

## ***Ethical Issues Posed by a Patient who Refuses to Preserve his Transplanted Organ and Chooses to Die***

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### **Introduction to the Case: Dr. Ruth Fischbach**

Our *Ethics for Lunch* series is made possible thanks to the generosity of the Arnold P. Gold Foundation. Drs. Arnold and Sandra Gold are renowned for their promotion of humanism in medicine. I consider these *Ethics for Lunch* events very important in demonstrating how care can be careful, caring, and compassionate. The Gold's promotion of humanism around the country has elevated a passion for compassion.

The Golds also understand that learning takes place best when you have some food in your stomach. So this series gives you both food for thought AND a free lunch. Very smart thinking indeed.

Now let me introduce today's important case. The case represents an extreme example of the dilemma that occurs when patient autonomy comes into direct opposition to physician beneficence. Both are worthy principles, but in this case, one will have to trump the other. I am now appointing you all as members of our newly formulated Ethics Committee to see which principle we should support.

The case involves a man who received a liver transplant at our hospital. We know how precious these organ transplants are. Currently there are nearly 17,000 people waiting for a liver transplant in the United States. The median national waiting time in 2006 was 321 days. Using data from Columbia from last year, there were 243 people on the waitlist when the period began in July 2007, and 302 people on the waitlist at the end of the period in June of 2008. Despite the fact that 120 received liver transplants, the waitlist actually swelled by 228 cases. So obviously, selecting the needy individuals from the waitlist who will receive a liver transplant involves a delicate balance of weighing medical need and personal circumstances that will support the transplanted liver.

As you may recall from the flier we distributed, we are faced with a man, post-transplant, who feels he is not doing well and has decided he doesn't wish to live with his current physical and mental limitations. He has decided to stop taking his anti-rejection medications and await death. You can imagine the angst of his doctors who believe his decision is premature and are upset over the prospect of a "wasted" liver. They wonder what their options are -- how aggressive should they be in saving the liver

-- and whether, given the man's lifestyle pre-transplant, this situation might have been anticipated. You are going to decide, led by your Chair, Dr. Prager.

Dr. Kenneth Prager is well known to many of you. He holds several titles – Director of Clinical Ethics for CUMC, Chair of the CUMC Ethics Committee, as well as Director of Clinical Bioethics for the Center for Bioethics. Those of you who did not know him before will, after today, remember Dr. Prager as a model of compassion and humanistic care.

So, let me now welcome, Dr. Prager.

### **Presentation of the Case: Dr. Kenneth Prager**

Dr. Prager presented the case of a 40 year old man admitted to the Emergency Room diagnosed with an accidental Tylenol overdose leading to acute liver failure. He presented with changes in his mental status due to cerebral edema and increased intracranial pressure. The patient immediately began a difficult course of therapy to correct the damage done to his organs and to improve his mental status. Because of his acute condition, he was fortunate to receive a liver transplant. But his post-operative course was complicated and prolonged as he experienced rejection, renal failure requiring dialysis, recurrent urinary tract infections, and pseudomonas wound infections. While his cognitive state slowly improved, he still had recurrent episodes of agitation and confusion requiring medical attention. Following a six-month stay in the hospital, he was discharged to go home on a regimen of high doses of antipsychotic medication and several months of hemodialysis.

The patient, a body builder, had a history of focusing on his looks and body image. Prior to his overdose and transplant, he spent up to three hours a day in the gym and had many courses of Botox injections to remove any wrinkles in his face which led to chronic pain, and thus a constant need for Tylenol. At the time he became a candidate for liver transplantation, these background issues were difficult to assess.

Following his discharge, he was seen every other week by many doctors as he continued to have a multitude of issues: abnormal liver chemistries, recurrent urinary tract infections, poor compliance with anti-rejection medications, and refusal of blood tests at times. A major problem was cognitive impairment, which left him unable to remember important dates and with short term memory loss that meant he was unable to drive or go to work. He was unhappy with the way his wound had healed, leaving a large scar. Additionally, he often experienced nausea and vomiting, something his medication was not helping. The doctors began to wonder if these were psychosomatic symptoms. Two months after discharge, his psychological evaluation revealed that although he was not depressed, he was emotionally labile and often became angry and/or tearful. He was recommended to begin cognitive rehabilitation and was prescribed psychiatric medication.

The patient soon began to miss more of his appointments, and was getting his lab work

done less frequently and monitored less often. His lab tests showed that his LFTs (Liver Function Tests) were fluctuating, indicating that his medication was not being taken consistently. At this point, his wife, who was very involved in his care and was supportive, felt that although her husband was making rational decisions, she was unable to ensure he would take his medications as prescribed.

At the 4-month marking of his discharge, the patient was informed that his lab reports and x-ray tests showed chronic rejection of his liver transplant. This could lead to a second transplant, if maximizing anti-rejection medications did not work to stop any further rejection. Even with this warning, the patient continued to take his medication at irregular intervals. He stated that his chronic conditions including nausea, short-term memory loss, inability to read or drive, and a generally poor quality of life.

The psychiatrist stated that the patient was suffering from transplant sequelae, “a pathological condition resulting from an injury or disease.” In his case, he was experiencing a massive blow to his masculinity and sense of self. The patient was having an increasingly hard time complying with taking his anti-rejection medication and finally stopped taking it completely, despite his wife’s pleading. He did, however, continue to take his Thorazine. His wife asked many family members and friends for help in getting the patient to take his anti-rejection medication; however, no one was willing to help. The only positive side effect of the patient not taking his medications was that he was more cognitively alert and his mood improved; yet, his health rapidly declined. It appeared that he had decided to die. His wife stated that she wanted her husband at home with her and the family as long as possible, but once his mental state deteriorated to the point that he would become delirious, she would have him admitted to hospice care to die.

The case brought up many significant ethical issues that the medical team was forced to confront. The patient’s autonomy was questioned, as the law states that a person has the right to accept or reject medical treatment if he or she is of sound mind. Autonomy, however, is not absolute; for example, almost all states do not permit physician assisted suicide. Therefore, the conundrum of the patient’s autonomy versus the sanctity of life was raised. Although the patient appeared to be “of sound mind” as is required by law, the issue of what is considered “of sound mind” arose. Is there a point when a person’s requests seem so unreasonable in light of medical realities that the person does not seem to be “of sound mind?” Who can determine when this point is reached and, if we feel this point IS reached, can treatment be forced upon a patient?

The transplant team, upset and worried at the course the patient was taking, attempted to find what could be done to avoid the patient’s death, as they felt that the patient had not given enough time to conclude that his quality of life was unsatisfactory. Many transplant patients take up to a year for their mental and physical improvement to reach full potential. Difficult questions were raised by the transplant team which Dr. Prager posed to the audience (“acting” Ethics Committee members):

- What was the law in this case?

- Were there legal precedents?
- Were the wife and the family acting in the patient's best interests?
- Did the patient receive adequate psychiatric care?
- Was the patient depressed?
- Was there any difference between this case and that of others where patients elect to stop life-supporting treatments (e.g., chemotherapy, dialysis, ventilator, Jehovah's Witnesses and transfusions)?
- Should an ethics consult have been called?
- Was there any role for coercion in this patient?
- Is there ever a role for coercion in a case like this?

The psychiatrist reiterated that the patient was not clinically depressed even though during the first few months following his transplant he lacked decisional capacity and when he went home he required constant attention. Of note, he became more rational and had decisional capacity at the time he decided to discontinue his course of medications. Furthermore, had his wife begged for the patient to be hospitalized, that might have been an option. Nonetheless, this did not occur, and it is unclear if hospitalization would have been helpful. His wife appeared to act in the best interests of her husband at all times, whereas the patient's father and brother did not care to be involved.

This case was brought by the transplant team to the attention of the hospital Ethics Committee following the patient's death. Difficult questions were asked of the transplant team: could this outcome have been prevented or anticipated by the transplant team when the patient presented with liver failure? Should transplant teams recognize more strongly the role of psycho-social issues in selecting a patient for organ transplantation? What are the difficulties in deciding whether to perform a liver transplant in a patient presenting with an intentional Tylenol overdose or overdose of any kind for that matter? Why did the transplant team feel so badly about this patient's decision to die rather than to "tough it out" for another six months? Was it because they felt that this was a case of a waste of a vital and scarce organ? Was it a waste of tremendous medical effort including the time and money spent pulling this patient through an extremely difficult post-op course?

Furthermore, shouldn't doctors determine whether or not the patient has decisional capacity prior to agreeing to the patient's wishes to stop life support? Lastly, why did the patient make the decision to die – was it because of quality of life issues or because he felt he was a burden to his family?

This case left everyone troubled by the ending of a patient's life.

At the same meeting of the Ethics Committee, a related case of a 15 year old boy was brought up who had received two liver transplants. The boy decided to stop taking his anti-rejection medications after the second transplant due to his poor quality of life. The medications, in his case, would only have served to prolong his life for a few more

months. Rather than allow the young boy to die in the peaceful manner in which he chose, social services took the boy from his home and put him in a hospital where he refused treatment. A judge finally intervened and allowed the boy to go home to his family as long as he agreed to psychological counseling. His doctor stated that even if the young boy took his medication, he would require a third transplant and would only have a 50% chance of surviving the surgery. The boy refused the surgery and said he also was refusing to take the medication because it caused him pain and suffering and prevented him from reading, his passion.

The two cases that were presented clearly illustrated the tremendously difficult ethical, medical, and social dilemmas that arise when patients who receive organ transplants subsequently decide to die. The grueling struggles and questions that are asked during this process are critical for the medical community to consider, as troubling cases like these are not that uncommon.