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ETHICAL COMMENTARY

Limited Medical Resources

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As Edmund Pellegrino always emphasizes, the primary concern for the health care practitioner is always the patient's good: we need to determine what the right and good course of action would be for this patient in these circumstances at this time.

The volunteer team -- no doubt with every good intention – immediately went about considering the medical intervention that might best lead to the boy's attaining the best possible level of physical functioning. The team then proposed surgical intervention to the boy's parents. The following analysis of the situation is based on that action. However, I will return to question that very decision and course of action at the end of this reflection. (I will respond to the two questions posed but will address the second question before the first.).

Assuming that the team has suggested the possibility of surgery to the boy and his family, the first thing we would want to ascertain was whether valid consent had been obtained: does the family truly understand the risks posed by the surgical procedure and the likelihood of success or failure? Have they been informed of alternative courses of action? How urgent is it that they take immediate action?

While the patient is particularly young, he has been living his entire life with this condition, and he is the one who would be undergoing treatment. Obtaining his assent to the procedure is crucial. While he has not reached the age of consent, he is old enough to understand what is happening to him and deserves to be informed and to participate in deliberations about his treatment. The patient's good cannot be determined without consulting the patient, himself.

Setting aside questions of financial, international, or political status and location, it is unclear whether surgery would be the appropriate course of action for a child of the subject's age at his particular stage of development. If he is in pain that could be alleviated with medication, and if he is not suffering from cardio-pulmonary or neurological impairment, a less invasive course of treatment, such as the use of braces to halt or to lessen the curvature of his spine, would seem to be the more prudent medical approach – particularly if the use of braces could help delay surgery and help the boy to develop to a point at which surgical intervention would be less dangerous. If the child is in irremediable pain or is suffering from cardio-pulmonary or neurological impairment, the medical urgency and appropriateness of surgery would be less worrisome.

As it is presented in the case description, surgery appears to be more likely to result in a worsening of the patient's state than in its betterment. Even if we assume that the boy's current condition is perilous, it would not be unreasonable for a surgeon to refuse to participate in a procedure that carried such a high level of risk. In such a case, the physician's medical judgment and conscience would have to be respected.

If the child is, indeed, suffering intractable pain and/or functional impairment, and the parents and child are aware of the risks of surgery and believe that the overall potential outcome of surgery would be preferable to the overall potential outcome of declining the procedure, and if a surgical team has agreed that it could, in good conscience, perform the procedure, a new moral concern arises: namely, the concern regarding the appropriateness of withholding trachestomy and mechanical ventilation should they become necessary during surgery (and, presumably, indefinitely thereafter).

At this point, it is important to determine the reasons that trachestomy and ventilation might be withheld. If the parents and child come to the determination that living in the state that would result from the trachestomy would be overly burdensome for the child, an advance directive refusing that particular treatment would be legally and morally valid. In such a case, the patient's physical survival is only one aspect of the patient's good as determined by the patient (or, in this case, the patient with his

parents/custodians). The patient's moral right to refuse treatment that the patient finds overly burdensome ought to be respected in spite of the fact that such refusal may result (and, in this case, would certainly result) in the patient's dying.

Again, the surgical team would have to be informed about the existence of such a directive and it might determine that it could not, in good conscience, participate in a procedure under such conditions. The surgical team could see such withholding of treatment as tantamount to their consensual participation in a patient's demise – particularly since the likelihood that a trachestomy would be medically appropriate would be quite high. The team would have to be permitted to withdraw if the members determined that withholding treatment would violate their moral integrity. Nevertheless, it is important to reiterate that refraining from performing the trachestomy under the conditions described would be permissible both legally and morally. In doing so, the patient would be respected; and his good, promoted.

On the other hand, if the hospital in which the surgery was being performed or the surgical team performing the operation were to decide to refuse to perform the trachestomy due to financial considerations, such refusal would be both immoral and illegal. It would also be immoral and illegal for the team or the hospital to coerce the parents and child into declining the trachestomy as a precondition for performing the surgery. In both of those instances, the patient's good would be subverted, rather than respected and promoted.

If the surgical team and hospital agree to perform the procedure, they must do so with a willingness to perform the trachestomy and connect a ventilator if the patient and family determine that such treatment is in the best interest of the child. It would be morally valid for the surgical team and hospital to refuse altogether to do the procedure for financial reasons, but to make the surgery contingent on the family's refusing trachestomy and ventilation would be to coerce the family. Therefore, the question of whether it would be morally justifiable to withhold the trachestomy turns on who the decision makers are and on what grounds they would use to justify their decision.

I would briefly like to address what is perhaps the more important issue in this case: whether the option of surgery ought to have been presented to the family in the first place. In this case, surgical intervention is likely to end in either the child's death or his life-long paralysis and ventilator-dependence. If it ends in the latter, it is almost certain that the child will never again see his family or the community in which he was raised and that he will receive the absolute minimal care that the state will support. Medical professionals are responsible for determining whether patients are "good candidates" for particular interventions, and that responsibility extends to their assessing the probability of an intervention's success. While I would hope that a clear explanation of the situation would convince the family that surgery was not appropriate in the circumstances in which they found themselves, I believe the medical team ought to have seen that the child was not a good candidate for such an intervention and ought either to have never suggested the intervention or to return to the family and tell them that the anesthesiologist's assessment of the situation convinced them that surgery was not medically appropriate. Offering surgical intervention in this case would be analogous to selling the family a devastatingly expensive lottery ticket with very poor odds of winning. It would not be a mere risky investment; it would be a foolish gamble.