

Session 8. Availability and Use of Pediatric Enhancements

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Overview

The advent of pediatric enhancements has introduced options and challenges, and the conversation must include unambiguous verbal parameters. Perhaps the most helpful and yet critical is the issue of whether an enhancement is to be therapeutic or nontherapeutic. If the former, the enhancement is designed and purported to be a replacement for a part or function that no longer functions well; if the latter, the enhancement is designed to exceed initial limitations. In essence, the enhancement can indeed be an option that makes the child's body "better than well."

Personal autonomy enjoys considerable endorsement, and even a minor child asking for a particular enhancement to make him faster, smarter, or stronger will likely result in a thoughtful—and perhaps even sympathetic—response from the parent and the pediatrician. As such, the use, misuse, and abuse of enhancements in the pediatric population should be of great concern to the parent and physician. Off-label use raises the particular concern of the safety profile of a drug (or procedure) as well as the ethics of such utilization. Of considerable importance with respect to the development of enhancements and enhancing procedures is the notion of allocation of resources and distributive justice.

Instructor's Guide

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Case Summary

A 24-year-old mother of 3 is your former patient. You recall she was an attractive and well-rounded teenager who excelled in many aspects of her high school life. Specifically, she was an accomplished gymnast with particular ability in the uneven parallel bars. In addition, she had stellar grades and on graduation from high school, had been accepted into an Ivy League college with aspirations of entrance into law school. You remember that she demanded increased doses of amphetamines and, from time to time, seemed to

require extra prescriptions. Reluctantly, at that time, she had admitted to you that she was taking extra doses of medications as she felt that the medication had helped her to concentrate better in gymnastics; in addition, she noticed that her study time had become more efficient. She had transferred her medical care to an internist some time ago. However, you had noticed her impressive legal career escalate as she had represented some high-profile plaintiffs in malpractice litigation. She now asks that you become the new pediatrician for her 4-year-old daughter. Apparently, her child shows promise in Suzuki string lessons, but she does not seem to have the temperament for prolonged practice times and becomes easily discouraged from lack of progress. She is confident that you will understand her predicament.

- Is this a situation in which the physician may have become morally complicit?
- The former patient legitimately expects a repeat of the prior situation—is there an obligation to protect the child from intervention?
- Does this constitute a violation of the principle of justice?

Alternative Cases

1. The parents of a short 12-year-old boy seek your endorsement of growth hormone treatment for their son. They are convinced that their own short stature has been a substantial hindrance to personal job promotion. The boy is presently free of relapse from acute lymphocytic leukemia recurrence for 5 years, and his growth has tracked at or below the third percentile for height over the past 6 years. The boy's parents have seen a recent infomercial extolling the benefits of increased final height in genetically short children. They plead with you for a referral to a local endocrinologist who has a reputation for being sympathetic to the use of growth hormone in situations with marginal medical indication.
 - How does parental pressure affect the care of a pediatric patient?
 - How should the pediatrician ensure that there is informed consent?
 - Does the pediatrician have a responsibility to help ensure the appropriate use of expensive medical resources?
2. A 21-year-old long-standing patient of yours is the lead alto saxophone for a local jazz group. The group has been offered a gig at a prestigious nightclub and a recording contract is a real possibility. Your patient must finance his own college education; to that end, he has a day job he must maintain. He has always required considerably more sleep than most teenagers. He informs you that the performance gig will be for an extended period and that he has taken "uppers" provided by the group's percussionist. Your patient has heard anecdotal stories about fatigued airplane pilots taking prescription medication to help keep them awake on long flights. He begs you to provide this medication for him so that he will "not let down" the other members of his group. Ought the pediatrician necessarily acquiesce to this request?

Learning Objectives

1. Understand the allure of enhancements in the pediatric population.
2. Recognize the potential complicity of parents and physicians in a pediatric request for enhancement.
3. Understand how the traditional goals of medicine may be in conflict with requests for off-label use of “lifestyle drugs.”
4. Recognize that the prescription and use of enhancements embody an allocation of resource issue that will affect the distributive justice of medical resources.
5. Be aware of the indications and controversies regarding the use of growth hormone.

Suggested Reading for Instructor

American Academy of Pediatrics, Committee on Bioethics. Informed consent in decision-making in pediatric practice. *Pediatrics*. 2016;138(2):1-7

American Academy of Pediatrics, Committee on Bioethics. Pediatrician-family-patient relationships: managing the boundaries. *Pediatrics*. 2009;124(6):1685–1688

American Academy of Pediatrics, Committee on Sports Medicine and Fitness. Use of performance-enhancing substances. *Pediatrics*. 2005;115(4):1103–1106

Further Reading

Borenstein J. Shaping our future: the implications of genetic enhancement. *Hum Reprod Genet Ethics*. 2007;13(2):4–15

Bostrom N. Dignity and enhancement. In: President’s Council on Bioethics. *Human Dignity and Bioethics: Essays Commissioned by the President’s Council on Bioethics*. Washington, DC: Presidential Commission for the Study of Bioethical Issues; 2008:173-206

Cheshire WP. Just enhancement. *Ethics Med*. 2010;26(1):5–6

Greely H, Sahakian B, Harris J, et al. Towards responsible use of cognitive-enhancing drugs by the healthy. *Nature*. 2008;456(7223):702–705

Larriviere D, Williams MA, Rizzo M, Bonnie RJ. Responding to requests from adult patients for neuroenhancements. *Neurology*. 2009;73(17):1406–1412

Parens E. Authenticity and ambivalence: toward understanding the enhancement debate. *Hastings Cent Rep*. 2005;35(3):34–41

Yates FD. Ethics for the pediatrician: the persuasion of enhancements in pediatrics.

Case Discussion

In considering the use of enhancements, the physician needs to consider the goals of medicine and the purpose of various treatment modalities.

The primary goals of medicine are to assist in preventive health; to assist in the process of healing and recuperation back to normalcy; and in the case of lost capacity as a result of illness, disease, or injury, to assist in restoring as much of normal function and ability as possible. To this end, we may consider such items as eyewear, dentures, prostheses, and even hairpieces as therapeutic. Treatment modalities that are designed to make the patient better than well are not consistent with the goals of medicine and fall outside the purview of medical care in the Hippocratic tradition. In addition, the American Academy of Pediatrics (AAP) has observed that the intentional use of performance-enhancing substances is morally and ethically indefensible, the use of such enhancements may pose a health risk to the patient, and the use of enhancements tends to devalue the principles of sound physical training and good health care.

How does (and should) the physician assess whether an enhancement is therapeutic or nontherapeutic?

If the physician is operating under the traditional goals of medicine, the distinction between therapeutic and nontherapeutic becomes appropriate and necessary. A therapeutic enhancement would be consistent with traditional goals; a nontherapeutic enhancement takes a different position, as these modalities typically are requested (or expected) to make an individual stronger, faster, smarter, or taller than others. Bostrom noted that an enhancement is “an intervention that improves the functioning of some subsystem of an organism beyond its reference state; or that creates an entirely new functioning or subsystem that the organism previously lacked.” This enhancement is designed and expected to help the individual exceed the inherent normal and genetic entitlements. Germane to this consideration is the intent of the requesting individual. That is, is the intention to purposely excel beyond what would be obtainable under ordinary circumstances?

The physician has considerable involvement in these situations, and it would not be unusual for a conflict of interest to arise.

Pediatricians are trained to provide ordinary and extraordinary care. Coupled with this education is the experience to know when the differing levels of care are appropriate. In addition to wanting the patient to flourish, the physician must help maintain the patient’s health and well-being. Inherently, one of a pediatrician’s goals is to provide a consistent level of care to all his or her patients. We recognize that from time to time, certain patients will require extraordinary care (ie, additional time and resources) to return to their prior state of good health, and this is a routine part of pediatric care. However, a purposeful request from a patient or parent for a specific enhancing treatment to exceed normalcy may (and perhaps even should) create some angst in the heart of the busy pediatrician. The actual conflict may arise at several different levels: parental preferences

for a minor child who may have incomplete comprehension and cannot execute informed consent; the physician who may have control over the distribution of resources and does not want to be pressured into acquiescing in the provision of resources; and physician desire to help the patient flourish and accomplish goals and yet not be aware of the long-term health issues of a particular enhancement.

When a parent requests treatment for a minor child, how does the physician balance the issues of parental authority and the best interest of the child?

The pediatrician's primary goal must be the health and well-being of the child, and our advocacy for the child should be unswerving. Parental authority deserves respect and proper consideration, and in most cases the request stemming from this authority aligns with the best interest of the patient or is no worse than value neutral (ie, no foreseeable harm for the patient). However, if a supplement or enhancement requires repeated injections or blood tests, the physician should seek age-appropriate, reasonable assent from the child for the actions to be performed. On occasion, these situations become highly charged, and it may be appropriate and necessary to seek an externally appointed child advocate in consultation. Legal recourse should always be one of the last options.

In agreeing to provide treatment, is it possible that the physician has become complicit and is violating the principles of justice?

Cheshire has observed that there are 3 types of justice: commutative, social, and distributive. The pediatrician should be familiar with each category because care for our patients may intersect with each of them. Commutative justice suggests that there should be fairness in competition. Enhancements augmenting our patients' abilities may well place others at a disadvantage. The principle of social justice is satisfied when patients take medication for cognitive disorders such as attention-deficit/hyperactivity disorder to restore mental capabilities to the point of full participation in society. Distributive justice ensures that there is equitable allocation of limited resources; medications, supplements, procedural treatments, and qualified professionals to distribute and monitor.

Alternatively, in encouraging the use of enhancements, Greely *et al* noted that the safety profile should not be different for off-label usage, there should be freedom to use enhancements without coercion from any perspective, and the fairness doctrine should not apply to the use of medications, supplements, etc, any more than it applies to the use of private tutoring. A primary care physician presented with 2 patients in similar circumstances, but one less affluent than the other, could provide a specific enhancement to one and not the other because of the family's personal finances. It is, therefore, possible that the pediatrician may become complicit with violation of the principles of justice without intending to do so.

How does the issue of informed consent affect the use of enhancements?

Informed consent requires that the patient comply with the triad of having adequate information, decisional capacity, and the opportunity to make a decision without coercion. In addition, having the ability to make decisions implies that one can understand and repeat the information, process the information by understanding the pros and cons, and balance the pros and cons to make an actionable decision and be able to explain the decision. Informed consent is appropriate in the use of enhancements, because

often there will be a financial cost at some level (most often to the patient and family) and there will be unknowns relative to future medical effects of the proposed or desired enhancement.

Does the physician have a duty to consider the issue of allocation of resources?

The pediatrician has the responsibility of being a good steward of the medical resources at his or her disposal; there is a simultaneous fiduciary accountability to the patient individually and to society at large. Because of the covenantal agreement with the patient, the pediatrician's primary allegiance is to the child and family. Nonetheless, this allegiance must be balanced with the responsibility to society, and the physician ought to be cognizant of future availability of resources.

Under what circumstances can the physician refuse to provide the requested enhancement?

The physician has the endorsement of the AAP in refusing to participate in many of these treatment requests for enhancement. The health of the patient is of primary importance. Issues of justice and fairness will always present themselves in these discussions, and the physician needs to be cognizant that the use of an enhancement in a particular patient will quite naturally affect the circle of individuals with whom the patient is involved on a regular basis. Right of conscience issues also often come to bear, and the experienced physician may well feel uncomfortable in participating when the stated intent is to have a selective advantage over the competition. The physician also needs to be aware that once started on this path, it will be very difficult to discontinue the provision of the enhancement.

Conclusions and Suggestions

The availability and use of pediatric enhancements will necessarily affect the medical, ethical, legal, and social aspects of our patients and the society in which we live and work. If the use of enhancements is promoted—and perhaps even encouraged—in nontherapeutic situations, the physician would be treating what was once recognized as part of the human condition, thereby obscuring the goals of medicine, jeopardizing the safety of his or her patients, and devaluing the child's future personal accomplishments.

This instructor's guide is part of a collection edited by Douglas S. Diekema, MD, MPH, FAAP; Steven R. Leuthner, MD, MA FAAP; Felipe E. Vizcarrondo, MD, MA, FAAP on behalf of the American Academy of Pediatrics Committee on Bioethics and Section on Bioethics.

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