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The Third Chair in the Examination Room: Practical Ethics of Decision-Making for the Pediatric Dermatologist

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Abstract Decision-making in pediatric dermatology follows a model common to pediatric care. The parent or legal guardian provides informed permission for interventions with the child's assent, where possible, acting in the best interests of the child. In most cases, this model works smoothly, but if the parent's wishes and/or parenting style or the physician's recommendations conflict with the wishes of the child, the minor patient may demand care that conflicts with the better judgment of the physician or parent, or the parent may not always act in what the physician believes to be the child's best interests. Practical strategies for dealing with the ethical challenges of shared decision-making are presented.

Keywords Pediatric bioethics · Dermatology · Ethics · Adolescent decision-making · Mature minor · Informed consent · Assent · Autonomy · Authoritative parenting · Parental authority

Introduction

In contrast to specialties such as neurology, neonatology, and critical care, most ethical challenges in pediatric dermatology take place within the four walls of the examination room. Astute observers will note that there is a third chair in the pediatric examination room. That is because in pediatric care, the physician-patient relationship, so fundamental to the practice of medicine, includes a third party, the parent or guardian. The role of this third party (hereinafter called the parent for brevity) varies depending on the age and maturity of the minor patient, the gravity and consequences of the decisions to be made, as well as legal and cultural factors. The decision-making model is fluid, depending on numerous situational factors. We will explore through case vignettes the ethical challenges of decision-making in pediatric dermatology practice.

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Some Basic Concepts and Terminology

Several terms and concepts need to be defined or introduced first. The concept of autonomy is a foundation of contemporary Western medical ethics. It is the concept that patients should be allowed to make medical decisions regarding their own care and that they should have as much information as a reasonable person would need to make such decisions. It forms the basis of informed consent, which is the decision to accept or decline a medical intervention by an individual who possesses the necessary information, decision-making capacity, and the legal right to do so. By common law legal definition, minors (under the age of 18 years), unless legally designated otherwise, are not considered autonomous and, indeed, are regarded as a vulnerable population, and therefore parents have the legal and moral authority to act as their surrogate decision makers. In 1995, the American Academy of Pediatrics (AAP) [1] endorsed the concepts of "informed permission" and "assent of the patient." Since children do not possess the legal standing to autonomously declare their wishes in an advanced healthcare directive to guide surrogate decision-making, parents are said to provide informed

permission, with the child's assent where possible. In contrast to consent, parents are granting permission for what they view as being in the child's best interests rather than what the child wants. Assent is an active shared decision-making process in which the child is presented with information at a "pace and level" that they can comprehend [2]. In the case of situations in which treatment is neither life-saving nor necessary to prevent serious harm, the Confederation of European Specialists in Pediatrics has endorsed the child's right to assent or dissent to the proposed intervention [2]. It is the responsibility of the healthcare provider to assess the ability of the child to provide assent. According to the AAP [1], this not only involves assessing comprehension, but the active process of helping the child achieve awareness of his/her condition, educating the child as to what to expect from the procedure or treatment in an age and maturity-appropriate way, assessing factors influencing his/her responses, such as fear or undue coercion or pressure, and soliciting the child's acceptance of the proposed intervention. Respect for the child's right to assent or dissent to the extent maturity permits is essential to the development of the child's trust in the healthcare provider.

In situations necessary to prevent serious harm or death, or where the child is too young or immature to provide assent, the parent is expected to act in the best interest of the child. The best interests standard was adopted to allow the interests of incapacitated or immature individuals to have legal standing independent of the surrogate decision maker's interests. It protects the interests of the minor should the decisions of the surrogate or parent endanger their life or welfare. The standard is not absolute or ideal; it allows for choosing options that are reasonable and maximize the benefits to the child relative to the burdens on the family and society's resources and values [3].

There are exceptions to the generally recognized age of majority of 18 years in medical decision-making. State laws in the USA, to a variable degree, have long recognized the rights of minors, regardless of maturity, to independently and confidentially seek testing or care for sexually transmitted diseases, sexual abuse, pregnancy, contraception, mental illness, and substance abuse [4]. In addition, the special status of "emancipated minor" has been accorded to adolescents of a certain age who are pregnant, married, are parents themselves, living independently from their parents, enlisted in the military, or are incarcerated [4]. In emergency situations, medical personnel can provide treatment to the child, as it is assumed that a reasonable parent would have provided consent in that situation [5•]. The concept of the "mature minor" is somewhat more ambiguous. While, in practice, there has been a shift from statutory age of consent to recognition and respect for the individual abilities, maturity, and experiences of minors to articulate consent [6], most jurisdictions require parental consent, even when the minor is considered to be cognitively mature [7••].

With the above background, we shall now examine a variety of scenarios depicting the ethical challenges of shared decision-making in which the opinions, desires, or interests of the parent, child, and healthcare provider are not necessarily aligned.

When Parental Paternalism Conflicts with a Child's Wishes

A 6-year-old boy with impetiginized atopic dermatitis vociferously refuses a wound culture.

Clinically, a wound culture is warranted and would benefit the child by enabling the correct choice of antibiotic. A 6-year-old, however, may not be able to comprehend the reasoning for the test and thus does not have the capacity to make his/her own medical decisions. Thus, in situations such as this, the parent would need to make the decision for the child without regard to the child's dissent. Parents are generally assumed to be in the best position to make medical decisions for their child because they are expected (a) to care about the well-being of the child; (b) to be mature, knowledgeable, and be emotionally competent to better understand and assess the various clinical scenarios that may arise; and (c) to be able to make decisions in the child's best interest with respect to family values, resources, and goals of care [8, 9].

While in most cases, parents do have their child's best interest in mind, it is important to involve the child in his/her own medical decision-making whenever possible. This includes explaining the reasoning behind certain tests and exploring his/her reservations and fears about the proposed plan. Did he have a bad experience previously with a culture swab? Is he afraid it will hurt? Doing the test may even involve physical restraint or "clinical holding" [10], as it would be out of medical necessity and not intended to cause harm or degradation to the child.

A 7-year-old girl presents with periungal and plantar warts on the hands and feet. Her mother is upset. She finds the warts unpleasant and is concerned her daughter will spread the virus to her siblings and demands treatment. After explaining the options for treatment, the mother states her daughter can "handle it" and she can hold her child for the procedure. She asks her daughter if she wants the warts gone and the child nods "yes."

Although the child has "agreed" to the procedure, it is questionable whether she understands the consequences of being treated for an otherwise benign self-healing process (significant pain, potential blistering, being restrained during the procedure). In this scenario, assent is clearly not informed and is likely tainted by subtle (or otherwise) parental coercion.

Assent is only valid when it is voluntary and informed. For children, autonomy and consent must be modified due to their limited development and ability to comprehend the risks and consequences to their medical decisions. However, children are considered a vulnerable population as they are dependent on their parents for guardianship and livelihood [11]. They also are often influenced by their parents' preferences and frequently default to their parents to make their decisions [12]. Thus, truly voluntary decisions by children are uncommon, as these are usually made on their behalf by a physician, a parent, or both.

While in most cases, the parents have their child's best interests in mind, there are certain procedures where the child is at risk for unintentional physical and emotional harm. Warts, in this example, spontaneously resolve and thus the medical necessity for treatment in the absence of symptoms is debatable. The discomfort and restraint required for treatment might be traumatic not only for the child but also the staff members involved [10]. Discussing alternatives (i.e., waiting versus over-the-counter keratolytic treatments) would not only be reasonable, but the child's refusal to cooperate for the procedure should be respected in this situation. In situations such as this, the pediatric dermatologist must weigh the wishes of both parties and come to a decision that respects the integrity and autonomy of the child while respecting the authority and wishes of the parent. In situations such as this that do not threaten the health or future well-being of the child, considerable weight must be given to the dissent of the patient.

When Authoritarian Parenting Clashes with the Patient's Interests

A 15-year-old boy with extensive vitiligo, under treatment with narrowband ultraviolet B phototherapy for over a year, returns for a follow-up visit. The dermatologist has cared for him since he was a baby; initially for atopic dermatitis, and then later for vitiligo. He is quite mature for his age both physically and also emotionally and seems to have a good understanding of his skin condition. Over the last several clinic visits, however, there clearly have been increasing tensions between him and his father who accompanies him for his visits. He reveals that he feels frustrated because his treatment regimen requires him to come to the phototherapy facility three times a week after school, which has prevented him from participating in after-school programs. He states that he accepts the depigmentation of his skin. He feels that the time investment in phototherapy treatment is more burdensome than pigment loss. His father adamantly insists that he continue his treatments. He states that his son is not old enough to understand the consequences of not treating his skin condition or to make his own medical decisions.

It is particularly challenging when parental authority clashes with the autonomous assent or dissent of an adolescent. While the patient in this scenario has not reached the statutory age of majority, he is cognitively mature enough to weigh the potential risks and benefits of his treatment. Furthermore, the physician has known the patient for many years and has a good sense of his level of maturity and overall comprehension of his disease. Ideally, the goal would be for the physician to involve the parent and son in shared decision-making that respects both the parent's moral and legal authority to make decisions he perceives to be in the best interests of the child while respecting the right of his son to make his wishes known and taken into consideration in the decision-making process. As previously noted, the "best interests standard" is flexible. Reasonable alternatives (i.e., in-home light box, flexible scheduling, or even treatment holidays during certain sports seasons) should be explored. The concerns and viewpoints of both parent and child should be heard and respected. Is it realistic to expect cosmetically acceptable repigmentation with further therapy? Is there a point at which the medical risks, let alone the inconvenience to the child, will begin to outweigh the benefits? Does the patient even care about achieving repigmentation? Once these questions and reasonable options have been explored, a satisfactory shared decision can be made that all parties can live with.

As children develop, they should take a greater role in their own medical decisions whenever possible. Physicians are also encouraged by the American Academy of Pediatrics to assess each patient's assent based on his/her level of maturity and level of understanding about the disease and recommended intervention(s) [1]. Learning about their treatment options and potential consequences as well as risks or benefits are developmentally important experiences. This is especially the case for adolescents. During these formative years, they are seeking more independence in various aspects of their life, which may not unreasonably include their own medical decisions [13].

When an Adolescents' Unreasonable Request for Care Conflicts with the Physician's Medical Judgment

A 16-year-old boy presents with his mother, requesting (actually, demanding) that all the moles on his face, chest, and back be removed because he "hates them." After the dermatologist calmly presents the risks of hypertrophic and keloid scarring on the trunk, as well as the costs of the procedure that are unlikely to be covered by health insurance because of the lack of medical necessity, he states, "I don't care! That's what I want. If you won't do it, I'll go to someone else who will!" His mother is conflicted. She wants to do what will make her son happiest.

The adolescent brain is both structurally and functionally different from the adult brain. Cognitive studies have shown that adolescents can make informed decisions like an adult in some situations but can display limited foresight or impulse control (executive cortical function) in other situations [14•, 15]. In fact,

in highly emotional situations, the limbic system, which is more mature, tends to dominate the prefrontal cortex, which lags in its development [16]. This can lead to high-risk behaviors. Teenagers, therefore, while capable of predicting and foreseeing risks, benefits, and outcomes associated with different decisions, may have biologically associated limitations on their ability to control their impulses and are more likely to make risky decisions in emotionally charged situations [17]. Thus, many would argue that it would be reasonable to deny a potentially cosmetic or medically unnecessary procedure to a teenager, as in the above case. The patient clearly lacks the maturity to factor the risks into his decision-making. The physician could offer a reasonable compromise of removing one mole that particularly bothers the patient, so that both parent and patient can see how the excision heals, as well as what would be involved in multiple procedures, but is under no obligation to suspend good medical judgment by acceding to the patient's (or a parent's) unreasonable requests for treatment (even after the patient reaches the age of majority).

Given their children's developmental limitations and lack of experience with decision-making, the challenge often falls upon the parents to walk the fine line between giving their children more autonomy in their own medical decisions while exercising parental moral authority. Authoritative parenting is meant to support a child as he/she develops into an effective and competent adult decision maker. In fact, higher self-esteem [18–20], fewer psychological and adjustment problems, and better academic performances [21, 22] have been attributed to authoritative parenting. Setting limits on behaviors and decisions thru authoritative parenting helps foster responsible and effective decision makers [23]. Children who are allowed to act as their own authoritative decision makers early in life tend to become less effective at making decisions later [23]. Thus, parents must assess each situation and choose whether to take on a more authoritative role versus advisory role.

When Parental Refusal of Treatment Conflicts with the Physican's Medical Judgment

A 15-year-old male presents with nodulocystic acne with early scarring. He has failed multiple oral and topical antibiotics, topical retinoids, and topical benzoyl peroxide. The dermatologist recommends isotretinoin, but after reading the patient information booklet and consent form, the patient's parents refuse to allow their son to be prescribed this medication. They insist on something "more natural." The patient is desperate to start isotretinoin. His well-being and psyche have been severely impacted by his skin condition.

Pediatric dermatologists have all encountered situations in which parents refuse treatment with topical steroids for eczema, isotretinoin (or systemic antibiotics) for acne, and systemic therapy for severe psoriasis. The physician needs to understand the basis of the parent's reluctance or fear in these cases. Often, it is hearsay, possibly interpreted inaccurately or out of context, or unfiltered information from the Internet or cable television. The information might be impactful, but inaccurate. The physician will need to present the factual information in a calm, reasoned, nonjudgmental way, discuss the alternatives and why they may not be indicated, and stress the obligation of beneficence owed to the patient. The parent may need time to ask questions, digest the information, and even get a second opinion, if necessary. Dialogue should be kept open. Ultimately, in a nonlife-threatening situation such as this, the parent has the final authority, regardless of the maturity of the minor patient. In a life-threatening situation, legal avenues to override the parents' authority might be open, but this would be considered a last resort once all avenues including ethics consultation and the intervention of trusted authorities such as the patient's primary physician failed.

Conclusion

While medical decision-making in the dermatology examination room is usually smooth and straightforward, the introduction of a third chair into the examination room when the patient is a minor introduces a layer of complexity in the process that can lead to conflicting wishes and interests. While acting in the child's best interests should be the guiding principle, imprecise definition of what this represents, differing cultural expectations and parenting styles, and widely varying levels of cognitive maturity of the child can present significant ethical challenges. Knowledge of the relevant law and having a practical framework for handling these challenges can lead to more satisfying and beneficial outcomes.

Compliance with Ethics Guidelines

Conflict of Interest AR Wang and L Bercovitch both declare no conflicts of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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- •• Of major importance

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