting the disease run its course while doing one's best to make sure the patient does not have unmanaged pain or symptoms. Just how much time it might take for a patient to die is often uncertain. Indeed, especially for patients who do not suffer from cancer, there is often uncertainty regarding whether the outcome of the illness episode will, in fact, be death.²⁷ Awareness of such uncertainty is important for all members of the health care team as well as the family. For many competent adult patients who request aid in dying, the requests are often motivated by a desire to be in control of the circumstances of death.^{28,29} For some physicians, there may be a similar desire to control the timing of what happens for their dying patients, and such a feeling may be one of the complex motivations that plays a role in choices about doses of medications.

Interestingly, both family members and the health care team may benefit by admitting we do not have full control over the timing of when someone dies.³⁰ Families may feel more comfortable discontinuing unwanted medical technology if they know that doing so does not guarantee an immediate death. Occasionally, patients do unexpectedly well for longer than anticipated once their symptoms are controlled. This time may be valuable to the patient and the family. Palliative interventions often exist in this area of uncertainty; treat the symptoms, and the patient will show us what the future holds.

Palliative interventions should also stand up to scrutiny. When a clinician is worried that a plan or a dose might “cross the line,” it is always a good idea to voice those concerns and discuss them with colleagues. Medication and dose titration guidelines may help all staff feel more comfortable that they are acting within the usual standards of practice. Being able to clearly explain to a family what we are or are not able to do, while reassuring them that medications will be escalated to whatever doses are necessary to make sure that their child is comfortable, helps to preserve trust both with individuals and with the general public.

FLUIDS AND NUTRITION

Withholding artificial nutrition and hydration at the end of life is another area in which the lines can be blurred.^{31–33} Withholding feedings in some patients may be reasonable when the goal is to diminish suffering; examples would be a patient who is actively dying, one who would require a procedure such as tube placement to receive artificial nutrition, or when feeding itself is actually causing suffering. For a patient who is clearly in the last hours or days of life, it is unlikely that death would come any sooner for lack of nutrition.

However, in the case of a patient who is not actively dying and who tolerates supplemental nutrition, withholding it becomes more problematic because the sole intent of doing so may be to hasten death. Even though the time frame is different from that of a lethal injection, the end result is still determined by the action, and the only relief of suffering provided is through death itself.

PALLIATIVE SEDATION

Palliative sedation refers to the provision of sedatives at the end of life to treat pain, agitation, or distress that is resistant to treatment by other means.^{34,35} Although it is also referred to in the literature as “terminal sedation,” palliative is a better descriptor because it more accurately reflects the intent of the medications. Although palliative sedation is often discussed as raising more challenging ethical dilemmas than other palliative measures, it should not. The medications are the same as those most often used to treat agitation or dyspnea.³⁶ Treatment should be titrated to effect; benzodiazepines may be used in low doses as anxiolytics, higher doses for distress not treatable by other means, and will be escalated to the point

of depressing consciousness only when there are no other alternatives. Clinicians should choose the “least harmful alternative” first and move on to riskier interventions or medications only if the first steps are not working.³⁷ Similarly to medications used for pain, if sedatives are escalated only as much as needed to relieve distress, doing so would be unlikely to hasten death.

CONCLUSIONS

In the opening vignette, the parents asked if their child could be preemptively anesthetized before discontinuing ventilation. Although some would argue that this course of treatment would guarantee that there would be no undetected distress,³⁸ there would also be a high likelihood of giving more sedative and respiratory depressant medication than required and a greater chance of hastening death. The ICU team informed the parents that no medication or anesthetic could be given that would intentionally hasten death, but that analgesics and sedatives would be continued to make sure their son was comfortable and would be escalated if needed. The team asked the parents to share their concerns if they detected distress not noted by the staff but also

TABLE 1 Rules of Thumb to Distinguish Appropriate Palliation From Euthanasia

Palliation	Euthanasia
The primary goal is to relieve suffering without considering life expectancy. These goals are clear to the health care team and the family	The primary goal is to end life as a way of ending suffering
Medications to treat suffering are escalated by using well-defined measures of treatment effectiveness to reach goal of comfort. Medication escalation is stopped once suffering is adequately controlled	Medications are escalated regardless of physical symptoms
The safest and least harmful medications are chosen first before escalating to medications that are more likely to cause adverse effects of respiratory depression. Medications that hasten death without treating symptoms are avoided	Medications are chosen based on efficacy of achieving death quickly
Use of medications and the process for decision-making are open and documented in the patient medical record	Tendency to keep knowledge about the use of specific medications secret

described signs of the normal dying process that are sometimes misinterpreted as discomfort. The parents understood and were able to hold their son for 2 hours after discontinuation of the ventilator until his death.

In the future, analgesic and sedative medications may be available that do not

have respiratory depressant effects, obviating the need to invoke the double effect principle. However, even in current practice, it is highly unlikely that medications appropriately titrated to manage symptoms lead to any meaningful shortening of dying. There is a far greater risk that symptoms will be

undertreated, leading to unnecessary suffering.^{39,40} An understanding that treating pain and suffering is both ethical and merciful will help all team members do their best to care for patients and their families without worrying about “crossing the line” (Table 1).

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