Pediatric Liver Transplantation In India- Social Aspects

Smita Malhotra, Anupam Sibal***
**Consultant Pediatric Gastroenterology and Hepatology, Indraprastha Apollo Hospitals*
*** Senior Consultant Pediatric Gastroenterology and Hepatology, Indraprastha Apollo Hospitals*
Address for Correspondence:
Professor Anupam Sibal
Group Medical Director, Apollo Hospitals Group
Senior Consultant
Pediatric Gastroenterologist and Hepatologist, Indraprastha Apollo Hospital
Clinical Professor
Faculty of Medicine and Health Sciences, Macquarie University, Sydney, Australia
New Delhi 110076, India
Ph: 91-11-26825608
Fax: 91-11-26823629
Email: anupamsibal@apollohospitals.com

One of the marvels of modern medicine has been the evolution of liver transplantation (LT) as an established therapy in the last 5 decades. In the US alone over 7.5 lac liver transplants have been performed of which about 54000 have been in children [1]. In the 80's and 90's LT in India seemed unthinkable till the first successful pediatric liver transplant was performed in 1998 at Indraprastha Apollo Hospital, Delhi [2]. The progress was slow over the next decade due to scarcity of trained personnel, poor awareness amongst primary care doctors, reservations regarding donor safety and the huge financial implications. By 2007 only about 318 LT's had been performed in India [3]. However, the last decade has seen a phenomenal growth with the advent of multiple liver transplant centres. Presently about 1700 liver transplants are performed in India yearly with about 10% being in children. The growth has primarily comprised living donor liver transplant (LDLT) though cadaveric donation is picking up, primarily in the Southern part of the country.

Many challenges still exist. There is still a lack of awareness and faith in the modality amongst many primary care paediatricians who are sceptical about the results, morbidity and need for long term care especially amongst those from smaller towns. This becomes all the more pronounced when disease is advanced, or child presents in acute liver failure with high risk of mortality with delayed referral. LT in India is largely limited to the private sector and this healthcare structure does not follow a specific referral pattern, thus limiting the opportunity to provide uniform level of primary, secondary and tertiary care. Awareness among general practitioners about the indications and success of transplant plays a vital role in timely referral. Dissemination of success stories of individual patients who receive constant input from their LT centres in an effort to enhance joint care with their referring units can greatly help in confidence building and promote early referral. Acceptance for LT needs to be boosted through more publications and CME's.

Early transplantation in children avoids growth failure and loss of schooling, and its associated downstream impact on both individual and societal development. Families need to be committed to the cause, as a young child will need the support of a caregiver for the greater part of his childhood. Children with liver transplantation have lower health related quality of life compared to normal individuals, these impairments are comparable, if not better, to those of children with other chronic health conditions [4]. Sadly, the commitment with its implications of investments in time, emotion, effort and money is more readily forthcoming for male offspring. The covert or overt bias against the girl child was reflected in our data as 72.2% of the recipients were male in the initial decade but the ratio has tended to equalise with 51.7% boys and 48.3% girls undergoing LT at our centre in the second decade of the programme. The changing social milieu is also evidenced by fathers coming forward in greater numbers as donors [5].

From the donor's perspective, the risk of not only morbidity but also mortality cannot be entirely denied. Also, donors do go through a lot on the physical, emotional and social front in addition to time lost away from their occupation. Donor safety concerns are a still a major factor limiting transplant despite stringent donor selection criteria being applied by transplant centres. However, in a patriarchal society like ours, increasing numbers of fathers as donors reflects encouragingly on the increasing acceptability for LT in our society.

Financial constraints continue to be the biggest challenge and the the most crucial limiting factor has been the prohibitive cost of LT. The concept of universal health care insurance is still evolving, and most insurance companies do not provide cover for perinatal onset or genetic diseases. Many charities and crowd funding programmes have actively helped poor families save their children by raising funds for their transplants. Many corporates support transplant programmes as part of their CSR budgets. Discounted packages have been offered by a few centres. The advent of crowd funding platforms has been a boon for the the needy as funds can be raised in a short period of time [6]. That strangers come together on the internet to fund a medical catastrophe for an unknown person is heart-warming and provides an insight into the social responsibility that the community is eager to take up when transparency is assured. This has enabled families with limited means to avail of lifesaving transplants even when they could pitch in only marginal amounts. Nearly 20% of our transplant patients in the last 3 years bore an individual expense of only 1.5 lac rupees. Campaigns for children evoke an emotional outpouring of help. This brings with it tremendous responsibility on institutions to use these funds judiciously for subsidised programmes only to maintain credibility and avoid a reputation of “commercialisation of transplantation”.

LT in India remains largely living related and encouraging deceased donor transplantation (DDLT) is the need of the hour. Southern states esp Tamil Nadu have robust DDLT programmes that contribute about a third to half of their total transplants. Increasing DDLT is also being reported from a few other states but remains minimal in Northern India. Society needs to be educated about cadaveric donation through multiple strategies right from education in schools, social media and other mass media campaigns, support from celebrities and hospital awareness programmes.

References:

1. US Department of Health and Human Services. Organ Procurement and Transplantation Network. Available from: https://optn.transplant.hrsa.gov/data. Accessed July 19, 2019
2. Poonacha P, Sibal A, Soin AS, Rajashekar MR, Rajakumari DV. India's first successful pediatric liver transplant. Indian Pediatr 2001; 38:287-291.
3. Kakodkar R, Soin A, Nundy S. Liver transplantation in India: its evolution, problems and the way forward. Natl Med J India 2007;20:53-56.
4. Limbers CA, et al. Health-related quality of life in pediatric liver transplant recipients compared with other chronic disease groups. Pediatr Transplant. 2011;15(3):245-253
5. Bhatia V, Sibal A. Are fathers catching up with mothers in liver donation? Indian Pediatr. 2013;50:158
6. https://www.thehindu.com/sci-tech/health/how-the-magic-of-medical-crowdfunding-works/article28407419.ece The Hindu, July 13, 2019