

# Bioethics in Practice

## A Quarterly Column About Medical Ethics

### Questioning Parents' Medical Decisions

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#### INTRODUCTION

Most parents' decisions about the medical care of their children occur in private and in obscurity. Parents bring their children to the pediatrician, who, after evaluating the patient, recommends and initiates a treatment plan. Some situations may require consultation with a specialist. Even in these cases, treatment recommendations are generally fairly routine and initiated without further review. In complicated cases, the pediatrician may present multiple treatment options to the parents who select a treatment course. The presumption is that the parents will act in the child's best interest.

The most common conflict regarding parental decisionmaking in medical care arises when the parents choose to forgo potentially life-saving treatment for a child. When not providing the recommended treatment is deemed risky, court interventions are triggered. Special situations—such as the need for institutionalization for psychiatric reasons or sibling donor procedures—generally have guidelines in place to protect children when the parents' and the child's interests do not align. Additional issues must be considered when children are subjects in research, a topic recently reviewed here by Dr. White.<sup>1</sup>

With few exceptions, parents' decisions about children's healthcare are subject to virtually no attention or legal limitation unless a particular decision is characterized as neglect. In rare cases, however, the parents' choices, even though they may reflect careful consideration and are thought to be made in the child's best interest, raise significant ethical questions and cause potential conflict.

#### CLINICAL SCENARIO

I was asked to see and consider elective surgical procedures for a young girl with profound neurologic impairment who was approaching the expected age

of puberty. The mother had obviously researched options to care for her child, who had no ability for verbal communication and could communicate little except to relate discomfort or pain. The girl depended on her family for all of her care, including all feedings and hygiene. She could not ambulate and was immobile except when moved by others. Her mother reported that almost all of the women in her family suffered from painful menstrual cramps and fibrocystic disease of the breast that caused discomfort. Many of these female family members also had problems with ovarian cysts.

Her mother requested that we consider performing on her child a hysterectomy, bilateral oophorectomy, incidental appendectomy, and bilateral subcutaneous mastectomies of the child's small breast buds. The mother believed that these procedures would significantly decrease the chance that her daughter would have pain or discomfort that she could not communicate effectively. The appendectomy would be an incidental procedure to decrease the risk of appendicitis—the early symptoms of which the child would not be able to communicate.

After meeting with the mother, I was convinced that she believed this request to be in the best interest of her child, and I discussed the request with colleagues. We were concerned about removing healthy tissue to prevent symptoms we could not be sure she would have in an invasive procedure that would cause pain and entail some small risk of complications. Following my discussion with the mother, I presented her request to our Bioethics Committee. The committee carefully considered the request and then recommended that the mother seek a court-appointed special advocate for the child. Any decision to proceed with elective surgery would be made after an independent review concluded that the procedures did appear to be in the best interest of the

child. I brought this recommendation to the girl's mother. I do not know whether the mother sought a court-appointed special advocate or found care elsewhere. Although the outcome of this patient is unknown, the mother's request raised several important ethical issues.

## DISCUSSION

When approaching any ethical dilemma in medicine, it is reasonable to start with basic, widely held ethical principles. These include

- Autonomy—the right of patients to make their own healthcare decisions
- Beneficence—the treatment should benefit the patient
- Nonmaleficence—the obligation to do no harm
- Distributive justice—resources should be used in an equitable manner

Children are not able to make their own healthcare decisions; parents make the decisions instead. Adolescent minors are generally expected to assent to treatment, even if formal consent is required from the parents. For neurologically impaired children who have no capacity for autonomous decisionmaking, such as in this case, healthcare decisions are generally deferred to the parents.

The main issues in this case revolve around the question of benefit and the risk of harm. The patient's mother seemed quite convinced that the procedure would alleviate future pain and discomfort that the patient could not communicate. The strong family history of significant menstrual discomfort, fibrocystic disease of the breasts causing pain, and frequent ovarian cyst problems drove her request. The mother was also concerned that when these symptoms developed, the patient would be unable to understand the cause of her discomfort or communicate it to her caregivers. Although the mother's request was not as radical as proposals in other cases involving additional treatments to attenuate growth, she was requesting the removal of healthy tissue that was not causing any symptoms.

The unusual cases in which growth attenuation was the objective of a procedure have received some publicity in the mainstream media.<sup>2</sup> One of the objectives of growth attenuation treatment is to make caregiving easier, raising additional ethical concerns that the procedure is not for the patient's benefit. In those situations, increasing the chance that the patient could be cared for at home was an objective. In the case presented here, the mother's request seemed more clearly focused on the patient's comfort. The question of benefit to the patient clearly hinged on the potential to develop symptoms rather than active problems.

Potential harm to the patient was also a concern. The procedures (hysterectomy and bilateral oophorectomy, incidental appendectomy, and subcutaneous mastectomies) could likely be performed with a low risk of complications, but a small risk of significant complications existed. There would certainly be postoperative pain, and the patient could not be expected to understand the cause of the pain or understand the potential benefit that the mother expected long term.

An additional ethical concern was performing a sterilizing procedure. Many states require specific court authorization for any sterilizing procedure in a minor. Although this patient would never be expected to exercise independent reproductive decisionmaking, the history of involuntary sterilization and other questionable medical treatment of disabled patients raises significant ethical concerns—even in a case such as this where sterilization was not the stated purpose of the procedure.

In this case, Bioethics Committee consultation was helpful in elucidating potential conflicts. As pointed out by Dr Taylor,<sup>3</sup> bioethics consultation is intended to accomplish 4 things:

- Promote ethical resolution of care questions in a specific case
- Encourage respectful communication among involved parties
- Teach those involved in the case how to work through ethical questions
- Help institutions recognize issues that may require policy development

After reviewing the Bioethics Committee's recommendations, I believe the mother had a better understanding of the ethical questions her request posed to me and other members of the healthcare team. I do not know if she agreed with our concerns and conclusion, but I believe discussions with the mother achieved the first 2 goals. I am certain that the third goal was achieved, at least from my own perspective.

The Bioethics Committee recommended that the mother seek the opinion of a court-appointed child's advocate to ensure an objective assessment of the procedures' potential benefit to the patient. This particular situation did not involve any specific benefit to the parents, and the level of care necessary would not be significantly affected. Avoiding menstruation might minimally affect the attention to hygiene required of the caregivers. Other situations, such as procedures to attenuate growth, possess more potential for conflict. Some parents have argued that growth attenuation makes the patient's physical and mental age more congruous and allows the family to

care for the child at home more easily—presumably a better situation for the patient. However, an invasive and painful procedure performed to make caregiving easier clearly creates a situation in which the patient's and the parents' interests may not be aligned. This circumstance is ideal for involving a court-appointed advocate to ensure that decisions are made with the primary goal of helping the patient.

An additional benefit of an independent child advocate is to ensure that appropriate treatments are made available, which is preferable to the strict legal prohibition of certain procedures in disabled children. Prohibiting treatments in disabled children that would be available to other children is another form of disability discrimination and would therefore raise additional ethical questions.

## CONCLUSION

Although the outcome for this particular patient is unknown, this case illustrates important ethical principles in the care of children. Parents are assumed to act in the best interest of their children when making medical decisions, and they are appropriately given liberal authority to make those decisions. That autonomy is usually questioned only when the parents refuse treatment that is considered potentially lifesaving or when forgoing treatment presents significant risks. Judicial intervention is available for the majority of such cases to protect

children and ensure that they are treated appropriately.

Special circumstances—such as the participation of children in research, institutionalization for psychiatric disorders, and sibling donation for transplant—are generally covered by specific and widely recognized protections for children.

However, some unusual situations do not fall into these categories. In these cases, consultation with a bioethics committee is a useful first step for defining the issues contributing to conflict. In situations when the interests of the child and the parents are not aligned or in situations involving questionable benefit to the child, seeking a court-appointed child advocate can help guide treatment decisions that are consistent with the basic ethical principles of autonomy, beneficence, nonmaleficence, and distributive justice.

## REFERENCES

1. White M. Bioethics in practice: a quarterly column about medical ethics - can children participate in research? *Ochsner J.* 2012 Fall; 12(3):188-190.
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