Should a Teenager Be Allowed to Leave the Hospital AMA to Attend His Father's Funeral?

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What should physicians do when an adolescent wishes to risk his physical health and leave the hospital to attend the funeral of his late father? What if the young man's mother, and only remaining guardian, both supports and encourages such a decision? In this *Ethics Rounds* discussion, we examine the legality, morality, and safety of discharging a minor under such conditions.

Pediatricians strive to provide compassionate, family-centered care at all times, treating patients in the context of their families, communities, and cultures. In most cases, patients' medical best interests can be successfully balanced with their psychosocial needs and the interests of their families. What should happen when this balance is not possible? Should we value nonmaleficence with regard to physical health over mental health and well-being? What about adolescent autonomy and parental authority?[1]

In this *Ethics Rounds*, we present a case in which a young man in need of urgent medical care requested to be discharged prematurely to attend his father's funeral, a choice that had his mother's support, despite delaying his diagnosis and treatment. We have asked 3 experts in pediatrics, patient safety, ethics, and law to comment on the case. Melissa Schafer is a pediatric hospitalist, pediatric quality officer, and assistant professor of pediatrics at SUNY Upstate Medical University in Syracuse, New York. Amy Caruso Brown is an assistant professor of bioethics and humanities and pediatrics at SUNY Upstate. Robert Olick is an attorney and associate professor of bioethics and humanities at SUNY Upstate. John Lantos is a professor of pediatrics at the University of Missouri-Kansas City School of Medicine and director of the Center for Bioethics at Children's Mercy Hospital.

THE CASE

A 15-year-old boy reported a 1-week history of progressive blurry vision bilaterally after the sudden death of his father. An optometrist examined him, noted bilateral papilledema, and referred him to the pediatric emergency department, where magnetic resonance angiogram and venogram were normal. An initial diagnosis of idiopathic intracranial hypertension was excluded after the opening pressure on a lumbar puncture was normal. The morning after his admission, the pediatric neurology service recommended urgent MRI of the brain to evaluate for optic neuritis, with a plan to start intravenous steroids immediately, pending results.

Unfortunately, the change in plan occurred 1 hour before the patient anticipated discharge and 2 hours before his father's funeral. Although aware that any delay might increase the patient's risk of permanent visual

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loss, both the patient and his family were adamant about the importance of attending the funeral. The pediatric hospitalist urgently discussed the situation with the neurologist, ophthalmologist, and social worker. All were concerned because the family lived some distance away and had listed 2 different towns of residence. They had also expressed mistrust of physicians, citing the patient's father's misdiagnosis before his death. Both the neurologist and the social worker were worried that if the patient left, he might not return for treatment and that, as a result, he might become blind.

Should physicians call Child Protective Services (CPS) and ask them to take protective custody of this teenager so that he can be treated immediately? Should he be discharged? Should he be allowed to leave against medical advice (AMA)? If he were allowed to leave, what follow-up would be appropriate?

Thomas Kania, BS, and Melissa Schafer, MD, Comment

The response to this question hinges on 2 areas of uncertainty: First, will the family bring the patient back to the hospital in a timely fashion? Second, how might delaying treatment affect the patient's outcome?

In response to the first question, the patient in this case appears to be cognitively intact with age-appropriate understanding of the severity of his condition, including the risk of potential blindness, yet neither he nor his family seem to have any hesitation about leaving. Several features of the social situation, the lack of a previous relationship between the hospital or providers and the patient, the uncertainty about his home address, and their stated distrust of physicians, would lead us to question their promises to return.

Second, it is extremely difficult to estimate what effect delaying treatment would have on the patient's long-term outcome.[2,3] The team itself has already changed their approach to the child's care and treatments at least once, and it is certainly possible that another change in plan will occur. Unfortunately, the potential urgency of this situation does not allow for obtaining a second opinion to better ascertain the risks.

It is understandable that the family would be upset about the change in treatment plan. Because it occurred only an hour before they needed to leave, it could be perceived as an unreasonable delay in decision-making on the part of the medical team. Given the heightened emotions present (grief surrounding the death of the patient's father, fear for the patient's health, and anger toward the medical team), there would be concern about the ability of the family to make a voluntary, informed decision under such stress. The involvement of the social worker (or other psychosocial support professional) is therefore particularly important to avoid escalating the situation. More so than the clinicians, the social worker may retain a neutral position that would allow the family to trust his or her advice.

Given the family's wishes and the psychological significance of attending the funeral, the team should still allow the patient and his family to leave AMA. Other options available for the team to consider include discharge with readmission after the funeral, or alternatively, active prevention of the patient from leaving the hospital, possibly requiring security staff involvement. Although it would be convenient to directly readmit the patient to the pediatric unit after the funeral, doing so would be highly unethical, because it would indicate that the team is in full agreement with the family's choice to leave. Voluntarily discharging this patient, who could lose his vision before his return, would be malpractice. Although the family seems to grasp the consequences, this might leave the physicians vulnerable to legal action.

Alternatively, physically preventing the patient from leaving would additionally damage the family-provider relationship and would cause significant long-term psychological consequences by depriving this adolescent of an important opportunity to mourn and bury his father. Allowing the patient to leave AMA is the best possible compromise. This decision maintains a firm stance on patient safety without completely disregarding parental decision-making authority and evolving adolescent autonomy, all while helping to salvage a strained physician-patient relationship.

Finally, calling CPS is necessary due to the mother's willingness to accept the possibility of permanent blindness. Regardless of the extenuating circumstances, this willingness would cause us to suspect the possibility of child neglect. The medical team needs to be honest with the family about the necessity and rationale of this call; they should also acknowledge to the family that they realize the call would increase the distrust between the family and the medical system.

Amy E. Caruso Brown, MD, MSc, MSCS, Comment

This young man and his family are faced with a deeply troubling dilemma: miss an irreplaceable opportunity to say goodbye to a loved one, or risk a delay in diagnosis and treatment that might result in a lifetime of blindness. The lack of certainty surrounding the risks of delay (risks which cannot be quantified based on current evidence), coupled with the family's acute grief, compounds the difficulty of making a truly informed decision. The urgency of the situation limits the team's ability to involve others who might help to support the family,

such as a chaplain or the patient's own religious leader, a psychologist, or the ethics consultation service.

The pediatrician is faced with an acute dilemma as well: how to proceed when a family's decision is informed, rational, morally defensible, and even sympathetic, and yet concern for professional responsibility (or liability) precludes actively recommending it as a course of action. This situation forces the providers to weigh their concern for the patient's physical well-being against their concern for his emotional well-being, and to balance both of these with concerns for their own legal and professional liability in the event of a poor outcome.

Are there alternative ways of viewing this situation that might allow the team to avoid both a designation of the discharge as AMA and a CPS referral?

With regard to the former, we should recognize that this case illustrates some of the gaps in systems that can limit providers' ability to provide optimally just and compassionate care. In medically underserved areas, shortages of pediatric subspecialists can exacerbate the existing ethical dilemma. For example, empirical treatment of the patient or review of an overnight MRI scan might be medically acceptable alternatives if a pediatric neurologist and neuroradiologist were available to assume ownership for implementing such a plan. Consultation with another pediatric neurologist might have also yielded a different recommendation: although steroids are certainly the standard of care, it is unclear whether they alter the long-term outcomes in pediatric optic neuritis.[4–7]

Such approaches may not be feasible, but it is nonetheless important that the team acknowledge that delays in care are not solely due to the family's different priorities, but also to limitations of the health care system. It is morally distressing to realize that a designation of discharge as AMA is a consequence of the system's failure to be able to offer a full spectrum of medically appropriate choices to a patient and family; if pursued, it should be done in a way that is not perceived as punitive or judgmental by the family, sentiments which can only damage the therapeutic relationship. As health care providers, we should judge our institutions and ourselves as rigorously as we judge our families.

With regard to the latter, many hospitals, including this one, require that the social worker be notified in all cases of discharges AMA, regardless of the patient's age. The social worker and the treating team can then decide if there is reasonable suspicion that the family's decision endangers the child's welfare and represents medical abuse or neglect. Although many cases of pediatric discharges AMA might meet these criteria, there are situations, such as this one, that do not. In such cases, I do not recommend allocating state or local resources to an unnecessary investigation. The investigation process can be traumatic, particularly for a family already coping with grief, loss, and serious illness, and might additionally impair their ability to trust physicians and adhere to medical advice.

Alternatively, a practical approach might be to consider the 15-year-old patient to be a mature minor, capable of making this decision himself and thus obviating any question of CPS referral. Such a designation would have been at the discretion of the treating physician. Despite the urgency of the situation, it is crucial that members of the team take the time to meet privately with the patient, to thoroughly assess his understanding of his condition, his appreciation for the possible consequences of leaving the hospital and delaying treatment or of remaining in the hospital and thus missing the funeral, and his reasoning regarding his decision. In doing so, the team should attempt to ensure that his decision is indeed voluntary and informed and not due to pressure from his mother or other relatives. Explaining the importance of this process to a family impatient to leave will require considerable empathy and diplomacy, and it is possible that the heightened emotions stemming from his recent loss and personal health crisis might render it impossible for this young man to reason optimally.

In the event that this approach yielded a satisfactory conclusion, I would note that, because capacity is decision-specific, the team's opinion of the patient's maturity regarding the decision to leave the hospital does not automatically extend to the conclusion that he is mature enough to choose no treatment whatsoever. Therefore, if the family failed to return, a call to CPS would still be warranted.

Robert S. Olick, JD, PhD, Comment

This case illustrates that sound ethical reasoning frequently requires physicians to consult pertinent law. It also shows how well-intentioned misperceptions about the law can influence the ethical analysis. In this case, the 2 questions at the intersection of ethics and law were: whether to discharge the patient AMA; and whether the law required that CPS be notified.

The decision to discharge AMA is fundamentally based on assessment of medical risk. This includes the risk that the patient may not return for care and treatment and an understanding of the personal and social reasons behind the patient's refusal to stay, which, in this case, centered on the patient's and family's insistence on attending the father's funeral just 2 hours after the anticipated discharge. Physicians are sometimes also moved by the presumption that discharge AMA

confers protection against legal liability. However, this medicolegal rationale is questionable. Whether documented discharge AMA in fact confers a valid legal defense in a particular case is, at best, uncertain.[8] To their credit, this team did not overtly use discharge AMA as a bludgeon to coerce the family's decision, as physicians sometimes do. Pursuing discharge AMA may increase, rather than decrease, the risk that the patient will not return. Resorting to discharge AMA can be counterproductive, because it may create an adversarial posture and perceived threat, causing patients to be less trusting, less likely to return for care, and more likely to seek legal recourse in the event of a bad outcome. In this case, there was a history of mistrust of physicians from the previous misdiagnosis of the father's condition, heightening these risks.

The team seems to recognize that, ultimately, the decision to leave belongs to the patient and family. Within the context of their own values, only they can weigh the relative importance of attending the father's funeral and the increased risk of lifetime blindness. It is hard to argue with a decision to respect patient and family autonomy under these circumstances. By contrast, the choice to allow the discharge only AMA is up to the physician. The physician's primary focus should be on strategies to manage the risks by engaging the patient and family in a fully professional and sensitive manner with compassionate and careful deliberation about the patient's medical needs, uncertainty about diagnosis and treatment, and his experience of loss and grief, all under urgent circumstances. Although beliefs about legal protection may still influence the discharge AMA designation, these beliefs may not be accurate as noted above.

Whether to place a call to CPS is surely influenced by a decision to discharge AMA. By definition, AMA means the patient and family are thought to be taking an unreasonable risk, suggesting the need for CPS to intervene to protect the adolescent patient on grounds of medical neglect and harm prevention. However, contacting CPS is discretionary, not mandatory, and is not automatically required by New York State law in cases of discharge AMA of a minor. The source of misconceptions regarding this are not known; perhaps there was a misreport of a previous case, or this view may have been passed from 1 provider to the next without being subjected to serious scrutiny or an opinion of legal counsel. It is important to mention that involving CPS in this case is not ethically warranted, as is reflected in the consideration of whether to treat the patient as a mature minor capable of making his own decision to be discharged in time to attend his father's funeral and assume the consequent risk to his own health, a step that would have removed the case from CPS jurisdiction. Even if the patient returns to the hospital and CPS does not pursue the matter, the fact of CPS notification would likely cause some distress within the family.

This case offers an important reminder that ethics and law are intertwined. Clear understanding of the law can be critical. When in doubt, health care professionals should be mindful to seek an ethics consultation or input from hospital counsel. Sound patient-centered ethical reasoning in partnership with patients and families should accompany clear comprehension of the law's meaning as the frame for decision.

CASE CONCLUSION

The patient was allowed to leave AMA with a promise to return the same day, and a CPS report was filed. When the patient's mother was informed of the CPS referral, she was understandably upset; the social worker helped the patient's mother contact the patient relations department so that the family could voice their complaints. On readmission later that day, the patient's symptoms were unchanged. An MRI of the brain was obtained and was read as normal. A second MRI was repeated 9 days later for persistent symptoms and revealed bilateral optic neuritis. Treatment with steroids, plasmapheresis, rituximab, and intravenous immunoglobulin was initiated: his vision improved only slightly before worsening again; he was ultimately blind, although it is too soon to know whether the blindness is permanent.[9] The CPS case was dismissed due to the extenuating circumstances.

John D. Lantos, MD, Comment

This is a tough case. Most doctors would strongly recommend that this teenager be treated immediately, even if it meant that he could not attend his father's funeral. It also seems plausible that his father would also want his son to take care of his own health and not risk blindness to attend the funeral. But that is not what the teenager himself wants. If his mother and other family members disagreed with the patient, then it would be appropriate and ethically defensible to override the teenager's wishes on the basis of best interests, parental legal rights, and perhaps a variation on substituted judgment by the father. But because his parents support his choice, the question becomes one of prognosis. If we knew, with a high degree of probability, that even a brief delay in treatment would lead to blindness and that immediate treatment would predictably avert that outcome, then it would be appropriate to seek a court order for protective custody. That, too, is not the case. Given the

teenager's and family's wishes and the uncertainty of prognosis, the issue becomes one of informing the family of the risks. If they fully understand the risks, and the uncertainty surrounding the increase in risks associated with a couple of hours' delay in treatment, then their wishes should prevail.

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ABBREVIATIONS

AMA: against medical advice
CPS: Child Protective Services

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