

How physicians should approach hard calls involving child patients

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Some of the most difficult medical decisions involve pediatric patients who may be unable to have a say in their own care. The AMA House of Delegates has adopted new ethical guidance for physicians to help parents and their children.

In its report presented at the 2018 AMA Interim Meeting, the AMA Council on Ethical and Judicial Affairs lays out some questions for parents and physicians to consider.

Those considerations include: overall goals for care, what the child's likely developmental course will be with and without immediate intervention, and whether interventions can reasonably be staged developmentally to allow the patient and family time to gain experience in living with a condition that is not immediately life-threatening.

"Few people know what they would do if faced with a life-altering medical situation involving their child," said AMA Immediate Past President David O. Barbe, MD.

"When confronting their child's unexpected diagnosis or uncertain prognosis, parents can struggle to balance their own hopes, fears and value commitments with the consequences of a medical choice. They need help," Dr. Barbe said. "The AMA's new ethical framework emphasizes a shared decision-making process where doctors help parents reach clarity and empower choices carefully tailored for each patient."

The new policy says that for health care decisions involving minor patients, physicians should:

- Provide compassionate, humane care to all pediatric patients.
- Negotiate with parents or guardians a shared understanding of the patient's medical and psychosocial needs and interests in the context of family relationships and resources.
- Develop an individualized plan of care that will best serve the patient, basing treatment recommendations on the best available evidence and in general preferring alternatives that will not foreclose important future choices by the adolescent and adult the patient will

become. Where there are questions about the efficacy or long-term impact of treatment alternatives, physicians should encourage ongoing collection of data to help clarify value to patients of different approaches to care.

- Work with parents or guardians to simplify complex treatment regimens whenever possible and educate parents or guardians in ways to avoid behaviors that will put the child or others at risk.
- Provide a supportive environment and encourage parents or guardians to discuss the child's health status with the patient, offering to facilitate the parent-child conversation for reluctant parents. Physicians should offer education and support to minimize the psychosocial impact of socially or culturally sensitive care, including putting the patient and parents or guardians in contact with others who have dealt with similar decisions and have volunteered their support as peers.
- When decisions involve life-sustaining treatment for a terminally ill child, ensure that patients have an opportunity to be involved in decision making in keeping with their ability to understand decisions and their desire to participate. Physicians should ensure that the patient and parents or guardians understand the prognosis (with and without treatment). They should discuss the option of initiating therapy with the intention of evaluating its clinical effectiveness for the patient after a specified time to determine whether it has led to improvement and confirm that if the intervention has not achieved agreed-on goals it may be discontinued.
- When it is not clear whether a specific intervention promotes the patient's interests, respect the decision of the patient (if the patient has capacity and is able to express a preference) and parents or guardians.
- When there is ongoing disagreement about patient's best interest or treatment recommendations, seek consultation with an ethics committee or other institutional resource.