Parental decisions for adolescent patients: Ethical considerations of information withholding

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CASE SCENARIO

Dr Snow cares for a 44-year-old female with atopic dermatitis and alopecia universalis. At the age of 38 years, the patient developed alopecia areata that rapidly progressed to alopecia universalis within a 4-week time period. She failed courses of prednisone, hydroxychloroquine, iron supplementation, and bimatoprost solution. She has resigned herself to the fact that hair regrowth is highly unlikely and now wears a wig and has eyebrows that are tattooed.

At the end of a routine atopic dermatitis visit, the patient became tearful as she described her fears that her 16-year-old daughter might be developing alopecia areata. The patient made an appointment to bring her daughter to Dr Snow the following week for evaluation of the patchy hair loss. The patient asks Dr Snow to treat her daughter if needed (ie, with intralesional steroids) but to avoid discussing the diagnosis and prognosis. The patient worries that a verbal diagnosis of alopecia would be emotionally and psychologically devastating to her daughter, who was old enough to have witnessed her mother's rapid progression to alopecia universalis just a few years prior. The patient's daughter is preparing for college admission; thus, the patient is worried that the appointment may add significant stress during a critical time period.

At the daughter's appointment, Dr Snow finds several foci of round patches of nonscarring hair loss with slight erythema on the scalp. Hairs along the periphery are easily removed with gentle pulling, and closer examination reveals exclamation point hairs. How should Dr Snow proceed?

Dr Snow should:

A. Explain to the mother that withholding medical information (ie, diagnosis, prognosis, and treatment) would be a violation of her daughter's autonomy. Discuss diagnosis, prognosis, and treatment options directly with patient.

B. Ask the mother to step out of the room during the visit, then ask the daughter what she understands of her hair loss and how much medical information she wants to know.

C. Respect the mother's request to withhold information but treat the daughter. Without divulging a technical diagnosis or prognosis, inject the scalp with intralesional triamcinolone. If the patient asks questions, defer all questions to her mother.

D. Agree to withhold information unless directly confronted by the daughter. Inject the scalp with intralesional triamcinolone. If the patient asks questions about her diagnosis and prognosis, answer them directly and openly.

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DISCUSSION

This case highlights the balance between patient autonomy, information control, and avoiding emotional and psychological harm. During her own distressful course of alopecia universalis, the mother has developed a trusting relationship with Dr Snow. She is a clear advocate for her daughter's emotional well-being and believes that a verbal diagnosis of alopecia would be devastating to her daughter's psyche and could possibly upset her academic and social tracks during a critical time in high school.

Parents, keeping the best interests of their child in mind, often deliberate whether full-disclosure of a medically poor prognosis is the right decision. This is an ethical question that many physicians and parents face within the fields of oncology and palliative care. Experts consider family values, the family's reasoning behind withholding medical information, and what the patient knows and wants to know before discussing progressive, terminal illnesses.[1] Patient's initial distress gradually gives way to comfort and calm when they understand and have clear communication around a diagnosis.[2] Physicians should balance respect for a family's decision with maintenance of personal integrity (ie, not lying if a patient asks specific, pointed questions). Although alopecia areata and alopecia universalis are benign, non—life-threatening conditions, the psychological ramifications are profound and the implications of diagnosis and prognosis deserve similar deliberation.

The American Academy of Pediatrics[3] asserts that parents are the legal and ethical surrogates for decisions regarding pediatric and adolescent patients under the age of majority. This is predicated on the notion that parents understand and have a comprehensive view of what is best for their child. Within the framework of respect for family autonomy, physicians should engage adolescent patients in decision making commensurate with their development. Allowing patients to take larger stakes in their care commensurate with their mental development produces understanding and treatment compliance.

Up to 25% of patients with alopecia areata can progress to alopecia universalis, with less than 10% experiencing full regrowth.[4] The mother is familiar with these prognostic values and wants to shield her daughter from that reality. The mother is making a decision that balances health care needs with social (religious, cultural) and emotional needs. Although withholding information may be uncomfortable, the physician would be reasonable to respect the mother's request to a certain extent. Unintentional deception, ambiguity, and omission of information may provide short-term benefits while the disease is mild, but it can also rob a patient of future opportunities to set realistic and achievable goals.[2]

ANALYSIS OF CASE SCENARIO

Option A would promote patient autonomy but directly contradicts what the mother has requested of Dr Snow. This violates the mother's autonomy and legal authority. Parents are assumed to know the most and understand the implications of medical decisions regarding their child. Unless the action (or lack of action) is dangerous, neglectful, or abusive to the child, physicians cannot legally overturn a parent's decision. In a state where the patient is younger than the age of majority (typically 18 years), the mother functions as the legal surrogate of the daughter. This supposes that the daughter is not an emancipated minor or obtaining medical care for sexually transmitted infections, contraception, mental health, or substance abuse.

With regard to option B, joint, informed discussion with competent adolescents is encouraged. Discussing complex diagnoses often does not cause the harm that patients and providers fear it will. In fact, direct discussion may help curb the misunderstanding or false perceptions that many children and adolescents have of their medical condition.[5] If the mother had invited open discussion with her daughter, this would be an appropriate option.

Regarding option C, parents have the right to make reasonable decisions that do not place the child in immediate danger or risk. Given the mother's knowledge and relationship with her daughter, it is reasonable to support her request to volunteer minimal information regarding diagnosis and prognosis. There is not enough risk or danger involved to override the mother's wishes. If the patient asks direct questions, physicians and parents should answer truthfully and age appropriately (option D).

In option D, the adolescent patient has demonstrated competence and understanding of her medical condition. Dr Snow should initiate a discussion with the mother and daughter about how much information the 2

would like to receive while being sensitive to the mother's earlier request. If the patient is interested in her health care, the physician should provide information on the illness and treatments commensurate with the patient's developmental age.

BOTTOM LINE

Physicians should encourage developmentally appropriate adolescent autonomy while having respect for parental autonomy and family values. Parents are recognized as the ethical and legal surrogate decision makers when the patient is under the age of majority. This assumes that the parent is making a decision that takes into account the patient's best physical, mental, and social interests. If prompted, physicians should address questions about diagnosis and prognosis in order to lay down tracks for realistic hopes, fears, and goals for management. Discussions should occur multiple times and be consistent with the patient and family's values.

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