

Ethical Issues Around Pediatric Death

Navigating Consent, Assent, and Disagreement Regarding Life-Sustaining Medical Treatment

Silvana Barone, MD^a, Yoram Unguru, MD, MS, MA^{b,c,*}

KEYWORDS

- Consent • Assent • Death • Life-sustaining medical treatment • Adolescents
- Decision-making

KEY POINTS

- The principle of pediatric assent recognizes the need to recognize and respect the wishes of children as they develop cognitively and mature.
- Health care providers should provide developmentally appropriate disclosures about illness and solicit the child's willingness and preferences regarding treatment to a level that is commensurate with their decision-making capacity.
- Adolescents displaying psychosocial maturity should be given a larger role in decision-making, including decisions regarding their end-of-life care.
- When prognosis is poor and disagreement arises regarding the use of experimental therapy or life-sustaining medical treatment, every effort must be made to explore goals and values and reach a consensus on the therapeutic plan.

INTRODUCTION

In modern society, we expect parents to outlive their children. Childhood death is a difficult reality, in part, because it defies the expected order of life events, challenging basic existential assumptions and threatening parental roles of protecting offspring.^{1,2} The death of a child is one of the most painful events a family can experience and is associated with complicated and traumatic grief reactions.^{3,4} In the United States,

^a Division of General Pediatrics and Adolescent Medicine, The Johns Hopkins Hospital, Johns Hopkins University Berman Institute of Bioethics, 200 North Wolfe Street, Baltimore, MD 21287, USA; ^b Division of Pediatric Hematology/Oncology, The Herman and Walter Samuelson Children's Hospital at Sinai, 2401 West Belvedere Avenue, Baltimore, MD 21215, USA; ^c Johns Hopkins University Berman Institute of Bioethics, 1809 Ashland Avenue, Baltimore, MD 21205, USA

* Corresponding author. Division of Pediatric Hematology/Oncology, The Herman & Walter Samuelson Children's Hospital at Sinai, 2401 West Belvedere Avenue, Baltimore, MD 21215.

E-mail address: zunguru@lifebridgehealth.org

between 40,000 and 50,000 children die every year from trauma, lethal congenital conditions, extreme prematurity, heritable disorders, or acquired illness.⁵ Of these, more than 1500 are adolescents who die of the effects of chronic illness, including malignant neoplasms, heart disease and congenital malformations, and chromosomal anomalies.⁵

Health care providers (HCPs) caring for children with life-limiting illness face many challenges, including, but not limited to, management of distressing symptoms, difficult conversations about prognosis and goals of care, facilitating longitudinal decision-making in the face of prognostic uncertainty, and navigating conflict with family members and other HCPs.⁶⁻⁹ For example, conflict in pediatric end of life can occur if parents ask HCPs not to disclose a poor prognosis to their child, even when cure is exceedingly unlikely. These requests can lead to moral distress for HCPs who must navigate tensions between coexisting principles of avoiding harm and enabling autonomy, while striving to uphold their professional integrity for truth telling.^{2,10} Furthermore, disagreement about the goals of medical care can be an important source of conflict; family members may disagree with medical recommendations because of different perceptions and expectations about the child's quality of life, different interpretations of the prognosis, or religious and culturally based beliefs that influence their sense of what is best.¹¹ Disagreement within the health care team about the direction of care may also occur, leading to fragmented caregiving and the communication of inconsistent or conflicting information to families.¹² For children with life-limiting illness, questions surrounding the use of experimental therapies or life-sustaining medical treatment (LSMT) often arise and can be a significant source of conflict and distress for both the health care team and the child-family dyad. How are such decisions made for these seriously ill children? Do, and should, children have a say in their care when their choices represent, quite literally, life and death decisions? If the answer to this question is yes, what would this look like in practice and, importantly, should limitations on a child's decision-making exist? The following sections explore issues related to pediatric decision-making in cases of incurable disease and provide some guidance for HCPs navigating these often emotionally charged and ethically challenging clinical situations.

Decision-Making for Minors with Life-Limiting Illness: Concepts of Consent, Assent, and Emerging Capacity

The pediatric model of patient- and family centered care recognizes that patients and their families are integral partners with the health care team and that the child and family's perspectives are essential components of high-quality clinical decision-making.¹³ With a few exceptions,¹⁴ parents are granted authority to make medical decisions on behalf of minor children, including adolescents. Parents are generally afforded a great deal of discretion in terms of the choices they make, so long as their choices do not place the child at risk of serious harm as compared with the alternatives.^{15,16}

For children with chronic life-limiting illness, medical decision-making is not a discrete event but a process whereby families assimilate new information and make decisions over time as the child's clinical condition evolves and, often, deteriorates. Such decisions can include whether to proceed with surgeries for a feeding tube and tracheostomy for progressive dysphagia and respiratory failure or whether to pursue further courses of aggressive chemotherapy for cancer after initial treatments have failed. Given the potential consequences of severe disability and/or death of the child, the process whereby these decisions are made can be fraught with challenges and conflict for both families and HCPs.

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