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Reports advise on obtaining informed consent from parents, assent from patient

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By the time a 16-year-old and her mother came to see a pediatric surgeon about a breast abscess, the girl's mother had concluded that the treatment should be an incision and drainage.

But surgeon Aviva Katz, M.D., M.A., FACS, FAAP, turned to the patient in a discussion of the options: Trying antibiotics first, she suggested, might lend itself to needle aspiration and minimize any scarring on the breast.

Initially, including the daughter in the discussion process didn't sit well with the mother.

"The mother was very insistent at first that I speak with her, that *she* makes the decisions," Dr. Katz said. "I was finally able to have the mom calm down enough that I could work primarily with the teenager and make a plan that met her goals for minimizing the number of days she would need to be at the hospital, while at the same time minimizing any scarring on her breast."

While parents generally are recognized as the ethical and legal medical decision-makers for their children, pediatric patients — especially teens and preteens — should participate in decision-making commensurate with their development, according to a revised policy statement and technical report, *Informed Consent in Decision Making in Pediatric Practice* from the AAP Committee on Bioethics. Dr. Katz is a lead author of the reports, which are available at http://dx.doi.org/10.1542/peds.2016-1484 and http://dx.doi.org/10.1542/peds.2016-1485 and will be published in the August issue of *Pediatrics*.

Essential part of health care

Previous AAP statements recommended obtaining informed consent from parents or legal guardians; the most recent (1995) statement affirmed that *patients* should be included in the process. The 2016 policy reflects how pediatric decision-making is evolving in response to changes in information technology, scientific discoveries and legal rulings.

Pediatric practice is unique in that developmental maturation allows for increasing inclusion of the child's and adolescent's opinion in medical decision-making. Despite the Academy's longstanding view that older patients should be involved in the process, the technical report says there have not been "widespread understanding and endorsement among practitioners" of pediatric assent or refusal.

"What we're hoping to make clear with this statement is that everything you would normally do, where you would normally ask the parents for permission, you should be working with the child in terms of assent," Dr. Katz said.

That doesn't mean soliciting a child's assent if the treatment or intervention is essential. But the patient should be told that and not deceived.

Age-appropriate discussion

Assent from children as young as 7 years can foster moral growth and developing autonomy, according to the policy. Around that age, children enter a stage of development that allows for limited logical thought processes and the ability to develop a reasoned decision. Older adolescents, especially those who have dealt with chronic health issues, may be perfectly capable of engaging in the informed consent or refusal process for proposed goals of care.

"Let's empower our preteen and teenage patients," Dr. Katz said. "Let's really empower them. The more we involve them in medical decision-making, the better they'll be at medical decision-making and the stronger they'll be in terms of partnering with their physicians as they become adults.

Being open is critical for those with potentially life-threatening diseases, as well, she said.

"We can't expect anybody to make good decisions when they are in the ICU on a ventilator on medication," Dr. Katz said, "which is why we have to be more transparent working with our teens … before they are at that point."

In discussions with minors, clinicians must be adept at using developmentally appropriate language, a skill most pediatricians already have mastered.

When it comes to parents, however, it's not always easy to gauge their medical literacy level. Low health literacy, including in non-English speaking families, can lead to bad health outcomes, so trained interpreters are vital during the informed consent process.

Resolving conflicts

When an adolescent turns down a recommended treatment, it can be ethically and emotionally challenging. The involvement of psychiatric counselors, ethicists, child life specialists, social workers or other consultants may be necessary to help resolve the conflict. That's why knowledge of state laws on such treatment refusals is critical.

But dissent by a patient should carry considerable weight if the proposed intervention is nonessential, according to the policy. Young adults older than 18 who have no cognitive impairments legally can make their own decisions.

The reports also state that informed consent and assent obtained from children involved in research are clearly mandated, in contrast to the "recommended" guidance in clinical care.

Other recommendations

- Informed consent/permission/assent/refusal is a process, not a discrete event. It requires information sharing in ongoing physician-patient-family communication and education.
- Surrogate decision-making by parents/guardians should seek to maximize benefits for the child by balancing health care needs with social and emotional needs within the context of overall family goals, religious and cultural beliefs, and values.
- Physicians have a moral obligation and legal responsibility to question and, if necessary, to contest both the parents' and the patient's medical decisions if they put the patient at significant risk of serious harm.