Living Donor Liver Transplant is not a Transparent Activity in India

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Living donor liver transplant has gained rapid popularity in India as a life saving procedure for end stage liver disease. The undoubted benefit for the recipient is clouded by a few unfavorable outcomes in donors which have led to allegations of lack of transparency. These factors are easily remediable with an attitude of self audit and self disclosure by transplant centers, enabling a truly informed consenting procedure. (J Clin Exp Hepatol 2013;3:66–69)

Living donor liver transplant (LDLT)—the term itself implies a perfectly normal healthy human being undertaking an act of supreme sacrifice, mostly with gratifying results but with a risk of major morbidity or even death. Inherent to the definition are factors like lack of compulsion, no incentive other than altruistic or emotional and a fatalistic acceptance of the outcome. On the face of it, there seems to be little reason to question the ethics behind donating organs for loved ones. LDLT in comparison to deceased donor liver transplantation (DDLT) has always been a hotly debated issue, sometimes being projected as a savior and sometimes vilified as a modern evil created by the hand of surgeons.[1]

LIVING DONOR LIVER TRANSPLANT—A BOON FOR DYING PATIENTS?

There is no denying that the LDLT as a procedure has opened new avenues to save patients dying on waiting lists. This is even more apparent in countries like India where deceased donors are far and few, and LDLT in the hands of competent surgeons has proven to be the panacea. The remarkable success and innovations have firmly placed India as a much sought after center for LDLT and thousands of people are given a renewed life through the noble altruism of others.[2] Even before the DDLT programme could get going LDLT has been touted as the answer to organ shortage.

Emboldened by the good results surgeons have extended the boundaries of resection and indications for transplantation are being stretched. LDLT was first successfully introduced to the world as an adult-to-child procedure with a good safety margin for the donor. As the initial problems were overcome, the scope of the harvested organ has steadily increased so much so that a right lobe donation with the right and middle hepatic vein is advocated as the ideal adult-to-adult graft.[3] All these are at the cost of only one individual—the living donor and looming in the background is the specter of unethical practice, be it the informed consent, the verification of results and outcomes and the morbidity statistics.

INFORMED CONSENT IN LIVING ORGAN DONORS

It is the right of every patient undergoing a major surgery to have a written informed consent. The process varies from country to country and is necessarily based on guidelines by the appropriate authority. The World Health Organization (WHO) has stated clearly in its Revised Guiding Principles[4] that "donation and transplantation activities, as well as their clinical results, must be transparent and open to scrutiny, while ensuring that the personal anonymity and privacy of donors and recipients are always protected." Even to date there are no national guidelines in India, countless committees notwithstanding. The Transplantation of Human Organs Act (THOA) Act 1994[5] does lay down stringent criteria for recognition of transplant centers but without a nodal database or registry there is no transparency on survival figures or outcomes. The THOA Act (Chapter IV, Section 13) mentions in the Appropriate Authority's powers in para V 'to inspect hospitals periodically for examination of the quality of transplantation...'. Although they inspect a center when it applies for renewal of registration, these results are not made public.

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Abbreviations: LDLT: living donor liver transplant; DDLT: deceased donor liver transplantation; WHO: World Health Organization; ALF: acute liver failure; THOA: Transplantation of Human Organs Act; UIDAI: Universal Identification Authority of India.
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A new center starting LDLT will go through a learning curve and will be loath to divulge the real statistics. LDLT should be considered unethical when performed at any center with suboptimal facilities or expertise. Large volume centers suffer from pooling of cases with advanced disease and are pressurized to do transplants in patients beyond criteria. In the USA an informed consent process with a standard patient information booklet is mandatory. In India each center has its own version and some none at all. With the added disadvantage of an emotional and largely low educated patient population the consenting process can often be sketchy. Literature supports this assumption even in western countries where it has been concluded that informed consent is a myth as most donors make instantaneous decisions without weighing the risks.[6] In this light it is even more important to convey the risk/benefit ratio clearly and lucidly. It does not matter whether the potential donor is a near relative or unrelated: the consenting process has to be the same, transparent and informed with true data and statistics.[7] An aggressive, detailed consenting procedure will also drive away potential donors and be counterproductive and hence most transplant units take the middle path.

VOLUNTEERS OR COERCION

Freedom from coercion remains a fundamental right of the donor. The Random House Dictionary aptly describes coercion as "dominating or controlling (an individual) especially by exploiting fear, anxiety, etc;".

An LDLT is a test of the emotional bond between donor and recipient. No other surgical procedure devised has the potential to harm than LDLT with no discernible health benefit to the donor. Without a complete transparent consenting procedure the role of emotional coercion cannot ever be put on the back burner as a non-issue. The sick recipient is usually announced as in dire need of a transplant and as the family desperately seeks a match from within, donation by one of its members is deemed justifiable since the family has accepted the risk/benefit ratio. However, this argument cannot be sustained in an unrelated donation where supposedly an emotional bond or sheer altruism is the driving force. The operation is always planned around the recipients need and not the donor's mental acceptance and personal commitments. A suboptimal timing of surgery for both parties is also detrimental to results.

Donors in India are under intense pressure by the family and counseling of the donor privately is a rarity. No system exists to offer the potential donor a choice to "opt-out", thereby negating pressure from the family. Largely done in private hospitals, LDLT will not be commercially viable if this option is exhibited to wavering donors. Nearly all centers make do with the transplant coordinator surrogating as a social worker as the whole concept of patient support from the social milieu is alien in India.

ACUTE LIVER FAILURE

ALF is a medical emergency which carries a high mortality without intervention, namely a liver transplant. DDLT would be the ideal solution as LDLT requires an emergency, harrowing work up with no regards for the donor's state of mind or acceptance of the risks involved.[8] ALF has a dramatic presentation and the element of anxiety driven coercion is at its peak. Though LDLT reduces the waiting time, its use in ALF is with a very narrow risk/benefit ratio and even large volume centers will agree that the results are inferior in comparison to chronic liver disease.

AUTHORIZATION FOR DONATION

Unrelated donors have a more stringent scrutiny from an external authorization committee which severely stresses the individual. The most altruistic of donors is viewed with utmost suspicion and an undesirable end result often vitiates the atmosphere between the donor and recipient families.

The composition of the authorization committees is so heterogeneous that compromising the integrity of the whole committee is difficult. The lacuna lies in the documentation that is provided to establish a bond between the donor and recipient. The documentation required by the authorization committee includes police verifications, Panchayat certificates, proof of residence, etc. The failure of the Universal Identification Authority of India (UIDAI) Aadhar card implementation[9] and the endless fake PAN card scams[10] are an ample demonstration of the ease with which fake identities are built up and the deep subversion of the process. Identities and relationships can be bought and as the kidney racket of Gurgaon laid open,[11] touts are available for this special purpose.

The "Red Market"—Scott Carney's[12] dramatic real life experience refers to the various medical activities through which the human body can generate a profit: surrogate motherhood, organ transplantation, drug testing, baby selling and blood farming. Middlemen take large profits and encourage the trade by assuring buyers that the transaction is conducted ethically. The relief at finding a suitable donor disguises what would otherwise be seen as exploitation. "The crimes are covered up," Mr. Carney writes, "in a veil of altruistic ideals." In a work of investigative journalism, he visits a tsunami refugee camp in Tamil Nadu whose inhabitants are so desperate (and the organ brokers so callous) that it is known as "Kidneyville." The trade persists, according to Mr. Carney, as a result of a major flaw in the transplant system; while the law prohibits the buying and selling of organs, it does not prohibit anyone from billing for the services involved in transplanting organs. This provides doctors and hospitals with a financial incentive to perform transplants, while the costs of the organ procured are absorbed into the billing and easily hidden from view. You can buy an organ without knowing where it came