An Unusual Conflict Between a Gravely Ill Teenager and his Mother Over End of Life Treatment

The Arnold P. Gold Foundation Ethics for Lunch Seminar Series

A Difficult Case from the Morgan Stanley Children’s Hospital Ethics Committee

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The Ethics for Lunch presentation began as Dr. Ruth Fischbach, Director of the Center for Bioethics of Columbia University, greeted the audience and thanked Drs. Arnold and Sandra Gold for their eight years of generosity that have made the current and the past Ethics for Lunch events possible. The Gold Foundation is committed to promoting humanism in medicine. Compassion is their passion.

Dr. Fischbach introduced the case by noting it was a particularly difficult case because the course of treatment that was desired by a dying child was in conflict with what his mother thought was best for her son. The patient, who is a teenager and therefore has no legal autonomy, wishes for aggressive treatment to prolong his life. This is in direct opposition to his mother’s sense of beneficence, whose sincere wish for her son is that he suffer no more pain. Both have acceptable reasons and values, but eventually one preference will have to trump the other. How is one to decide whose wishes to follow?

Dr. Fischbach went on to introduce the speaker, Dr. John Lorenz, who is a professor of clinical pediatrics at Columbia University College of Physicians and Surgeons, the Director of Network Nurseries at The New York Presbyterian Health Network, and a member of both the Columbia University Medical Center’s and the Children’s Hospital of NY (CHONY) Ethics Committees.

Dr. Lorenz introduced the case as follows: Tony (not his real name), a sixteen year old boy diagnosed with end stage cystic fibrosis, was transferred to CHONY for evaluation for a potential lung transplant. Born in Ecuador, Tony came to America at the age of five, and shortly after was diagnosed with cystic fibrosis. He is well adjusted, compliant with his medication, and was not in critical condition until a few weeks prior to his hospitalization. At that time his health went into a rapid, unanticipated decline that required mechanical ventilation. His condition continued to dwindle, and without a lung transplant it was evident he would die during his stay in the hospital. Even if Tony wanted to wait for a transplant, he would need an aggressive course of medication with risks of its own. Whether he had enough time until a transplant took place was indeterminate. As both Tony and his mother desperately wanted the lung transplant, Tony was put on extracorporeal membrane oxygenation (ECMO) and when his condition improved he was placed on bi-level positive airway pressure (BiPAP). A tracheostomy was planned, and though Tony’s mother was worried about Tony’s decision to go through with the “trach”, she relented to his preference. Unfortunately the situation became more complicated and dire, when Tony’s coagulation status worsened, and his tracheostomy had to be postponed. Now seriously ill, Tony wanted to continue with undergoing the tracheostomy, but at this point, seeing what her son was having to endure, his mother believed that he had been through enough and so she refused the tracheostomy.

Dr. Lorenz explained that the ethical complexity in this case was exacerbated by the fact that both Tony and his mother had rational reasons for their treatment preferences. Yet by law, pediatric patients are deemed incompetent to make medical decisions by themselves until the age of eighteen. In reality, it is not so easy to delineate the age at which one is mature enough to make self-determined medical decisions. As for Tony, he has been very sick for a long time and is well aware of his options and his
prognosis: given these circumstances, is he really too young to be autonomous? At the same time, his mother definitely has his best interests at heart; she is supportive, but does not want Tony to suffer more than he has to. Even if he received a successful lung transplant, his future would include years of hospital visits, more medications, and low chance of long-term survival.

Given the challenging situation, it was difficult to deem whose decision was ‘better’. Fortunately, after consultation with the Ethics Committee and efforts to promote clear communication, Tony’s mother relented and consented to the tracheostomy. The next day Tony’s condition again worsened, and for a while he was deemed unfit as a transplant candidate. His condition was unstable, but following aggressive medical procedures his condition improved enough to enable the lung transplant to proceed providing him with a set of new lungs. After a few months he was decannulated and discharged to a rehabilitation center.

The lesson worth taking from this case is this: good ethical judgments are grounded upon good medical facts and clear communication between all parties. Oftentimes there is no decision that can be declared as ‘best’. Even with all medical knowledge at hand, physicians should be guarded against assuming to know everything that will happen. The only thing one can do is to make sure that the patient and his or her loved ones understand what is at stake, and what each party wants, and are able to come to a consensus so ultimately, everyone can be at peace with the final medical decision. And then, there is only hope.