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**MEDICAL NARRATIVE**

## Liver Transplantation: The Illusion of Choice

Carol Panetta Zazula, RN, BSN, CCTN

They stood at my nurses' station, two men, fiftyish, physically unrelated, yet brothers in disease. Their skin color might be mistaken for a tan with a yellow cast or they might have the glow of yellow jaundice to skin and sclera. I have seen skins tainted grey; others a shade of green no human should be, but those patients are unable to stand at my station. Their arms exhibit muscle loss, always a stark contrast to the oversized, sometimes enormous abdomens, taut and shiny with ascites. Fluid waves and shifts in the body, causing legs swollen with edema, shortness of breath from pressure on the diaphragm, and scrotums sometimes the size of a grapefruit. The thin white feeding tube snakes from nares, another line on sallow complexions, a nutritional necessity for these men with no appetite. Loose and plentiful daily bowel movements are the side effects of the drug that keeps the brain lucid. Then there are the coagulopathies, those at risk of bleeding out at any time. Yes, these are some of my patients waiting for their only option: a liver transplant.

My patients so sick, so at risk for infection, bleeding, kidney failure, and encephalopathy, and they must await another's death so that they may live.The longer one is on the transplant list the greater one's chances for walking along the long yellow road. The end of the road has no choice at all: liver or death.

Who gets a coveted spot on the transplant list, who doesn't, and how does ethics guide us and our patients in the process? There are many tests to be passed to be considered for transplant. In addition to an EKG, chest x-ray, pulmonary function test, abdominal CT, doppler echocardiogram, bone-density test, endoscopy, flex/sigmoidoscopy, and labs upon labs, there are the evaluations: dental, nutritional, psychological, surgical, and psychosocial. It is with these and other measures that we assess fitness to wait on the transplant list and survive major surgery.

You must also have family and friends to get a liver; that is, you must have a reason to live for a liver transplant. And these wives, husbands, mothers, fathers, and siblings will be crucial to your posttransplant course. Sometimes after the transplant there are months of feeling ill in addition to the many follow-up appointments, and boy will you need someone to walk this road with you. Alcohol can no longer be part of your life. You must have a brain that works reasonably well, so that the hundred-page binder of pre- and post-transplant instructions can be read and understood. You must have the ability to show up and follow the rules; be unable to do this and you will not be listed.

All the patients' test results and evaluations are presented to a committee of doctors, nurses, social workers, psychologists, and others to decide who gets an opportunity to wait for a healthy organ with their blood type. Some patients may be de-listed and some—due to infection or other conditions—may be made inactive.

The last such committee meeting I attended had 33 people in the room. The atmosphere is always earnest and a bit somber. We bring our own knowledge, practices, professional opinions, and, at times, personal biases to the table. We who are human, able to distinguish right and wrong, determine placement on the lists leading to a liver and life. Hoping for a good outcome, we weigh patients' information and each other's comments carefully. We want to be fair. Who will take good care of that scarce item, a liver, one made possible through death. Do we choose to list those who don't meet all the criteria so that they may hope and pray that a liver becomes available?

Who gets this scarce commodity is greatly scrutinized, as it should be. But when something is scarce and an imperfect human is in need of it, allotment and choice can have shades within shades of grey. Many of those awaiting a liver transplant are alcoholics. A question many wrestle with is, if your last drink was 6 months ago, have you taken actions that will allow you to live your life alcohol-free after the transplant? Some stopped drinking only because they became too sick to drink. That may have been 2, 6, 10 months ago. When they feel better posttransplant, then what? There is a small percentage that falls back to drinking, something they think made things better in the past. Knowing all that has transpired in order for the patient to have a new liver, we transplant professionals are greatly saddened by this choice; a transplanted liver is not meant to process alcohol, and forcing it to do so can be harmful.

There is a way to skip all of this process and it is called fulminant liver failure, a condition that puts you right at the top of the list. You could have been to China and picked up the wrong parasite. Maybe you picked the wrong mushroom to harvest; the death's cap mushroom is deadly to your liver. Then there is the person who attempts suicide with acetaminophen. This patient tries our souls. For reasons I cannot fathom, there are those who seek to end their lives with this seemingly benign over-the-counter drug. Many times, the desired outcome, death, is not obtained—just a dead liver or one that will not support life. Because many of these people are young, we in the field want to give back to them the life they have thrown away. So they get a new liver and a new life, but at what cost to them? They have no idea of the payment expected on the other side: countless follow-up appointments and labs and a different state of health for the rest of their lives. Each of these scenarios, right or wrong, causes the list to grow just that much longer for others waiting. See paragraph one.

What about the incarcerated? Although they aren't often able to meet the requirements, it happens. Do we need to know their crime or when they will be released in order to get them on the list? Is it ethical to suggest to patients of means that they move to Florida, that land of car, boat, and motorcycle accidents generating

a bounty of organs. Do you try to list that 52-year-old-man, one with a wife and 3-year-old, who has drunk great empty spaces in his frontal cortex?

If being morbidly obese can cause many postsurgery complications, should the obese be unable to get listed? What about the person unable to stay on a low-salt diet, demonstrating an inability to be compliant at this point in his life? And just how well must one's brain work to earn a place on the list?

The philosopher and psychologist William James wrote,"An act has no ethical quality whatever unless it be chosen out of several all equally possible" [1]. For our patients, there may be no higher truth. Yet we in the field of transplantation are required to make choices: who has or has not met the requirements, list or not, now or later. We choose and our patients take a chance. The chance is to continue in this world.

I must be able to believe in the process and trust in the members of the committee. Sometimes being able to give a patient another chapter in life's book, perhaps an opportunity for some redemption, is enough. Yes, this is an imperfect system. Yet we come together, medical professionals working within a system of moral judgment and standards in an open environment and choose who should be listed for liver transplantation. My patients, glowing and starving and swollen, rely on us to choose wisely. So as I care for my patients I give them their medicine, I give them a smile, I adjust a pillow and I say, "I hope you get a liver soon."

**References**


1. James W. *The Principles of Psychology*. Quoted in: Bartlett J, Kaplan J, eds. *Bartlett's Familiar Quotations*. 16th ed. Boston, MA: Little, Brown & Company; 1992: 545.



Carol Panetta Zazula, RN, BSN, CCTN, has worked on Farr 10, the transplant floor of Beth Israel Deaconess Medical Center in Boston, for 10 years. She has an associate degree in nursing from Bunker Hill Community College in Charlestown, Massachusetts, and a bachelor of science degree in nursing from Northeastern University in Boston and is a certified clinical transplant nurse.


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