The History of Liver Transplantation in India

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1.1 Introduction

In 1988 starting a liver transplantation programme in India seemed to be a distant dream for many of us because there were so many hurdles to overcome—it was an exorbitantly costly procedure, there was no local expertise available at that time, the trade in human organs especially kidneys was widespread and the law only recognised cardiorespiratory death and not brain death so that transplants from beating heart donors could not be done. However with a consistent and combined effort we were able to overcome most of these problems gradually and, although some still remain, we have reached a stage where there are now 135 centres in this country which have been registered to carry out liver transplants and, till May 2019, 16,806 procedures had been performed with the results in some centres matching the world's best. And India does the fourth largest number of liver transplants internationally following the USA, China and Korea.

In this chapter I will chronicle our journey from how it all started to where it has reached and although it is, of necessity, a rather personal account, I wish to pay tribute to many of the generally unnamed doctors, journalists, bureaucrats and politicians who helped bring about this momentous change.

1.2 Background

In 1988 there were an estimated 120 centres elsewhere in the world performing 4500 liver transplants annually with an 80% success and 70% five-year survival rates. In stark contrast, there was no liver transplant facility in India and there were an estimated 300,000 deaths from liver failure annually. A small group of us made an initial attempt to sensitise the public to this problem through popular television programmes like 'The World this Week' as well as articles in newspapers and medical journals. But probably the main impetus was provided by the then Prime Minister, Shri Rajiv Gandhi who, after one of his trips abroad, asked the Health Minister why heart and liver transplants were not being done in this country. The Health Secretary then constituted a small group of four people to report on this and we defined the problems that had to be overcome, i.e. the cost, the lack of local expertise, the organ trade and the absence of a law which recognised brain death. To move forward we identified the first move should be to educate the public on the benefits of starting a liver transplant programme in India.

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1.3 Step I: Public Education

This was done through a series of newspaper articles and television appearances. Although there were major opponents to starting such a programme—it would cost 20 lakhs, there would be an enormous wastage of blood and blood products (the blood requirement for a single procedure was usually about 20 units at that time; now it is about 4–6 units); it would become the focus of hospital attention and distract from many other activities which benefited many more people. It was likened to having a 'CT scanner on a malarious swamp'!

The counterarguments were that the procedure would save many young productive lives, it would be available locally, the cost would be much lower than it was in western countries, the quality of doctors and hospitals would be upgraded and there would be national pride that such high-end medical care was available in our own country. No longer would our very rich compatriots need to go abroad for transplants where they were placed at the bottom of the waiting lists and often received 'marginal' livers that had been rejected for use in the indigenous population. We held conferences and workshops in Calcutta, Bombay, Madras and Delhi to which we invited prominent social workers, journalists and religious leaders to discuss whether the concepts of brain death and liver transplantation were acceptable and necessary. There was a generally positive response. The next step would be to try and change the existing law defining death and to allow beating heart organ transplantation.

1.4 Step 2: Changing the Law

After the conference in Delhi in 1991 the government appointed a small committee chaired by Dr. L.M. Singhvi, the eminent lawyer, to examine and report on the concept and definition of brain death, its desirability and implications, to suggest safeguards against misuse and how it might facilitate the availability of organs such as the heart and liver for transplantation.

The Singhvi Committee presented its report to the Cabinet and the Bill was placed in 1992 before the Rajya Sabha where it received overwhelming support. However when it went to the Lok Sabha there were serious objections raised to some of its clauses like including only first-degree relatives as living donors and it was referred to a Select Committee for further debate. Two years passed without any progress and we felt that the law would never be passed but in 1994 the Bill was placed before the Lok Sabha again and after a brief debate in a sparsely attended house it was accepted. The Transplantation of Human Organs Act became a law in 1995.

Its rules stated that only registered hospitals would be allowed to perform transplantation and listed the criteria for organ retrieval. Brain death would be determined by clinical tests alone, i.e. the cause of coma should be known, there would be an absence of cranial reflexes and there should be a positive apnoea test. All these would be verified twice by four specially designated doctors 6 h apart.

An 'Appropriate Authority' was also created which would be responsible for the registration of hospitals, maintenance of standards, would investigate breaches of the law and audit the indications and results of the transplant procedures. For living transplants only first-degree relatives would be allowed to donate organs but if the recipient did not have a suitable donor then someone 'emotionally' related would be permitted to donate. The 'emotional' attachment would by verified by a designated 'Authorisation Committee'.

Trading in human organs was made illegal and a non-cognisable offence.

1.5 Step 3: The Initial Procedures

The first procedure after the Bill was passed was a heart transplant done in the All India Institute of Medical Sciences (AIIMS), New Delhi, by Dr. P. Venugopal and was a success. It was announced by the then Prime Minister, Shri Atal Behari

Bajpayi, in Parliament to loud cheers. However liver transplantation took a long time to gain any sort of momentum. There were a few performed, mostly unsuccessfully, in 1995 in the Apollo Hospital, Chennai, and then at AIIMS Delhi. The first successful deceased donor liver transplant was done on a 43-year-old man in the Apollo Hospital, Delhi, on November 6, 1998, by Dr. AS Soin and Dr. MR Rajasekar. This patient lived for 12 years after the transplant. He had recidivism and died of recurrent alcoholic cirrhosis of his transplanted liver. The second successful transplant in India was a live donor (left lateral sector) liver transplant on November 15, 1998, on an 18-month-old male child with biliary atresia. This patient is alive and well.

1.6 Step 4: Sustainable Programmes

1.6.1 Numbers

In spite of the law being passed there were very few deceased donor transplants and the main activity, albeit small in number, was centred around living donors (Fig. 1.1).

There were very few done up to 2008 after which there was a spurt in activity after the year 2009 with a gradually increasing number of deceased donors especially in Tamil Nadu. The main impetus for this increase was the farseeing Tamil Nadu Government orders of 2008 which made brain death declaration mandatory and doctors who were in charge of such patients were required to ask their relatives for organ donation. It also decreed that a State level waiting list be maintained, laid down norms on how the procured deceased organs should be distributed, required that Transplant Coordinators should be appointed in all registered hospitals, provided government subsidies of up to 30 lakhs towards the cost of the procedure, established 'green corridors' so that the harvested donor organs could be moved quickly in spite of heavy traffic to the recipient hospital and supported non-governmental organisation such as the MOHAN Foundation which has done such sterling work in promoting deceased organ donation throughout the country.

In 2011 there were amendments to the existing law passed by Parliament which mandated a video recording of Authorisation Committee meetings, delinked transplantation registered institutions from those which could diagnose brain death, allowed intensivists and one other doctor to confirm the diagnosis (rather than the four designated doctors, including neurosurgeons, previously), included grandparents and uncles as near relatives and allowed 'swap' donations across family members according to blood group matching. It also established the NOTTO, ROTTO and SOTTO (National, Regional and State Organ and Tissue Transplant Organisations) in addition to the already existing ORBO (Organ Retrieval and Banking Organisation).

Thus Fig. 1.2 shows the rapid increase in liver transplant numbers since 2009 when there were

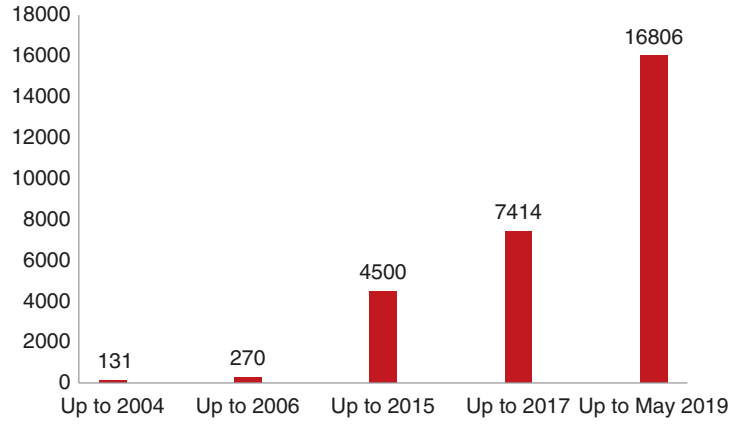

Fig. 1.1 Liver transplantation activity in India up to May 2019

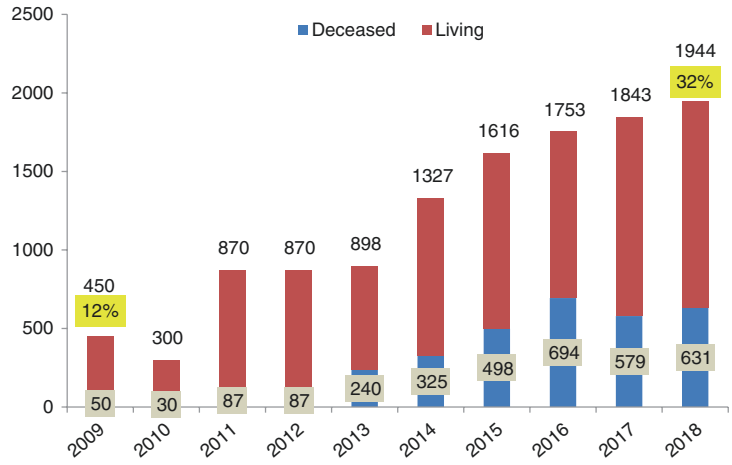

Fig. 1.2 The total transplants performed annually in India between 2009 and 2018 with the numbers and proportions of deceased and living donor procedures

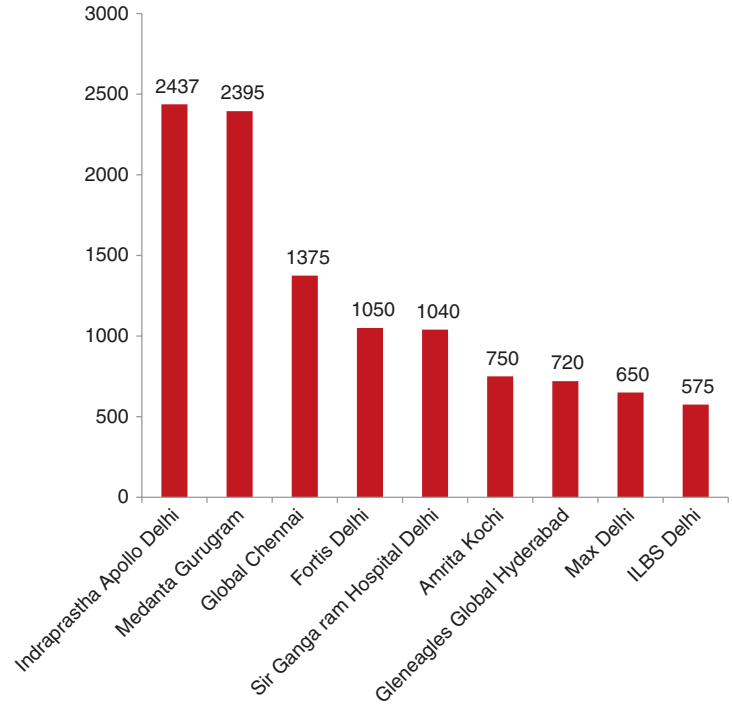

Fig. 1.3 Total liver transplants up to May 2019, Individual Centre Data (>500)

450 done with 12% from deceased donors to 2018 when 1944 were done and 32% were from deceased donors.

However in 2019 after we asked all members of the Liver Transplant Society of India to share their total numbers out of 135 registered centres 40 responded and the individual centre data are provided in Figs. 1.3, 1.4, 1.5, and 1.6.

The activity of hospitals in a single year (2018) is provided in Figs. 1.7, 1.8, and 1.9.

Thus only 4 institutions performed more than 200 in a single year (2018), 11 did 50–100, 30 did 1–50 and 90 others who were registered to perform the operation did not do any liver transplants or did not answer the questionnaire (Fig. 1.10).

When we repeated the same exercise recently in 2020 we only had one reply; perhaps because of the increasing competition or fall in numbers centres are now unwilling to disclose these figures.

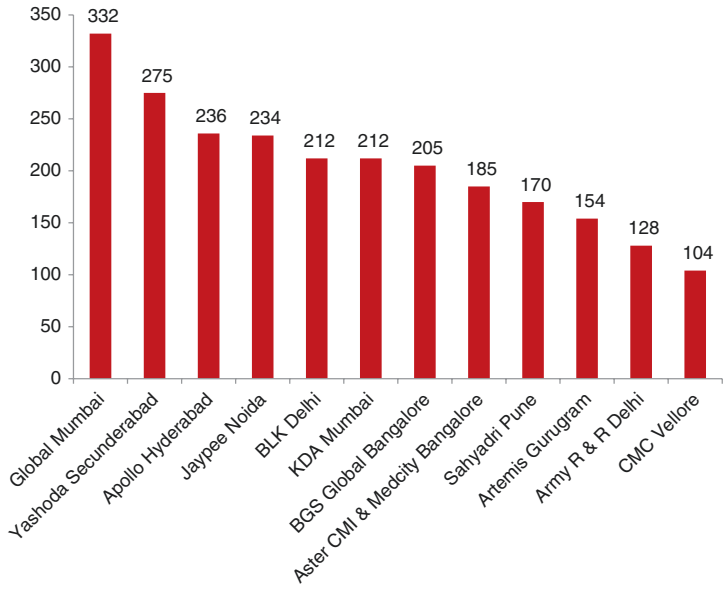

Fig. 1.4 Total liver transplants up to May 2019, Individual Centre Data (100–500)

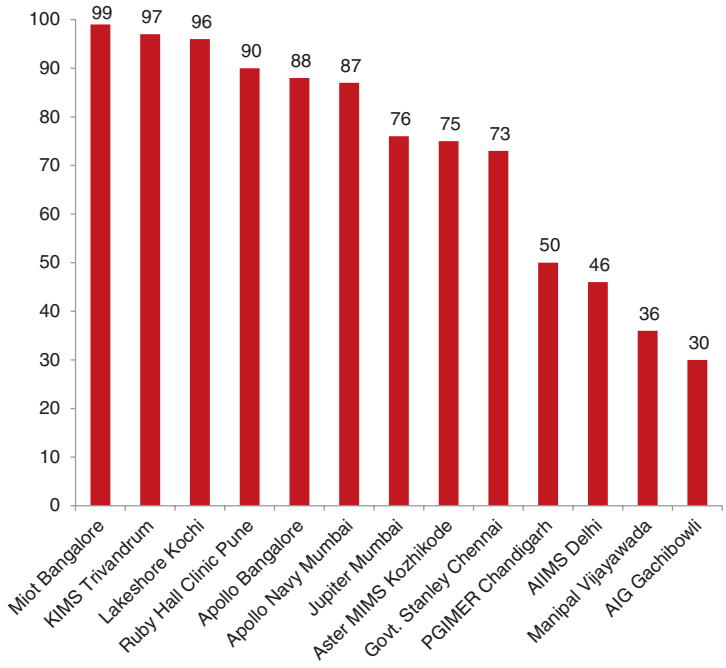

Fig. 1.5 Total liver transplants up to May 2019, Individual Centre Data (<100–30)

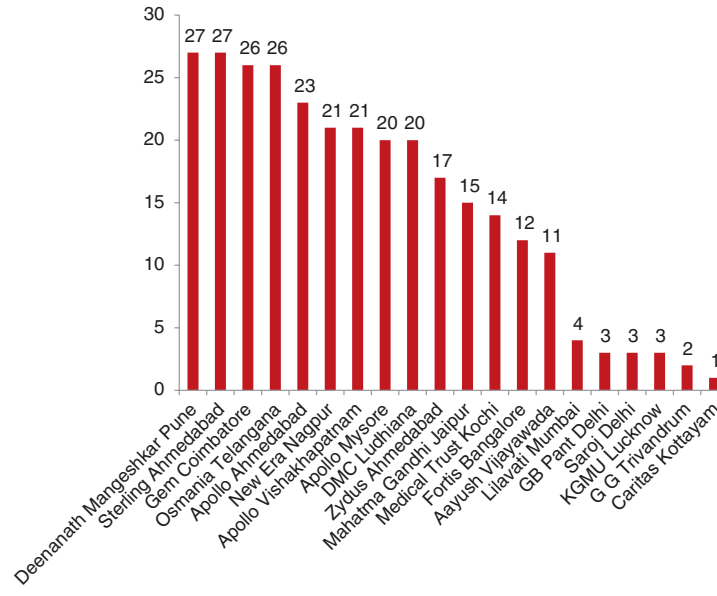

Fig. 1.6 Total liver transplants up to May 2019, Individual Centre Data (<30)

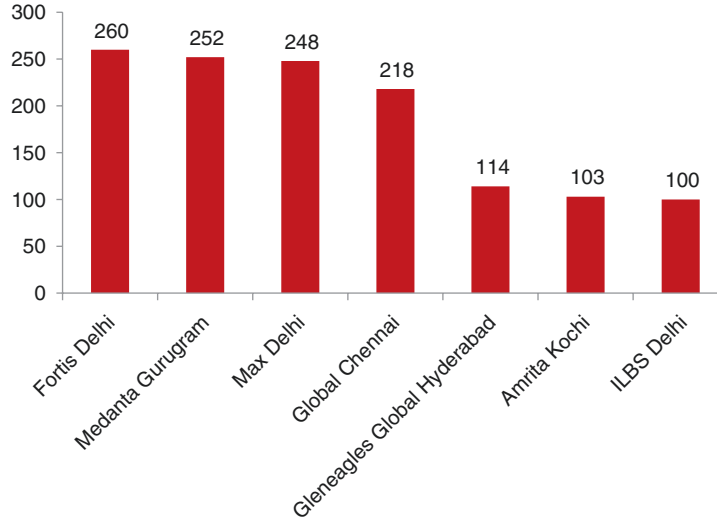

Fig. 1.7 Liver transplants in India in year 2018, Individual Centre Data (>100)

1.6.2 Statewise Distribution

Figure 1.11 shows the distribution of liver transplant centres in India with most in the South, West and North but very few in the Central and Eastern states.

The largest numbers of transplants done in 2018 were in Delhi (1161), which in 2020 has apparently 16 centres, but these were almost all from living donors (Fig. 1.12).

But if the numbers of deceased organ donations are depicted (Fig. 1.13), we will see that most of the activity has been in the Southern and

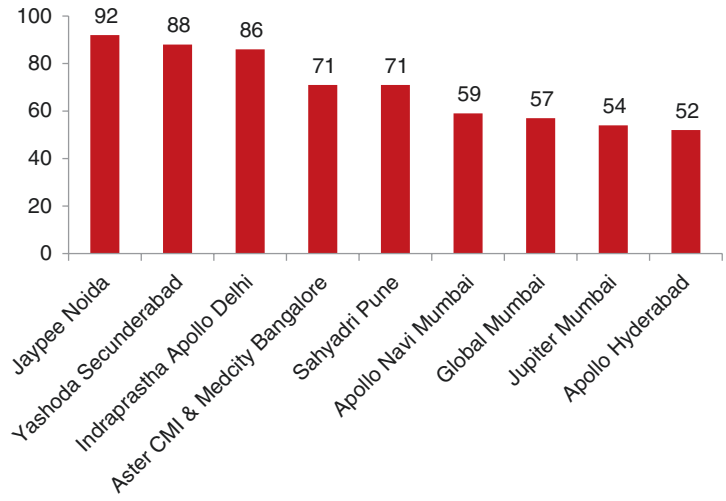

Fig. 1.8 Liver transplants in India in year 2018, Individual Centre Data (<100–50)

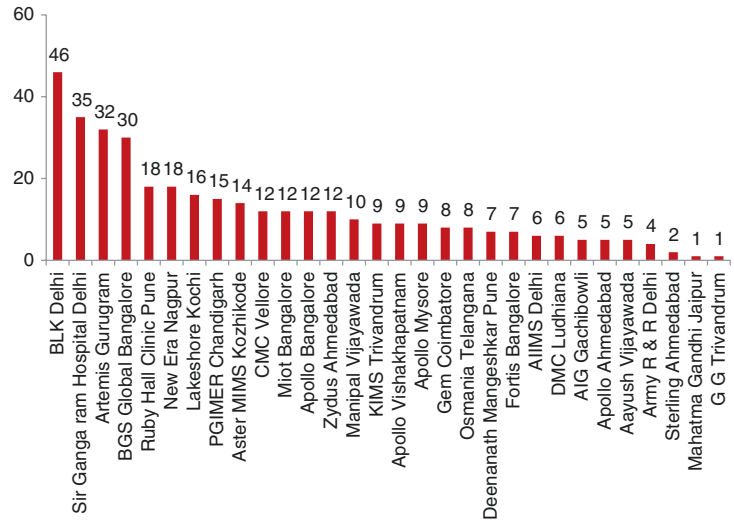

Fig. 1.9 Liver transplants in India in year 2018, Individual Centre Data (>50)

Western states with Tamil Nadu leading the way (Figs. 1.13 and 1.14).

In fact that state has been in the forefront of all deceased organ transplants including the lung, heart, liver and kidney (Fig. 1.15).

1.6.3 The Situation in 2020

The total number of centres registered to perform liver transplants in India is now 135 (compared to a total of 149 in the USA), and this is increasing rapidly as the procedure has become a marker for not only the prestige of a hospital but that of a state. However, it is rumoured that many of the centres although registered have not performed a single transplant or that they have had such bad results that there is little or no continuing activity. Thus the 'star' performing surgeons and their teams are sought after by most large hospital chains by being guaranteed astronomical salaries. Consequently the public sector is now performing only 3% of the transplants not only because it is losing its surgeons to private hospitals but it does not have the committed and dedicated large teams required to collaborate and perform such complex procedures. The cost of a living donor transplant is now anywhere between 16 and 30 lakh rupees.

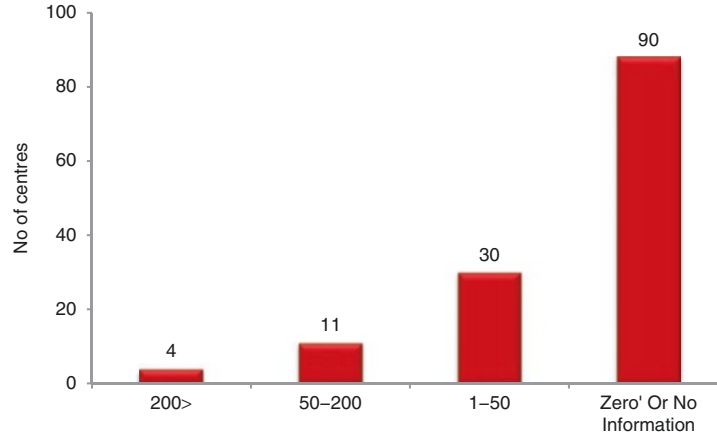

Fig. 1.10 Overview of liver transplants in India in 2018

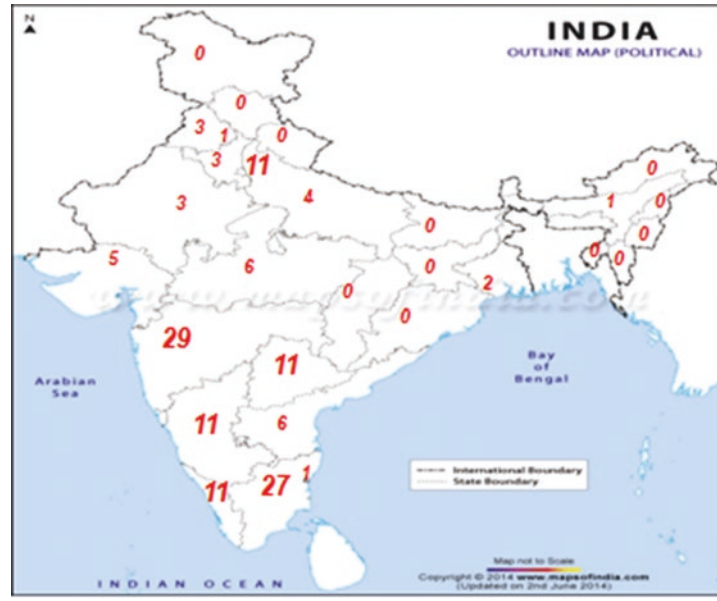

Fig. 1.11 Liver transplant centres

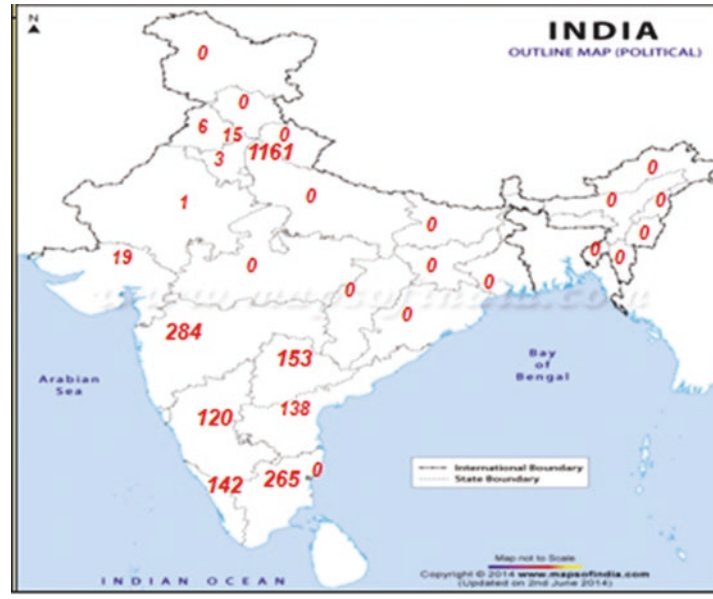

Fig. 1.12 Liver transplant numbers statewise

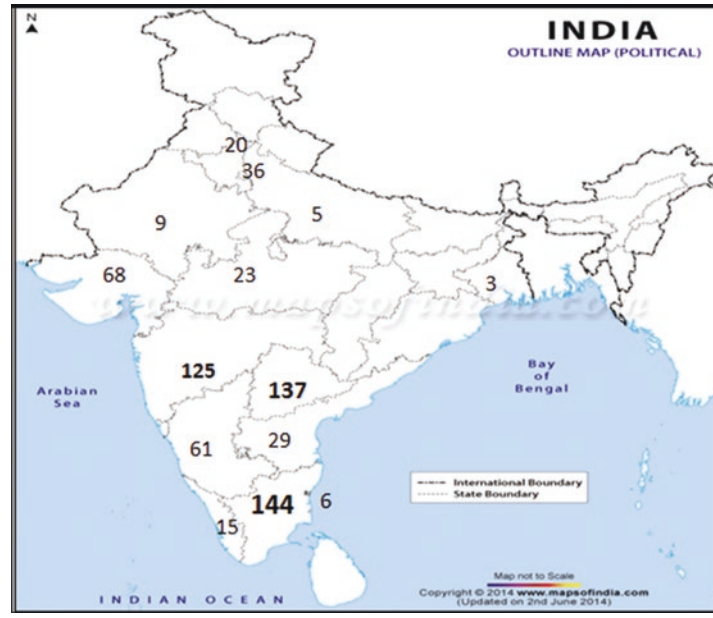

Fig. 1.13 States—deceased donations 2018

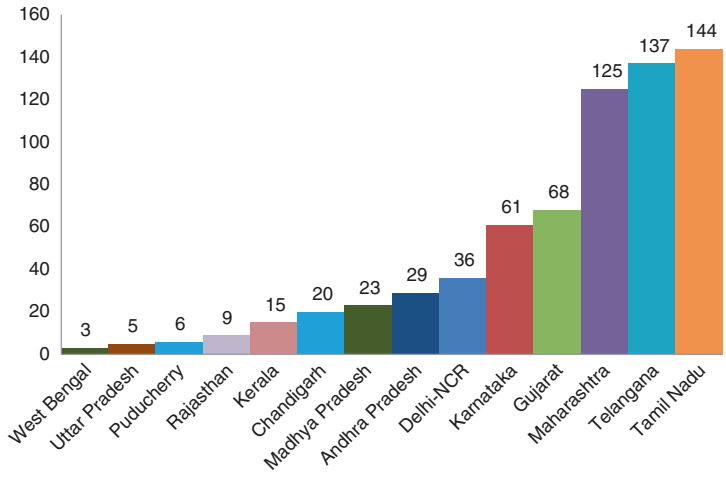

Fig. 1.14 Statewise deceased donor liver transplants 2017

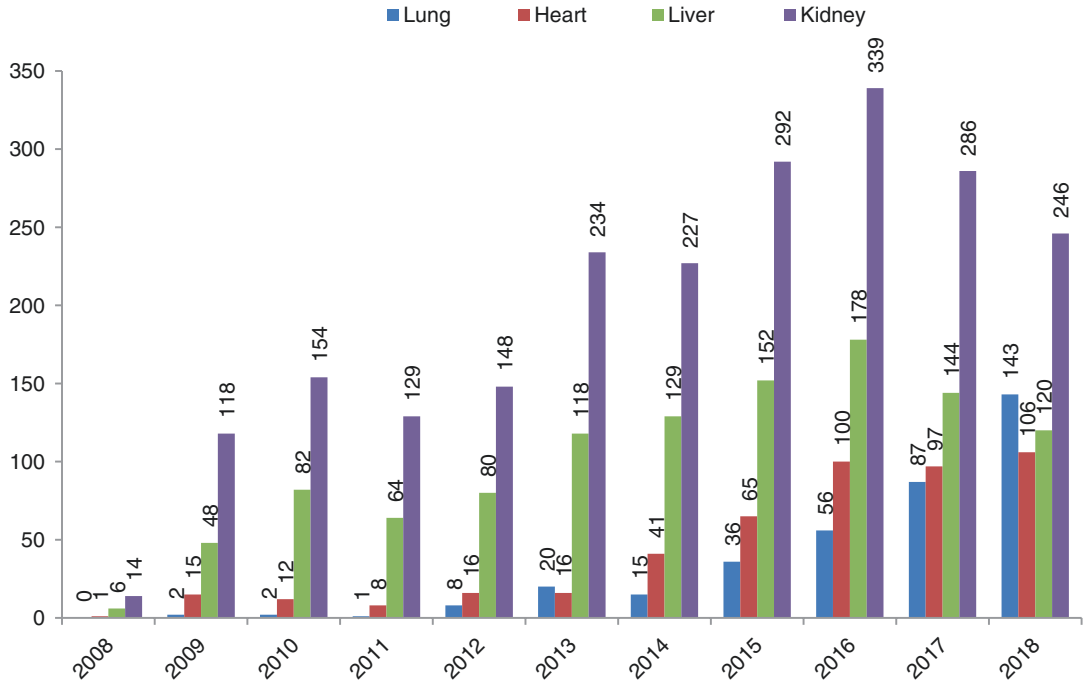

Fig. 1.15 Tamil Nadu deceased organ transplants

1.7 India Vs the World

In 2018 there were a total of 1944 liver transplants performed in India which followed only the USA (8241), China (5149) and Korea (2854). However for the proportions of living donor liver transplants the figures vary considerably from Japan where 87% of transplants were from living donors to 4% and 2% in the USA and UK. In India and South Korea the majority of organs were taken from living donors (68% and 65%). In China although deceased donors are the largest source of organs for transplants most of these are alleged to have been obtained from condemned prisoners. This practice has been decried by the international transplant

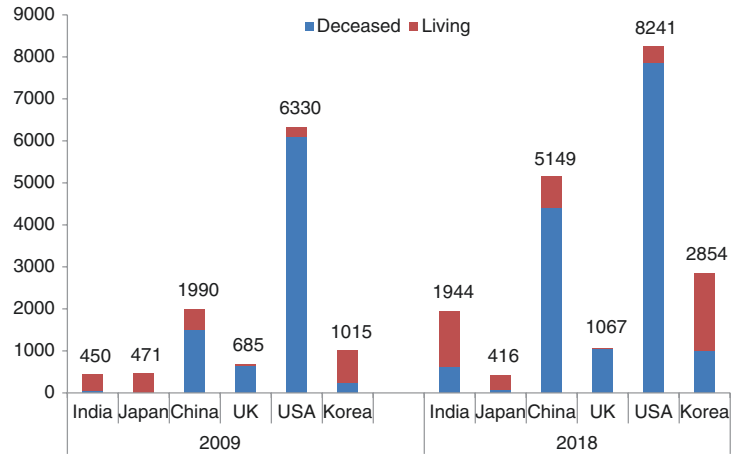

Fig. 1.16 Liver transplants in India vs World (2009 and 2018)

community and is now banned by the Chinese government. Figure 1.16 shows the changes in the numbers of transplants in some selected countries comparing 2009 and 2018.

All have shown increasing numbers except for Japan and what is noteworthy in that is India has probably shown the largest proportional increase of 4.3 times in total with an encouraging rise in the number of deceased donor transplants.

1.8 Concerns

But there are concerns. All the transplant programmes rely mainly on living donors and although deceased donation is increasing in the South and West in the central states, it remains poor in the North and East. This is because of a lack of awareness of the concept of brain death and the benefits of organ transplantation but also perhaps due to an absence of altruism in these areas. Public hospitals have not managed to mount regular programmes and the private sector where profit generation is the main concern this has resulted in large kickbacks to referring physicians, there is immense pressure to increase numbers and many 'marginal' livers which would not be used abroad are transplanted. The system continues to be opaque in that the living donor complications and deaths remain unknown and the results of transplantation are enormously variable ranging from 90-day recipient mortality rates of between 5% and 100%. There is a major gender gap with organ donors being predominantly female and the recipients male. In Tamil Nadu the proportion of females receiving kidney grafts is 23% and livers is 7%. The organ trade continues but it is small and clandestine.

1.9 Recommendations

The first priority should be to improve cadaver donation by strictly enforcing the law especially the 2011 amendments which delinked transplant hospitals from those from which organs could be harvested, enforce mandatory brain death declaration and required request, ensure a transparent and fair organ distribution system and even consider incentives to donor families like free lifetime railway passes. There should be many more centres in the public sector which would lower the cost of the procedure and perhaps improve the gender imbalance.

The dormant Appropriate Authority should collect data on the indications and results of transplantation, help raise public awareness, and encourage the exchange of problems, results and expertise between the private and public sectors. It should also punish unethical practices.

In spite of these problems the results have been gratifying as illustrated in Fig. 1.17.

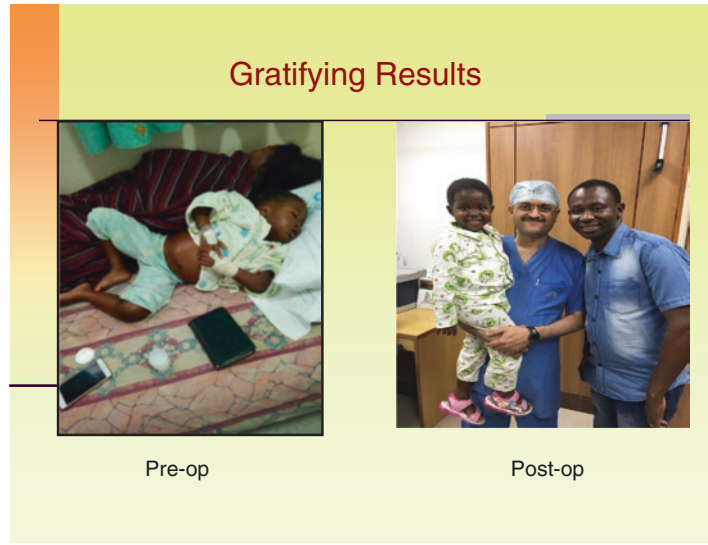

Fig. 1.17 A three-and-a-half-year-old Nigerian girl with a large liver tumour before and after liver transplantation (now well 5 years later)

1.10 Conclusions

Liver transplantation has had a major impact on Indian health care. It has saved thousands of lives of middle-class Indians who could not afford to have the procedure done abroad, it has improved the quality of surgery, anaesthesia, haematology, nephrology, blood transfusion and pathology, the results of the best centres match the world's best and although there are attendant problems these can be solved.

In fact liver transplantation has revolutionised Indian medicine.

Key Points

1. The Transplantation of Human Organs Act of India in 1994 recognised brain death and made the trade in human organs illegal.
2. This allowed liver transplants to be performed in this country.
3. After the first decade when few procedures were done the main impetus came in 2008 when the Tamil Nadu government orders made the declaration of brain death in hospitals mandatory and required doctors to ask relatives for organ donation.
4. There are now 135 centres registered to perform liver transplants in 2020.
5. Most transplants are done in the private sector and are from living related donors.
6. Deceased organ donation occurs in the Southern and Western states but in Delhi, where 54% of the total liver transplants in India are done, the majority are from living donors.
7. India's total liver transplant numbers rank only after the USA, China and Korea.
8. Unfortunately the results regarding indications and operative mortality are opaque and there needs to be closer regulation of the activity throughout the country.
9. Liver transplantation has enhanced the quality and reputation of Indian health care.

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