

the only morally relevant variable here. Some treatments may be effective, according to Ross's definition of the term, and yet extraordinarily burdensome for the child, not only because of their painful side effects or the complicated course of care, but also because of their negative impact on the minor's ability to lead something like a normal life. Should not parents be able to refuse such treatments under these circumstances? And more controversially, should not at least some mature adolescents have the right to do so, even if their parents disagree?

Notes

1. Blustein J, Moreno J. Valid consent to treatment and the unsupervised adolescent. In: Blustein J, Levine C, Dubler N, eds. *The Adolescent Alone*. New York: Cambridge University Press; 1999:101.
2. See Leffert N, Petersen AC. Adolescent development: Implications for the adolescent alone. In: Blustein J, Levine C, Dubler N, eds. *The Adolescent Alone*. New York: Cambridge University Press; 1999:31–49.
3. See also her book *Children, Families, and Health Care Decision-Making*. Oxford: Clarendon Press; 1998.
4. Rawls J. *A Theory of Justice*. Cambridge, MA: Belknap Press of Harvard University Press; 1971:62.

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Response

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Professor Ross argues that it is immoral not to provide what she describes as highly effective life-saving medical treatment to adolescents, regardless of their wishes or those of their parents. The clarity of her explication is extremely helpful, making clear exactly what the issues are. Professor Blustein has critiqued her argument on two grounds, both of which I will expand upon briefly before raising additional concerns. My comments focus in part on the role of the legal system in compelling treatment because the law is ultimately what makes children get treatment they and their parents do not want, not moral arguments.

Ross argues that it is reasonable to defer to the decisions of young adults "at some point," which she then defines as age 18. Although Ross is to be commended for refusing to lower the line based on the myriad minor

consent laws and the mature minor doctrine—these are designed to protect physicians and nurses who provide teenagers with healthcare they need, not as paeans to the wisdom of youth—Blustein has elegantly demonstrated through his practice and his scholarship the enormous variability of capacity that exists among adolescents. Some adolescents *can* make these choices, and some parents can reasonably believe that supporting their child's choice is the right thing to do, even at the cost of their own loss. Admittedly, the orderly conduct of society depends to a large degree on having clear rules, but when the stakes are high enough, as they are when teens wish to forgo life-sustaining medical treatment, individualized assessment is warranted. It *is* possible to ask teens whether they understand that they are very likely to die without treatment

and that they may live if they receive it. It is possible to ask parents whether they are actually focusing on their child's interests rather than pursuing some other agenda. It is probably true that some refusals are ill thought out or based on misperceptions or perhaps reflect lack of appropriate parental regard. This inquiry can occur either in the healthcare setting, perhaps with consultation from an ethics committee as occurs in our institution, or in the courthouse. Each setting has its particular strengths and weaknesses, which have been laid bare in the ongoing debates of end-of-life decisionmaking, but those characteristics point to the need for clear processes, not to avoiding individualized consideration altogether.

While Ross acknowledges that some treatments may be too onerous to be required, I join Blustein's insistence that she provide more specificity regarding how much is too much. Chronicity of disease and treatment matters. So do the burdens of treatment, which include not only the invasiveness of intervention and physical responses to therapy but also the psychosocial implications and social understandings of disease. Cancer, the disease in all three of the examples that Ross presents, is particularly intriguing in this regard. Cancer is now an incredible rallying cry in our country, evidenced by a rainbow of ribbons and bracelets as well as the frequency with which obituaries refer to courageous battles against this, but not other, causes of death. Cancer looms large in the public imagination, larger in fact than its actual impact on population health. Yet childhood cancer is particularly feared in part for the toxicity of its therapy, both in the immediate and longer terms, as evidence of secondary cancers and other sequelae mounts.¹ It is no surprise that some people, including some teenagers, say no to conven-

tional medical treatment. This concern almost certainly contributed to the passage of Abraham's Law as well.

This brings me to two further points. These cases become matters of public note because healthcare providers and their institutions report them to state agencies. Although all states require providers to report cases in which they suspect children are being harmed as a result of abuse or neglect, the reporter's motivation is ethically relevant. Physicians should comply with the law, but they need to recognize that their role is using their expertise to determine when a child is being harmed. The disposition and protection of the child are matters for the state. Making a report in order to invoke the law to force treatment is completely different; this radically transforms the physician-parent relationship from one of collaboration to one of coercion. Physicians, of course, should advise parents how best to take care of their children; that is what doctors are supposed to do and generally what parents seek. They can even try hard to persuade parents. But coercion to override the parents' (and child's) wishes is a step that should be taken with fear and trembling. I have been involved in evaluating cases of potential child abuse and neglect for long enough, however, to know that physicians frequently want to report to "get the state to [take Johnny out of the home] [give Susie a parent transplant] [get permission to treat]." I do not know what was motivating the pediatricians and hospitals in the three cases that Ross cites, but it is worth at least entertaining the possibility that the desire to make the parents "follow doctor's orders" was involved and asking to what extent that is appropriate.

As is so often the case, religion is involved in some of these cases. Billy Best, "a self-described born-again Christian ... 'put his life in God's

hands.”” Dennis Lindberg, a Jehovah’s Witness, in a case reminiscent of many ethics discussions and a fair number of legal decisions, died from leukemia after refusing a blood transfusion. The topic of what deference should be given to religious beliefs regarding the medical care of children is complex. Although a full exploration of that topic is beyond the scope of this commentary, the fact that this issue is not mentioned at all seems odd, particularly in light of the heated debate about the role of religion in our culture as well as in the physician–patient relationship. And although I recognize that the Committee on Bioethics of the American Academy of Pediatrics came out strongly a decade ago against religious objections to medical treatment of children,² there is something disquieting about saying that Dennis should have been transfused, probably repeatedly, given the usual course of therapy for leukemia, preserving his life at the cost of his soul.

In closing, and to agree once more with Blustein, survival is important, but it is not the only thing that matters. One hopes that the cases in which

teenagers and their parents knowingly reject highly effective, life-saving medical treatment will be rare. Clinicians can certainly try to change the minds of teens and their parents, probing their reasons, hopes, and fears, and using all the moral suasion possible, but if their decision to reject treatment is well considered and resolute, it should be honored.

Notes

1. Shankar SM, Marina N, Hudson MM, Hodgson DC, Adams MJ, Landier W, et al. Monitoring for cardiovascular disease in survivors of childhood cancer: Report from the Cardiovascular Disease Task Force of the Children’s Oncology Group. *Pediatrics* 2008; 121(2):e387–96; Nunez SB, Mulrooney DA, Laverdiere C, Hudson MM. Risk-based health monitoring of childhood cancer survivors: A report from the Children’s Oncology Group. *Current Oncology Reports* 2007;9(6):440–52; Nandagopal R, Laverdiere C, Mulrooney D, Hudson MM, Meacham L. Endocrine late effects of childhood cancer therapy: A report from the Children’s Oncology Group, Hormone Research 2008;69(2):65–74/
2. American Academy of Pediatrics, Committee on Bioethics. Religious objections to medical care. *Pediatrics* 1997;99(2):279–81.