

Section on Bioethics 2009 Essay Contest 1st Prize Essay

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Advocating Autonomy: Fulfilling Our Duty to Adolescents at the End of Life

In the last half-century the physician-patient relationship has dramatically shifted from the Hippocratic tradition of medical paternalism to a model based on respect for patient autonomy. The ideals of beneficence and nonmaleficence gave way to the doctrines of informed consent and shared decision-making. However the application of “respect for persons” is not straightforward when the patient is a minor. Our societal traditions allow parents almost complete discretion in shaping the course of their children’s lives. The presumption extends that parents hold the best interests of their child at heart when making medical decisions. But even as we practice deference to parental autonomy, pediatricians are compelled by a stronger commitment to the ideal of beneficence, the welfare of our patient. We describe this as *advocacy*. In our role as child advocates we override parental autonomy when we suspect abuse or neglect and when we strongly disagree with a parent’s medical decisions. Because our purpose is more often to *protect* children than to support their individuality I believe our commitment to advocacy is philosophically more consistent with traditional paternalism than the modern values of self-determinism and autonomy. This paradox is rarely apparent, as most of the time we achieve consensus between a parent’s decisions and our own opinions regarding the best interests of their child. But as that child becomes an adolescent and develops the maturity to make his or her own decisions we are confronted by another *person* who deserves respect. Ironically, the intrinsic ambivalence of our specialty towards the principle of autonomy may prevent us from recognizing and supporting this transformation, especially in the setting of chronic illness and at the end of life (EOL).

Katherine (not her real name) was a shy, respectful 16-year-old when she underwent bone marrow transplantation for myelodysplastic syndrome. Her course was complicated by numerous infections and multiple organ dysfunctions necessitating

repeated intensive care unit (ICU) admissions, advanced support technologies, and invasive procedures. Katherine participated in the initial consent conference and gave written consent for the transplant along with her parents. But as her illness progressed she was progressively less engaged with the medical care team. Her increasingly protective parents avoided any discussion of her illness in her presence, and she did not ask questions. Katherine's physicians offered the option of accepting natural death (AND) to her parents in a conference held outside her room. Tearfully, the parents expressed that they still hoped for a miracle and were unwilling to limit her care in any way. A few days later Katherine developed progressive respiratory failure. When the ICU team arrived, they asked permission to explain what was happening to Katherine and to ask what her preferences for EOL care would be, but her parents refused. Katherine was sedated, intubated, and transported to the ICU, where her condition worsened despite maximal pharmacologic and mechanical support. Eventually her parents agreed to an AND order, and she died soon after.

Pediatricians, ethicists, and lawmakers continue to debate the decision-making capacity of adolescents and the degree of autonomy they ought to possess. Weithorn and Campbell tested specific components of competency, showing that adolescents \geq 14 years of age did not differ from young adults in their ability to understand diagnostic and treatment information, rationally consider alternatives, and make reasonable choices.¹ Developmental analyses indicate that by age 11 children begin to understand the physiologic basis of disease,² and children as young as 8-10 years may be capable of an "adult" understanding of death as universal, unalterable, and permanent.³ With support from legal cases and professional societies this body of work has resulted in general agreement that we ought to obtain informed consent from adolescents with "appropriate decisional capacity", usually those \geq 14 years, and that we should seek the assent of younger children along with informed permission of their parents. These guidelines are followed stringently in research settings and less consistently in clinical practice. Permitting adolescents to *dissent*, especially to life-sustaining medical treatment (LSMT), is more controversial – and more difficult for both parents and pediatricians to accept.

Lainie Friedman Ross is among the most prominent voices cautioning against allowing adolescents autonomy in making EOL decisions. She argues that competency does not equal good judgment and that adolescents lack the real world experience to make important decisions. She worries that we risk sacrificing their “long-term autonomy” in the name of “present-day autonomy”.⁴ Schoeman and others argue that the best interests of both the child and the society are closely tied to the integrity of the family⁵ and that when medical teams intervene we send a dangerous message. Certainly as pediatricians we recognize the importance of family and know that our patients need their parents’ presence and involvement. Since cognitive development occurs along a continuum, we also recognize the danger in setting age-specific rules to determine when an adolescent’s health decisions should take precedence over the parents’ opinions. But “long-term autonomy” matters little when an adolescent approaches the end of life, and familial integrity is unlikely to be enhanced by allowing the adolescent to experience an emotionally disconnected, medically invasive death.

The AAP has stated that because of the gravity inherent to EOL situations the wishes and feelings of children in regards to treatment ought to be carefully elicited and respected. They support the right of competent adolescents to make their own decisions regarding EOL care,^{6, 7} and this position has been echoed by the courts.⁸ But how often do we give adolescents this opportunity? Based on published cases it seems this right is not routinely offered to all, rather granted only to those assertive enough to claim it. When adolescents are asked about their preferences their responses are not dissimilar to those of adults. They want their physician to initiate discussions about EOL issues and they want to share (but not abdicate) the decision-making process with their family.⁹ Why then do we so often exclude our adolescent patients from these discussions? Often it is in deference to parental wishes. Even when adolescents are cognitively capable their parents may fear that they will be unable to deal emotionally with the information. Parents want to avoid burdening their child with difficult decisions, and they may believe that the adolescent will lose hope if the truth of the prognosis is revealed. These concerns echo those of families of adult patients who ask physicians not to disclose a terminal diagnosis. This dilemma is dealt with in several ethical discussions and invariably the primary duty of the physician to respect the

autonomy of the patient is upheld.^{10, 11, 12} By gently eliciting the preferences of the patient (What do you wish to be told? How do you want decisions to be made?), a physician allows the patient to choose their level of involvement without forcing them to accept unwanted burdens, and may open important avenues of communication within the family.

Common experience holds that children with chronic illness are likely to have a more mature appreciation of their disease, the possibility of their death, and the consequences of various treatment options than healthy peers.¹³ But when stressed by a prolonged or recurrent hospitalization they may regress emotionally and behaviorally. Depression, fatigue, and constant pain may contribute to a feeling of helplessness, making it difficult to advocate for a place at the decision-making table.¹³ Adolescents are sensitive to the expectations and desires of their families and may hesitate to assert their own wishes when in conflict with those of their parents. Conversely, parents who are stressed, grieving, or in denial may be unable to initiate EOL discussions with their children. Therefore it is dangerous to assume both that a sick adolescent has not asked about EOL issues because he or she does not want to be involved and that a parent always knows what their adolescent wants. If we do not ask dying adolescents about their hopes, desires, and concerns, we risk leaving them without a voice. We do not expect children to advocate for themselves in any other circumstance; why then would we require them to do so at the end of life?

If we ever hope to reconcile our devotion to advocacy with the principle of autonomy, we must respect the persons our adolescents are becoming. We must offer them the opportunity to become medical decision-makers not only by providing them with factual information but by assisting them in recognizing their personal values, by soliciting their thoughts and answering their questions, and by facilitating the uncomfortable transition they must undergo within the child-parent dyad. Rather than clashing or colluding with parents in medical paternalism, we must help families recognize the vital importance and healing effect of open communication with their child, and we should model respect and support as the adolescent begins to deal with the reality of their mortality. This discussion should begin as early in the disease process as possible and at least as soon as the probability of death is recognized. We

owe it to our patients – and their families – to remain their advocates until the very end.

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