

## Myths and Challenges in Liver Transplantation - Experience at Tertiary Care Centre of Northern India

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## 1. Abstract

**1.1. Background:** Liver disease is a common cause of morbidity and mortality all over the world, including developing country like India. The three most important causes of liver disease are alcohol, Nonalcoholic fatty liver disease and Chronic Hepatitis B & C. Many patients require liver transplantation as definitive treatment but only minimal percentage of patients get it done due to many myths and challenges associated with it.

**1.2. Discussion:** There are multiple myths associated with liver diseases, especially in developing country like India and same applies to its definitive management which includes liver transplantation. One of the most important hurdle is financial constraints and minimal availability of liver transplantation in government hospitals.

**1.3. Conclusion:** The Government should take urgent steps for making easy availability of facility of liver transplantation in significant number of government hospitals, equally distributed all over India. Moreover, there should be mass awareness campaign for dispensing all the myths associated with liver disease and transplantation.

## 2. Introduction

Over the last 17 years, liver transplant in India has evolved from a rarity to a common procedure available in the country with survival data comparable to the best centers in the world. India is now in the forefront of Living Donor Liver Transplant (LDLT) in the world with 90% success, with low incidence of vascular complications

and biliary complications. While Deceased Donor Liver Transplants (DDLTs) have picked up steam in Southern India, there is still a large gap between demand and supply of organs for patients suffering from end-stage liver disease and Hepato Cellular Carcinoma (HCC) confined to the liver. In 1990, liver transplantation, the only effective treatment for end-stage liver disease was being performed in most of the Western world and Southeast Asia. The operative success rate then was 86% and the 5-year survival 70% [1]. At the same time, more than 200,000 people were dying in India every year from liver failure without any hope of receiving a transplant. The Transplantation of Human Organs Bill was passed by Parliament in the year 1994 and became the law in 1995 [2]. The initial transplants that were performed were unsuccessful, and it was only in 1998 that the first successful cadaver transplant and a living donor LT were performed [3]. There was little progress until 2004 since when there has been a major increase in numbers of LT operations and centers in India. Until 2004, only 131 transplants were performed in 15 centers across India. Since then in the last 17 years, the transplant activity has picked up in India. The transplant act amendment that was notified in 2014 has brought significant changes in the certification of brain death, simplified procedures required for certification and allowed organ retrieval based on the temporary license.

## 3. Discussion

Our experience regarding these myths and challenges about liver transplantation has been collected during interaction with patient and

relatives over eleven years of continuous running of special dedicated liver clinic where suspected cases of liver disease are referred from various specialties/ superspecialties at PGIMS, Rohtak, different government and private hospitals from all over haryana and nearby states. Hence, these myths in mind of patients and relatives of liver transplantation have been understood from the day of diagnosis to their long term follow up of eleven years. India being a developing country faces huge problem of poverty, illiteracy and non-accessibility of proper health care services which leads to flourishing practices of quackery.

#### 4. Delayed Diagnosis of Liver Disease

The widespread poverty and illiteracy in India leads to quacks becoming first line treatment providers whose easy and economical availability is widespread in the society. The most common problem which occurs with hepatitis B and C is that many patients are put by quacks on alternative medications and monitored with hepatitis B surface antigen (HbsAg) and anti HCV antibody levels without even getting viral loads done. This leads to delay in treatment and significant proportion of patients have reached cirrhotic stage when they consult specialist for their illness. Many chemists, themselves that too against rules, take role of doctors and instead of dispensing prescribed medicines, start treating on their own patients with various kind of ailments including liver diseases. As there is no consultation fees, hence poor patient easily fall prey to these so called self-styled doctors who commit mistakes and this leads to delayed diagnosis of their baseline diseases including which are liver related. They are doing so for increasing their sale of medicines which can easily be given without prescription due to lack of stringent laws and their effective applicability. The other common thing which has been noticed over prolonged interaction with patient and family members is that in every home there is some elder who takes the role of doctor despite being having no knowledge of medical profession. These elder play negative role in proper interpretation of symptoms and leads to delayed diagnosis.

#### 5. Myth Associated with Treatment of Liver Disease

There is strong myth that whenever there is any impact on liver then patient has to take overall less calories, boiled food which is rich in carbohydrate and deficient in fat and protein as it cannot handle and digest the load of fat and protein in the diet. This approach of patient and relatives is detrimental pre-transplant as well as in post-transplant period. High protein/high energy intake are required to promote hepatocyte regeneration and fat restriction is contraindicated. Protein turnover in cirrhotic patients is normal or increased and stable cirrhotic have increased protein requirements [4, 5]. Patients with compensated cirrhosis do not appear to need modification of their energy intakes but with decompensated liver disease, there is requirement of 35– 40 kcal/kg/day [6]. After persistent convincing of patient and relatives, only half of them will follow the

advice of eating nutritious and balanced diet. It is easy to monitor and feed the proper diet in admitted patients but is a real challenge on outdoor basis treatment. It is so frequent to be enquired by patient, after their complete recovery for restarting use of fat and protein in diet, despite being the fact they were motivated to take all kind of vegetarian food during course of illness. The other myth is that in any kind of jaundice or liver disease, there is need of complete bed rest, till Icterus is completely resolved. Many patients do not believe recovery from their current illness because of remnant Icterus in sclera which persists for longer duration due to conjugation of sclera proteins with Bilirubin pigment.

#### 6. Unawareness Regarding Need, Availability and Success of Liver Transplantation

In India there is lack of awareness regarding liver transplantation in general society as well as many baseline health care workers. In India majority of liver disease patients are first seen by Quacks or doctors who are not specialist and minority are seen by specialist or super specialist who have experience and clear cut concepts regarding need and timing of liver transplantation. The significant amount of population including health workers are unaware about availability of liver transplant in India. Thus in many cases there is delay in reporting at liver transplant center. There is false perception in society regarding limited success associated with liver transplantation which is not true as India is achieving almost 90% success rate which is comparable to other parts of World.

#### 7. Organ Donation Challenges

In India, there is strong myth that if organs are donated in brain dead patients, then the soul of diseased will not rest in peace and this deters family members from organ donation. Moreover, there is lack of awareness about organ donation in society and even health care workers. Many do not know about possibility, process and hospitals for organ donation. There are so many trauma centers and Intensive care units in India where significant number of brain dead patients due to road side accidents or other reasons are being taken care of but due to non-availability of organ retrieval facilities and no linkage with transplant centers, precious organs are being wasted on daily basis.

#### 8. Financial Challenges

Many confirmed patients of End Stage Liver Disease (ESLD) in whom liver transplantation is the only definitive treatment, cannot afford the same. The main reason behind this is that a significant number of patients of ESLD, especially in which Alcohol and Chronic Hepatitis B & C are etiological factors, belong to below poverty line. In India, approximate cost of one Liver transplantation is Rs 20-25 lakhs in private set up and Rs 10 lakhs in government set up which are limited in number. Moreover, post transplantation care also requires significant amount of expenditure. Usually this much amount cannot be easily borrowed from relatives or friends.

## 9. Donor Challenges

In India the awareness and pace of voluntary organ donation is very slow, hence majority of organ transplantation are live related. Many Non-Governmental Organization (NGO) have been active for many years in Southern India and now Northern India is also seeing small positive outcomes of their efforts. The scarcity of cadaveric liver transplantation leads to major burden on live related and in many cases despite having no financial constraints, organ donation becomes challenging due to none of family member comes forward for donation or sometimes blood group incompatibility and organ fitness of donor becomes limiting factor. The most important fear in the concerned family members is regarding safety of donor. They are very much apprehensive not only for operative & post-operative complication but also for long term survival of donor. They think that physical and mental capabilities of donor are reduced after transplant.

## 10. Limited Availability of Liver Transplant Centers

There is a paradigm shift in availability of high end and latest treatment at government hospitals in India. In the earlier times, there were limited number of corporate or big private hospitals, hence government hospitals had maximum availability of talented and senior faculty along with best equipments and infrastructure available at that point of time. Now situation has totally changed with passage of time, and now latest techniques and cream of specialist of every field are maximally available in chain of corporate hospitals where they get much better perks and facilities as compare to government hospitals. This has led to limited availability of facility of liver transplantation at government set up and majority are being done at private set up which are beyond the reach of many needy patients.

## 11. Conclusions

In order to increase liver transplantation in developing country like India, there is strong need of continuous and dedicated efforts which starts with dispelling the myths surrounding liver diseases, transplantation and organ donation in health care workers, family members and general society. There should be application of stringent laws for curbing the practice of quackery and general practitioners should be trained for proper diagnosis and referral to liver transplant center in a patient who has reached the stage of liver transplantation. The government should work on warpath for increasing facility of liver transplant in government hospitals, so as to make it in reach of general population. Till that occurs, government can plan to tie up with private liver transplant centers and bear half of expenditure i.e. subsidized treatment can be given to needy patients. As, it is always said that prevention is better than cure thus preventive strategies for etiological factors causing end stage liver disease should be taken on head on for decreasing the need of liver transplantation. This fact is supported by the success shown by National Viral Hepatitis Control Program in which free treatment is being given for hepatitis B & C all over India which has significantly reduced the overall need of liver transplant in this group of patients.

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