VIEWPOINT

Pediatric Euthanasia in Belgium
Disturbing Developments

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On February 13, 2014, Belgium's Parliament approved an amendment of the 2002 Belgium Act on Euthanasia to allow euthanasia for chronically ill children. The amendment, supported by a majority of Belgians and recently signed into law by King Philippe, permits euthanasia for children who are experiencing "constant and unbearable suffering." In addition to requiring the child's own voluntary and explicit request for euthanasia, the new law requires parental consent, excludes children with an intellectual disability or mental illness, and mandates a multidisciplinary team carefully examine the child's capacity for discernment.[1]

The passage of this law marks the culmination of years of increasing acceptance of euthanasia in the Benelux region. To date, the Netherlands, Belgium, and Luxembourg are the only member states in the European Union in which euthanasia is legal. In Belgium, euthanasia for adults has been lawful since May 2002.[1] A study examining the attitudes of physicians involved in the care of Belgian children under the age of 18 years who died between June 2007 and November 2008 revealed that the majority (69%) favored extending the Belgian law on euthanasia to include minors.[2] Those physicians favoring extending the law were more likely to engage in practices intended to shorten their patient's life.[2]

In March 2005, recognizing the rising incidence of pediatric euthanasia without any legal sanction, physicians at the University Medical Center of Groningen, in the Netherlands, published practice guidelines for the ethical implementation of euthanasia for severely disabled newborns.[3] The Groningen protocol stipulates that the provision of active euthanasia is justifiable for a class of infants "with a hopeless prognosis who experience what parents and medical experts deem to be unbearable suffering."[3] The protocol specifies that the termination of a child's life is acceptable if 4 requirements are met: the presence of hopeless and unbearable suffering, the consent of both parents, consultation with physicians, and the termination procedures comport with "medical standards."[3] In contrast to the Belgium law, the Groningen protocol represents a form of nonvoluntary active euthanasia, in which the patient—a neonate—never possessed the capacity to develop preferences.

Meanwhile, US support for physician aid in dying for adult patients is slowly evolving, as evidenced by legislation legalizing the practice in the states of Washington, Oregon, and Vermont and favorable court opinions in Montana and New Mexico.[4] Although US laws only apply to competent adult patients, developments in Belgium and the Netherlands may stoke the debate about the ethical permissibility of pediatric euthanasia in the European Union and in the United States.

Assent and "Capacity for Discernment"

The Belgian pediatric euthanasia law seeks to respect the moral status of children as agents who possess the nascent capacity for self-determination. Specifically, the law requires the medical team to demonstrate a patient has the "capacity for discernment," indicating that he or she understands the consequences of a choice for euthanasia.[1]

What the law does not consider, however, is that adults choose euthanasia for reasons that go beyond pain. For adults, the decision to end their life can be based upon the fear of a loss of control, not wanting to burden others, or the desire not to spend their final days of life fully sedated. These desires might be supported by the experience they have had witnessing a loved one express a loss of dignity or because they understand what terminal sedation is and wish to refuse it. Children, however, lack the intellectual capacity to develop a sophisticated preference against palliative interventions of last resort. Instead, in the case of the new Belgian law, children seem to be asked to choose between unbearable suffering on the one hand and death on the other.

This possibility causes the Belgian euthanasia law to fall short of the standard required for valid assent. The criterion related to the "capacity for discernment" runs the risk of ignoring the fact that children and adolescents lack the experiential knowledge and sense of self that adults often invoke—rightly or wrongly—at the end of their lives.

Ethical guidelines pertaining to end-of-life care for children stipulate that children younger than 7 years lack the necessary foundation of experience upon which to form relevant decision-making preferences and values.[5] Although defining a precise age of maturity sufficient to exercise experience-based discernment is problematic, certainly neonates and very young children fall short of this threshold.

Although a child can surely feel pain, concepts like loss of dignity or the fear of losing self-determination are outside the realm of young children's capacities. Ensuring adequate pain control is thus a more reasonable response to their needs than seeking to involve them in decisions about euthanasia that exceed their experience and abilities.

The Belgian law specifies that euthanasia would be permissible only for "terminally ill children who are close to death, experiencing constant and unbearable suffering."[1] That suffering of such magnitude exists in

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modern pediatrics is an inexcusable tragedy. But the solution need not and should not be euthanasia.

All patients, including children, must have access to adequate palliative care. Although access to adequate comprehensive palliative care is limited in many settings, it ought not be in developed nations such as Belgium. Competently provided aggressive palliative care is generally adequate to relieve pain.[6]

Conclusions

The amended Belgian euthanasia law aims at empowering children who are able to provide assent to life-ending interventions. The goal of reducing suffering in children at the end of life is a laudable one. However, the ethical way to achieve this goal should be expanded education and clinical guidance around the provision of aggressive palliative care.

In the face of intolerable suffering in a newborn or child, aggressive interventions, such as palliative sedation, that risk, but do not intend, death are ethically justified.[7] Such interventions are far more ethical than allowing clinicians to euthanize children who do not possess the cognitive and emotional sophistication to either need or comprehend what they might appear to seek. Assistance in dying is best left to the competent adult. Aggressive pain management is best for those whose dying entails the relief of their pain.[6]

ARTICLE INFORMATION

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