

Balancing Parental Wishes with Medical Judgment

Doctor and parents have conflicting views and wishes in designing treatment plan for an 18-month-old child, critically ill with a rare form of pediatric cancer.

Commentary by Joal Hill, JD, MPH

Jonathan Roland, an 18-month-old boy diagnosed with a rare form of pediatric cancer 4 months ago, is critically ill. Initial chest surgery and chemotherapy went well, but complications developed 3 months into treatment. His parents agreed to emergency surgery, even though Jonathan was at high risk for hemorrhaging because of the medications used for his cancer treatment. This complication did occur, and Jonathan went into shock. He was placed on extra corporeal membrane oxygenation (ECMO), but has not done well. Because of swelling and infection, his surgical wound is open, and he remains at risk for bleeding, which greatly complicates routine care.

The medical staff disagrees about the propriety of placing Jonathan on ECMO, given his diagnosis of a cancer for which survival rates are very low and the risks imposed by chemotherapy drugs. One of the primary physicians asked to be removed from the case, explaining that Jonathan's care has been driven more by his father's unwavering insistence that "everything be done," than by sound medical decision making and consideration of Jonathan's best interests. Some staff share this view, and several have expressed concern that, for Jonathan, the cure is worse than the disease.

Other staff members believe that medical judgment has been responsibly exercised. A consulting oncology specialist notes that few established standards exist for treating Jonathan's rare form of cancer. Therefore, while he agrees that the prognosis looks grim, he does not believe that the decision to continue ECMO is unsupportable, particularly if the parents understand the situation and wish to proceed.

At issue today is the parents' refusal of a DNR order. A family and staff conference is called, to which the physician-chair of the pediatric ethics committee is invited. One of the physicians tells her, "We want you to convince the family to withdraw treatment, or at least agree to the DNR order."

Before the parents join the conference, members of the team—social worker, chaplains, nurses, and physicians—summarize their perspectives of the case. While everyone exercises self-control, it is evident that tensions run high, and that the morale of the entire unit is affected by the case. Disagreement continues about how Jonathan's care should have been handled when complications first arose, but there is consensus that: (1) Jonathan's parents love their son; (2) Jonathan's prognosis is very poor; (3) His parents appear to understand the condition and outlook for their son. The team is divided about whether treatment should be withdrawn or continued, and also about whether or not Jonathan's parents should have the final say about that question.

When they join the conference, Jonathan's parents describe their son's condition accurately. They know he is likely to die, but believe it is their duty to give him every possible chance. "Even if the odds are only 1 in 10,000 or less," his father says, "We must make sure he has every opportunity. He has survived to this point. Only God knows whether he will live or die. Whether in this life or in the next life, I do not want my son to ask me, 'Daddy, why didn't you fight for me?' We cannot agree to stopping any treatment that gives him a chance of survival." One of the physicians asks, "If we exercised authority to withdraw treatment against your wishes, how would you respond?" Jonathan's father replies,

"If you do everything for my son and he dies, that is the will of God. But if you do not do everything, then I would blame you for his death."

In the face of this impasse, what should the pediatric ethics committee chairman recommend? Should Jonathan's parents decide whether his treatment continues with full code status, or should the medical opinion of the physician directing Jonathan's care override their preferences?

Commentary

Decisions regarding care of critically ill babies are among the most difficult deliberations in patient care. It is impossible to know what these patients would want if they could speak for themselves, and, as this case illustrates, the emotional investment of parents and medical staff is considerable. Death may be harder to accept since it cannot be seen as a "natural" end to a long life.

For Jonathan's father "doing everything" seems compatible with the sacrificial nature of parental love. On the other hand, it is Jonathan who bears the burdens of treatment, which, in view of his prognosis, members of the medical team view as disproportionate to the benefits.

Compelling reasons exist for allowing Jonathan's parents to determine his treatment, provided they have decisional capacity and are adequately informed based on sound medical judgment. It is they who are primarily responsible for their child, and who, regardless of the outcome, will live with the result for the rest of their lives. However, the considerable deference we give to parental decision making is not absolute. Certainly we would question parental decisions for this patient if they seemed primarily motivated by personal convenience, potential financial reward from his survival or death, or other factors not directly related to Jonathan's well-being.

The medical team will also live with the results of this case in the future. This includes the possibility of being blamed by family members for a patient's death. The emotional burden of such cases can be difficult for those whose life's work is giving care. Although there is no ethical distinction between appropriately withholding or withdrawing treatment, real but often unspoken feelings of defeat and abandonment often make the latter more emotionally difficult for families and physicians. The purpose of medicine is to provide treatments that are beneficial to Jonathan, not merely those that make an impact physiologically. When there is genuine uncertainty about the efficacy of a particular course of treatment, error should be on the side of preserving life. However, the fact that treatments are initiated does not mean that they can never be withdrawn.

Several factors complicate this very difficult case. The number of physicians involved in Jonathan's care make it possible that his parents received mixed signals about the purpose and efficacy of various treatments. The continued lack of consensus about how Jonathan's complications should have been treated may also indicate lack of continuity in which physician has been the primary coordinator of care and communicator with Jonathan's parents.

Certainly there is some confusion about the ethics committee chairman's role. The fact that she is a physician does not mean that she is there to help other physicians "convince the family." Rather, she should ask questions and help the team determine the range of options available to them.

Assuming that initiation of ECMO was an appropriate recommendation for this patient, it should have been made as a treatment trial to be reassessed at appropriate intervals. Recommendations should then have been made to continue or discontinue treatment with other appropriate changes in the patient's care plan. In some cases this entails transition from potentially curative treatments to those that are palliative. Judgments about the burdens and benefits of treatment are not entirely medical, since they involve perceptions and preferences around quality of life issues. However, the physician's role requires making recommendations (and providing the rationale) for particular courses of treatment, not merely presenting all "doable" options as a menu from which patients are to pick and choose. This case offers an opportunity for the care team to evaluate how it coordinates complex care in terms of which physician remains in charge of Jonathan's case and how medical recommendations are communicated to families over time. These issues are not always straightforward, particularly in teaching hospitals where staff rotation may interrupt continuity of care.

Deliberation about how to better manage such cases in the future, however, does not solve the problem of how to proceed in this case. The question to be answered is not merely whether or not to continue this therapy, but for how long and with what criteria for justifying withdrawal. If that point is reached and the parents continue to refuse, it may be necessary to initiate appointment of a guardian to represent Jonathan's interests. This would no doubt make the current impasse even more adversarial. However, while assessment of the burdens and benefits of treatment cannot be made without regard to parental preferences, the medical team should not abdicate its role by agreeing to continue ECMO indefinitely or until the parents agree to stop.

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