

Speaking for Myself

Devil's alternative

Will you donate a part of your liver to save an ailing relative?

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I think the starting point of this whole affair was that phone call from Dr Sharma.* He introduced himself as an associate professor of surgery in a medical college. He was speaking from Pune and sounded very disturbed.

The reason for his emotional disturbance became apparent from what he said. 'My son Ravi* is serving in the Army and is presently admitted in a local military hospital for hepatitis. He has been diagnosed as having fulminant hepatic failure (FHF). Doctors in Pune have told me about the bad prognosis of this disease. Will you accept him if he is brought to you?'

After a pause he added, 'I would like him to be shifted to your hospital in Delhi because I've been told that you have a liver transplant unit there.'

I gave a guarded reply, 'Sir, our own transplant programme is likely to start in March 2007, but we will be happy to look after him if the treating physician at that hospital decides to transfer him to Delhi.'

I also felt it necessary to clarify, 'We have not yet started our own liver transplant programme, but if required we can get this done at any of the other liver transplant units in Delhi.'

After talking to him I contacted the service doctor who was treating Ravi. I was told that the diagnosis of FHF was fairly certain and the physician in-charge had already decided to transfer Ravi to our hospital at Delhi. An Air Force plane had been arranged and Ravi would be reaching our hospital in about 4 hours. I ended my call by giving some instructions about the precautions to be taken *en route* by the accompanying intensivist.

It was a Friday and I realized that all government offices would be closed for the next 2 days. Therefore, I took a pre-emptive verbal sanction from the authorities, so that I could refer Ravi for liver transplantation to an external hospital if required during the next 48 hours.

Ravi was deeply comatose when he arrived and fresh tests revealed his international normalized ratio (INR) to be 12. This clearly indicated poor prognosis and urgent need for transplantation.

Ravi's father, Dr Sharma was also in constant telephonic contact with a hepatologist in the USA. The hepatologist had primed him about the need for liver transplantation as the 'standard of care' for FHF in USA. Dr Sharma had anticipated that I would be discussing this option with him and he was mentally prepared for it. 'Dr Anand, I am aware that we do not have a cadaveric liver transplantation programme in India. I and my wife both are willing donors and I would like you to arrange living donor liver transplant (LDLT) for our son as early as possible.'

With the help of his friend in the USA, he went on to choose a private hospital where he wanted his son's transplant surgery.

When I tried to engage him in conversation about the risks of donor surgery, he cut me short by giving a clear statement, 'Whatever the risk, we are willing to take it.'

I officially referred Ravi to his father's choice hospital for considering an adult-to-adult LDLT. A sum of Rs 2 200 000 as a package deal was quoted to him by the private hospital. Donor assessment was started after the relatives deposited a major proportion of the money as an advance, and Dr Sharma was found suitable for donating a part of his liver. He was then hospitalized for donor surgery.

The private hospital, where the LDLT was to be done, sent its ambulance and an intensivist to pick-up Ravi from our hospital. Ravi was being wheeled out on a trolley. I walked behind the trolley with his mother to the ambulance, trying to reassure her. It was like a tight-rope walk, i.e. telling her to be optimistic while trying not to be untruthful at the same time. Believers find God very convenient for such occasions.

Just as Ravi's ambulance moved, I saw tears welling up in his mother's eyes. I knew what was going on in her mind. All her treasures—the lives of her son and her husband were at stake that night. I am sure the money they had borrowed to pay for the procedure was not at all a consideration. As she left, I closed my eyes for a moment, turned my face to a side and prayed for them.

I wasn't mentally prepared for what happened after this.

The minute I opened my eyes, another familiar face came into focus. I was still trying to put a name to that face when she cheerfully introduced herself, 'Remember me, sir? I am Rina!* I did my internship with you some years back.'

I remembered her as the most inquisitive of the interns who had worked with me. She was inherently intelligent and always questioned my decisions. And then she would go on to examine the evidence to check if my answers were correct.

'Of course I do, but what are you doing here?' She had left Army service a few years back and I had lost track of her.

'I came to see a relative of mine, who is admitted to your hospital after a road traffic accident. He is okay now.'

'And what are you doing these days?'

'I have done Pathology. You know, I love solving problems.'

Creating problems would be more accurate, I thought. Unexpectedly, she added, 'I just came out of casualty and saw you standing there with eyes closed. The expression on your face was something I had never seen before. I was wondering what is behind this peculiar expression. All well, I hope?'

'You seem to have done well!' I tried to change the topic.

But she was persistent. 'You can't fool me. Why would the chief of medicine stand in front of casualty, looking sad with eyes closed and face turned up? You have to answer that.'

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* All names are fictitious though the narration summarizes all true events.

I was aware of her perseverance. My problem was that my own thoughts on the problem at hand had not yet fully crystallized. I tried to be evasive, 'It's a long story and you must be getting late.'

'I always have time for stories. If something is worrying you, it would be interesting.'

And I fell for it.

I told her the whole story of Ravi, his mother and Dr Sharma.

She had a look of disbelief on her face, 'What is the big deal! Lots of people donate kidneys. Liver donation should be similar?'

'Should be, but unfortunately it is not. In liver transplantation, a donor may have a lot to worry about. First, as you know, we have only one liver. Therefore, the surgeon will have to carve out a baby liver out of that one by cutting through it. Second, the liver is criss-crossed by 4 sets of structures—arteries, veins, bile ducts and portal veins. More often than not, the natural course of these structures within the liver has variations. Then there are problems associated with the cut surface of liver. So, even the donor surgery is associated with significant morbidity and even mortality. It is not usually the case in kidney donation where one whole kidney can be removed for transplantation.'

She looked genuinely surprised, 'Oh I didn't realize that.'

I went on, 'Actually no one is comfortable with this morbidity and mortality, which though small may be at least five-fold that of kidney transplantation.'^{1,2}

She suddenly remembered something, 'You just said Dr Sharma didn't let you explain the risks of surgery. I feel both parents must have been in a state of shock. In such a mental situation, do you think he is going in for surgery without actually understanding real risks?'

'Dr Sharma is a surgeon, who feels that he has all the information he needs. It is not unusual that many persons without any medical background may also behave in the same manner if they have a strong desire to save their near ones.'

She asked, 'Do you think informed consent is valid in such circumstances?'

I could expect nothing less from Rina. I was regretting my decision to tell her the whole story.

I was more careful this time, 'This is actually an area of concern. Informed consent in this setting is problematic because, in most cases, the decision to donate has already been made before full information has been provided, and is seldom withdrawn.'³

Her next question was innocent enough and I thought she was asking for some information, 'What is it that you would want the donor to know before he signs on the dotted line?'

'Several things! For starters, a potential donor must realize that:

1. Donor hepatectomy carries a risk of death which may be >1%.⁴ At least 19 donor deaths have been recorded in the western literature,⁵ and possibly 3 in India. Among survivors, there is a significant (10%–55%) risk of biliary complications.⁶ Some authorities have gone on to suggest that there may even be a risk of developing secondary biliary cirrhosis in donors.⁷
2. Recovery from surgery may take up to 3 months.⁸
3. The success of living donor graft is not always assured. Success in LDLT for FHF is poorer and many centres are not performing adult-to-adult transplants for this indication.⁸
4. Left lobe donations for paediatric liver transplants are fairly safe, but right lobe donations are associated with a very high risk of serious complications in over one-third of donors.^{9,10}
5. There is also a significant psychological cost for the survivor in the unfortunate event of either donor or recipient death.¹¹

She remarked, 'I have also read a bit of immunology. I believe

that liver from the blood relative would have higher chances of being accepted by the recipient. Isn't that so?'

'Logically yes; unfortunately, the real answer is no. Experience has shown that this logic does not translate into better outcomes. First, relatives with different blood group will not be suitable donors. And, contrary to what you expect, there is a higher complication rate with LDLT in comparison with cadaveric whole liver transplantation.¹² Usual problems are early biliary leak, late biliary stricture, hepatic artery thrombosis and sepsis.'^{5,13}

I saw that the colour in Rina's face was now changing. 'And you still feel you are justified in asking an absolutely healthy asymptomatic person to donate liver? Does your ethic allow you to put a perfectly healthy person to so much risk? Don't you feel hesitant before recommending this procedure?'

I should have guessed that she was not going to stop there. I started fumbling for an answer.

'Rina, how much risk can be considered acceptable in this setting is not clear at present. Even less clear is whether the treating doctor, who is focused on the treatment of recipient, is really competent enough to decide.'

I was now treading on very thin ice. 'You see, in this situation, there seems to be a bit of conflict within the three accepted principles of medical ethics: Autonomy, beneficence (doing good)/non-maleficence (not causing harm) and justice (fairness of treatment for all individuals).'

She candidly said, 'I'm afraid I don't understand this!'

'It is the right of the donor to choose what may be a *high-risk donation*. In this situation a surgeon may rule out potential donors on the basis of their assessment of excessive clinical risk, but most would prefer to go by universal thinking (read international guidelines) on this subject, which, so far does not exist. And the real catch in this situation is that a donor determined to undertake a particularly risky donation may not realistically comprehend risks or be in a state to assess his or her own emotional competency, financial burden or the impact on his or her extended family!'¹⁸

'Then how is the doctor supposed to decide what is right?'

'First, the doctor is supposed to explain the limits of current knowledge; that is, statistics are affected significantly by the short history of the procedure, variety and changes in technique, and self-reporting bias. In our case, I could not explain it to Dr Sharma to my satisfaction as he had plenty of input from his hepatologist friend in the USA. I sincerely hope the surgeon would follow a copy-book approach while obtaining the informed consent.'

She was still prodding me, 'What do you mean by short history of the procedure?'

'This procedure is barely a few years old and still evolving. Living donors encounter known as well unknown perils.'¹⁴

'What exactly is meant by that?'

'Living donations of liver lobes is still considered an innovative procedure by many authorities and so far we do not know *everything* about its impact on the subsequent life of the donor.⁸ These circumstances have been compared to testing a new drug in healthy human volunteers, who agree to it solely on the basis of altruism. In this situation, unexpected events can happen. It is best shown by Ellen Roche's story.'³

'What is that story?'

'Ellen Roche was one such volunteer who died while taking a trial treatment for an asthma study in the USA. This event stimulated new efforts for the protection of human subjects in research; not only at Johns Hopkins where the event occurred, but across that country.¹⁵ We sincerely hope we don't get any unpleasant

surprises in living donation. Presently, a 7-year multicentre study is in progress to determine living donor outcomes.¹⁶

She was keenly following me, 'You mean, at the time of informed consent, the donor should be told that the surgical procedure is new and not yet fully evaluated?'

'Something like that. The doctor should also explain his country's and his centre's data regarding deaths, complications and most frequent patient complaints.'

'And what are the Indian results like?'

'I don't know.'

'What do you mean—I don't know? How can you refer patients without knowing that?'

'As far as I know, we do not have any detailed publication in a peer-reviewed journal about liver transplantation in India. We only know what surgeons tell us in meetings.'

'I cannot believe it!'

'It's true. There can be several reasons for lack of publications. Initial results are often not as good as those from established centres. In any case, no centre has done enough transplants so far to have meaningful publications. Doctors say they are so busy that they have no time to publish their results! We have to live with the idea that our knowledge is incomplete. You see, in India there is no transplant or donor registry, and every hospital is free to do what it likes. We are a true democracy!'

'Then why have you referred your patient there?'

'Because I know the capability of the surgeons involved. In Dr Sharma's case, he made a bold choice on the basis of what he heard from his friends. Do you think he should be denied the right to opt for what he thinks is "life-saving" surgery?'

'Then why do you want to go into so many details with the donor?'

'You see, healthy individuals who have never been seriously ill often underestimate the amount of pain, fatigue and other disability they will experience after major abdominal surgery. It has been reported that postoperatively, they often report unexpected pain, a larger surgical scar than anticipated, or delayed normal bowel function.'¹⁷

Rina has a habit of catching you by the throat, 'What about the ethical principle that states "cause no harm"?'

'In organ donation, the obligation of non-maleficence does not dictate that absolutely no harm may be done to the patient, but allows for some degree of injury as long as there is an intended benefit to another.⁸ The procedure recommended must be reasonably successful both in donor and the recipient.'

As if to justify what was being done in our case, I added, 'LDLT is considered to have also stood the test of "justice", the third ethical principle. In western world, where cadaveric transplant programmes exist, it augments the number of patients that can be treated. In case of recipient organ failure, recipients would be granted regional priority for a cadaveric re-transplantation, which would lead to cadaveric organs to be allocated out of turn.'⁸

'What would happen in our country where no cadaveric programmes exist?'

'I guess it will be a disaster, but fortunately such events are rare.' I saw a car drive close to us. Rina recognized it as her car and asked the driver to wait.

'Sir, one more question. Suppose, Dr Sharma was found unsuitable as a donor and the mother was found suitable instead. What would have been the status of your "informed consent"? Would you have educated her about all these strange sounding words for a lay person?'

'That is a difficult one for me. In our case, Dr Sharma is a

medical doctor. If he said he understands risks, one may accept it. But many Indian women see the world through the prism of their husband's opinion. For many, the impulse to sacrifice one's comfort or even life would be so great that no amount of risk will deter them. We in India have strong emotional bonds. Even extreme risk would be regarded as acceptable, when you show them hope of saving the life of a near one. Even our family pressures are such that many persons would prefer dying rather than face the risk of living with the guilt of not saving the husband or son when they could have.'

'It's a Hobson's choice for the donor! You are in effect asking the donor to part with half of his liver and face the risk of death or live with the guilt for rest of his life!' Her exclamation was followed by another question. 'What is your opinion? Can it be considered a reasonable risk to take for the donor by any standards?'

'People make decisions about future based upon their emotional state at the current time.¹⁸ Fear of losing a loved one may lead to decisions that are not entirely logical.¹⁹ Most decisions to donate may be influenced by fear, preconceived notions and perceived lack of choice. In one survey members of the lay public were willing to accept mortality rates as high as 21% in order to save the life of a loved one. Unacceptable by any medical standards.'

She tapped her head with her index finger and popped a totally unexpected question. 'I vaguely remember having read about some trouble over an LDLT in Hyderabad a few years back. Did you also read that somewhere?'

I respected her for her ability to bring out issues that were long forgotten. 'I think, no doctor who is related to this form of treatment would like to remember that.'

'What made it so unusual?'

'That was the story of Mr A. V. Srinivas (*av_srinu@yahoo.com*) and it was published along with a comment from the hospital involved, in the *Indian Journal of Medical Ethics*.²⁰ Mr Srinivas had an unfortunate experience with an LDLT in relation to his father, who was suffering from cirrhosis of liver. In this instance, Mr Srinivas's mother was the *hesitant* living donor, who agreed for donation because she saw it as the only hope of survival for her husband. Surgery was organized in a private hospital, was carried out by a foreign surgeon from the UK. The foreign surgeon operated and left for his country, leaving postoperative care in the hands of local doctors. The outcome was disastrous. Mr Srinivas's father (the recipient) died and mother (the donor) was left in a persistent vegetative state due to ischaemic brain damage. *The story underlines the bottom line that in an attempt to save one life, two lives can be lost.*

'Mr Srinivas must be shattered and furious?'

'That would be an understatement. He was upset on several counts. He maintained that

1. the family was not told about the difference in risk between an adult-to-child LDLT and adult-to-adult LDLT.
2. surgery was done by a foreign surgeon from the UK. At that time this surgeon was not permitted to do an LDLT surgery in the UK under the National Health Scheme.
3. the hospital initially promised that donor care would be free. But subsequently, after a complicated course, he was presented with a bill for Rs 4.5 million.'

'My God, that's terrible if it's true.'

'I agree. You can read full details on website even today.²⁰ In western world, two widows of donors have challenged the decision-making process for donor screening.^{21,22} All professionals are concerned about these issues²³ and agree that potential donors

should be protected from undue pressure to donate but “how” is the question that has not been answered.’

‘What is preventing us from having a cadaver donation programme?’

‘If it was easy, kidney transplant surgeons would not be looking towards unrelated donor transplants.²⁴ It is all a question of public attitude. We recently had a patient who was awaiting kidney transplantation. He did not have a suitable relative to donate kidneys and his relatives used to crib every day about the lack of cadaver donation programme in our country. They felt that the doctors were not doing enough. Due to an unfortunate complication, the patient developed massive intracerebral haemorrhage and was declared brain-dead. When a coordinator approached them to become an organ donor, they became angry and refused it outright.’

‘Does that mean India cannot have cadaveric donation programme?’

‘I never said that. I guess the main road-blocks are ignorance among doctors as well the lay public about this issue. There are several organizations, especially in southern India, which are doing very good work in this direction and have achieved reasonably good results.^{25,26} I think results are proportional to the effort that is put in, and that means we have not yet invested enough time and energy in this direction.’

‘One last question and then you are a free man. And I want your frank opinion.’ She looked directly into my eyes as if trying to judge the truthfulness of my answer.

‘In our setting, is consent for an adult-to-adult LDLT really above board, when cadaveric liver transplant programmes do not exist?’

‘You are pushing me into a back-to-the-wall-situation.’ I carefully thought what my answer should be. ‘An adult-to-adult LDLT involves complex interplay of psychosocial and family dynamics. Potential donor’s perceptions will entirely depend on surgeon’s explanation. The ethical soundness of an LDLT, therefore, will primarily depend on those who will deliver the service.’²⁷

POSTSCRIPT

At the time of going to press both Ravi and Dr Sharma were doing well over one month after surgery. The first cadaver liver transplant at Army Hospital R&R was done on 8 March 2007.

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