Balancing act: Weighing the decision to withhold life-sustaining medical treatment

by Alyson Sulaski Wyckoff, Associate Editor

When faced with the decision on whether to forego life-sustaining medical treatment for a child, clear communication among family, patient and health care personnel is essential.

That is a key recommendation in an AAP policy statement - updated from 1994 - that offers guidance on how to promote the best-possible end-of-life care for children.

The policy, Guidance on Forgoing Life-Sustaining Medical Treatment from the AAP Committee on Bioethics, Section on Hospice and Palliative Medicine and Committee on Child Abuse and Neglect, is available at https://doi.org/10.1542/peds.2017-1905 and will be published in the September issue of Pediatrics.

Life-prolonging interventions

With the advancement of medical and surgical technologies, pediatricians, parents and other family caregivers have to confront when it is ethical to use available interventions to sustain the life of a severely ill child, always considering the child's best interests.

Interventions that can involve life-sustaining medical treatment include assisted ventilation, medically administered nutrition and hydration, renal replacement therapy, vasoactive infusions or implanted electronic instruments such as cardiac defibrillators or ventricular assist devices. In some cases, treatment also can include transfusions, supplemental oxygen and various medications such as antibiotics and insulin.

Listening to all voices

Input from specialists in palliative care, ethics, pastoral care and other disciplines can be helpful when families and medical staffs are faced with how best to proceed in a child's care. Collaboration is common, though every case is different, said Kathryn L. Weise, M.D., M.A., FAAP, a lead author of the policy.

"Certainly, in some cases there are disagreements, but I tend to think of it more as a need for every person involved to listen to the values, hopes and fears of all stakeholders in the case, whether they are family members, distant family members, nurses, etc. ...Every case deserves very careful consideration of the values, hopes and best way to treat the child compassionately," said Dr. Weise, who is with the Center for Ethics, Humanities and Spiritual Care at Cleveland Clinic.

One example, she said, is a chronically ill child with life-limiting illness who is dying. A child with complex medical problems likely has input from many different subspecialists, perhaps a gastroenterologist, a cardiologist and an infectious diseases specialist, along with the general pediatrician. All have developed a special relationship with the family and feel a responsibility about what happens to the child.

"It can be very complex to manage communications with all of these providers," Dr. Weise said. "They may want to have input but may not have (all the) expertise. So choreographing communications, giving clear messages within the team but also to the family, requires very careful communication that can't be rushed."

The professional opinions behind treatment recommendations are critical to informing family decision-makers even when these views conflict, the policy states.

If a child is in hospice care or hospitalized in intensive care, primary care pediatricians may not be making the
bedside decisions, but they have an essential role in helping the family through decision-making and communicating with hospitalists and other staff members about the family's values, Dr. Weise noted.

Allowing the patient a say in his or her care also is critical, according to the policy.

"Some children, mostly teens but sometimes younger than that if they've had the illness for awhile, also deserve to know as much as they want to know communicated to them in an age-appropriate fashion so they are not left out," Dr. Weise said. "They may not be able to make decisions for themselves but still deserve to be respected as a major player as this unfolds."

In all instances, the Academy and other organizations support continuing palliative measures to manage a child's pain and suffering.

**Recommendations**

- Forgoing life-sustaining medical treatment is ethically supportable when the burdens of treatment outweigh benefits to the child. Communication should be respectful, truthful and thorough among the medical and family/patient decision-makers.
- Children are entitled to open and honest communication as age-appropriate.
- Ethics consultation can be useful to the health care team and family.
- Understanding of institutional, regional, state and national regulations related to forgoing life-sustaining medical treatment, including the Child Abuse Prevention and Treatment Act, is important to practice ethically within legal frameworks.
- While perceived disagreement among professionals can be stressful to families, the professional opinions behind treatment recommendations are critical for families' decision-making.
- In rare instances, it can be ethically supportable to forgo life-sustaining medical treatment without the family's agreement if there is an extreme burden of treatment with no benefit to the patient beyond postponement of death.
- Physicians who decline to participate in limitation or withdrawal of life-sustaining medical treatment due to their own moral, religious or personal beliefs should continue to care for the child until they can arrange for care by another physician.

**Resources**

- National Hospice and Palliative Care Organization
- AAP policy (2013) "Pediatric Palliative Care and Hospice Care Commitments, Guidelines, and Recommendations"