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Supporting Her Autonomy: The Obligations of Guardians and Physicians in Adolescents' Refusals of Care

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ABSTRACT

This commentary on "Her Own Decision: Impairment and Authenticity in Adolescence" by Campbell, Derrington, Hester, and Lew¹ adds further consideration of obligations for guardians and physicians of minors who struggle in making serious decisions regarding medical treatment.

While considering the ethical, legal, developmental, and philosophical aspects of C.M.'s case, the authors of "Her Own Decision: Impairment and Authenticity in Adolescence" raise several central concerns, but do not clearly delineate a set of obligations for guardians and physicians.

First, Micah Hester and Cheryl Lew acknowledge the role that adult guardians may play in decision making, but do not discuss these adults' responsibilities to C.M. or the criteria they should use when participating in medical decision making for a minor. I would like to consider one set of standards to which guardians can be held, as well as identify a

theory of autonomy that would support these standards.

Second, all of the authors acknowledge that C.M.'s likely drug addiction and depression should affect whether we grant her decisional capacity, but do not address any additional obligations this poses for her physicians. I would like to explore what obligations medical professionals should have when confronted with patients, either minors or adults, who are refusing care and appear to be depressed.

THE RESPONSIBILITIES OF ADULT GUARDIANS IN MINOR PATIENTS' MEDICAL DECISION MAKING

Hester emphasizes the importance of the involvement of guardians in decision making for minors, but he does not delineate what standards they should use when making decisions. Additionally, only a minimal discussion is offered by Lew of an ethical justification that would allow a guardian to overrule C.M.'s refusal of treatment. C.M.'s grandmother appears to be her legal guardian, but she may be too ill to participate in decisions for C.M.'s care. Either if C.M.'s grandmother were to participate in decision making, or someone else were to be

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granted her role—for example, a guardian *ad litem*—it is important to know what responsibility that individual would have to C.M.

For younger children, it is assumed a “best interest” standard should guide guardians (or the state) in determining whether treatment should be provided. Parents are assumed to have the authority to define a child’s best interest in light of their understanding of a good life. This authority is constrained, however, to ensure that parents meet their child’s basic medical needs. If parents refuse a highly efficacious medical treatment for a condition threatening their child’s health, the courts may overrule the parents’ medical decision by focusing on the child’s best interest, in general. The parents may be deemed neglectful, and their parental authority and autonomy may be overridden.

There is disagreement among ethicists about whether mature minors—older adolescents who may be treated as an adult for certain decisions—should be allowed to possess decisional capacity for all medical decisions. Those in favor of recognizing the decisional capacity of mature minors state that adolescents know what is in their best interest, and a parent is no longer needed to protect their basic needs. There is no consensus on what the criteria should be for determining whether adolescents can be granted decisional capacity, and this target may be shifting, as more information becomes available about adolescents’ behaviors and ability to make decisions.² In what may be seen as a departure from previous practice, there is empirical evidence that some pediatricians would respect a mature minor’s refusal of treatment over a parent’s request to treat, even in cases of highly effective treatment.³ However, it still remains the case that pediatricians are more likely to allow a refusal when there is agreement between the mature minor and a parent to forego treatment.⁴

As Lew briefly mentions, Lainie Ross is opposed to allowing adolescents to refuse lifesaving treatment and argues for a constrained parental autonomy that allows guardians to make these kinds of decisions for their children, but within the context of respecting their child.⁵ For Ross, to respect a child means first and fore-

most not to harm the child’s basic needs—in these cases, understood to be the child’s medical needs. After this requirement is met, guardians are also expected to help their children develop the capacity for autonomy that they will exercise as adults. This includes respecting children’s current projects and goals, but not to the same degree as if they were already adults. One justification provided for overriding adolescents’ refusal for life-sustaining treatment is to give them an opportunity to develop long-term autonomy. Ross emphasizes that adolescents lack worldly experience and often still need to develop habits, such as self-control, before exercising their capacity for autonomy independently.

Lew acknowledges that adolescents may lack the emotional maturity to make sound decisions, even if they possess the analytic capability. If one adopts a relational understanding of autonomy, which emphasizes the role of third parties in the development of adolescents’ capacity for autonomy and the prevention of the degradation of their capacity for autonomy,⁶ the role of parents to engage their children in discussions about these decisions is essential and offers children the opportunity to exercise their burgeoning skills. While parents have this responsibility to ensure their child’s medical needs are met, their ability to override an adolescent’s refusal diminishes significantly if the treatment is less efficacious or the outcome of treatment is less clear. While C.M.’s case does not discuss how effective chemotherapy would be in preventing rejection of the transplanted kidney, it is presumed that dialysis is the alternative, and one or the other treatment is essential to preserve C.M.’s life.

If C.M.’s guardian would be granted the authority to override C.M.’s decision, it must be within the context of supporting C.M.’s capacities for autonomy more generally, and thereby respecting her. This would include, as Hester and Lew allude, a discussion with C.M. about her experience as a transplant patient and how treatment would allow her to reach other goals in the future—assuming she is able to imagine future goals. Lew acknowledges that C.M. has unique insight into the challenges of post-trans-

plant care, and therefore her guardian is particularly responsible to learn from her about the burdens of continued management when assessing her medical needs. Foregoing these considerations would fail to meet the criteria of respecting C.M. and promoting her autonomy.

CONCRETIZED EMOTIONS AND THE RESPONSIBILITY OF PHYSICIANS TO BE EMPATHETIC

In contrast to adolescents like C.M., those above the age of majority are presumed to be able to make medical decisions for themselves, assuming they possess decision-making capacity. Amy Campbell describes capacity as a minimal requirement in which the patient understands the prognosis or disease, appreciates the consequences (in the case of C.M., rejection of her transplanted kidney leading to lifelong dialysis or death), and can reason through options and can communicate a voluntary choice. While our intuition may question whether a person with depression should be allowed to make life-threatening decisions for her- or himself, traditionally depression has not qualified as sufficient reason to override a person's decision-making capacity if he or she meets the other criteria. However, Jodi Halpern offers an account of autonomous decision making that requires an individual to be able to continue to both imagine her- or himself in new futures, even in the face of loss.⁷ Often depression creates a "concretized" emotional state in which individuals' "suffering may impair people's self-efficacy as well as their ability to imagine goals for the future."⁸ If we acknowledge that these two components are essential for exercising autonomy, then depressed individuals who are unable to imagine possible futures and weigh and balance the risks of non-treatment as they apply to their own life may not be exercising their capacity for autonomy.

Even those who would grant mature minors like C.M. the ability to refuse treatment may be hesitant to grant that authority to C.M., due to her depression. I would like to argue that her depression raises another set of obligations for her physicians, which must be met before fol-

lowing through with her request, even if she were 18. By stating that only crystal meth makes her feel good and that she is indifferent to losing her kidney or dying, C.M. demonstrates that she may be in such a "concretized" emotional state and therefore temporarily irrational.

In these circumstances, physicians have a responsibility to engage C.M. empathetically and attempt to understand her emotional experience. Halpern argues for a new conception of empathy that requires discerning the emotional aspects of patients' experiences, both to derive an accurate diagnosis and to help patients regain psychological autonomy by helping them to process challenging emotional information.⁹ Grounded in an understanding of deliberation as a socially situated emotional reasoning, under this approach it is not only acceptable for patients to engage with others—including physicians—in their reasoning, but it is beneficial. When physicians take a detached approach of noninterference in patients' decision making, they are inadequately meeting their responsibilities. Physicians can offer to a patient like C.M. the sense that she is not alone in her experience of suffering, as well as help her believe that she can be effective in the world, increasing the possibility that she will regain a sense of self-efficacy. By engaging empathetically with a patient like C.M., the goal is to re-engage her own curiosity about her imagined futures, even ones that may not include her grandmother. A decision to forego treatment can and should be respected by physicians, but only after engaging empathetically with the patient to ensure that the reasoning process by which she reached that decision was not impaired by an emotional state limiting her capacity to envision her future.

CONCLUSION

There is no consensus on whether it is acceptable to allow mature minors to refuse treatment over the objections of a parent or a medical team when the treatment has high efficacy. However, for mature minors and adults, Halpern has offered a compelling reason why physicians have an obligation to engage empathetically

with patients, to identify the true experience leading to their decisions and to empower their autonomy. If patients are paralyzed by emotional states like depression, physicians have additional obligations to aid patients in regaining a sense of self-efficacy before carrying out their wishes to forego treatment.

NOTES

1. A.T. Campbell, S.F. Derrington, D.M. Hester, and C.D. Lew, "Her Own Decision: Impairment and Authenticity in Adolescence," in this issue of *JCE*.

2. Committee on the Science of Adolescence Board of Children, Youth and Families, Institute of Medicine, National Research Council, *The Science of Adolescent Risk-Taking: Workshop Report* (Washington, D.C.: National Academies Press, 2011).

3. E.D. Talati, C.W. Lang, and L.F. Ross, "Reactions of pediatricians to refusals of medical treatment for minors," *Journal of Adolescent Health* 47, no. 2 (August 2010): 126-32.

4. *Ibid.*, 131.

5. L.F. Ross, "Arguments against respecting a minor's refusal of efficacious life-saving treatment redux, part II," *Cambridge Quarterly Healthcare Ethics* 18, no. 4 (Fall 2009): 432-40; discussion, 440-442; L.F. Ross, "Against the tide: arguments against respecting a minor's refusal of efficacious life-saving treatment," *Cambridge Quarterly Healthcare Ethics* 18, no. 3 (Summer 2009): 302-15; discussion, 315-22; L.F. Ross, *Children, Families and Health Care Decision-Making* (New York: Oxford University Press, 1998).

6. C. Mackenzie and N. Stoljar, ed., *Relational Autonomy: Feminist Perspective on Autonomy, Agency, and the Social Self* (New York: Oxford University Press, 2000).

7. J. Halpern, *From Detached Concern to Empathy: Humanizing Medical Practice* (New York: Oxford University Press, 2001).

8. *Ibid.*, 104.

9. *Ibid.*, 111-8.