



## Paediatric liver transplantation in South Africa in 2009

The Paediatric Liver Transplant Programme in Cape Town commenced in December 1987 at Red Cross War Memorial Children's Hospital (RXH).<sup>1</sup> The first transplant was on a 6-year-old child with alpha-1-antitrypsin deficiency, cirrhosis and liver failure. The child died of complications (ruptured mycotic aneurysm of the hepatic artery and septicaemia) in January 1988. The programme re-commenced in November 1991. To date, 94 transplants have been done on 91 patients; the most in any one year was 9 (in 2002) and the least was 2 (in 2008). Patients have come from all over southern Africa (Western Cape 37, Gauteng 28, Eastern Cape 9, KwaZulu-Natal 6, Northern Cape 5, Free State 3, Mpumalanga 1, Namibia 1 and Zambia 1). The pattern of referrals changed in the last 3 years since the Wits Donald Gordon Medical Centre (WDGMC) programme commenced in August 2004. Fewer patients are being referred from the northern part of the RSA, and referrals of patients with some form of medical aid support have all but ceased. Nevertheless, 20 new referrals were seen in 2008 at RXH, of whom 5 were accepted onto the transplant waiting list. Of the balance of 15, 4 died and 2 were refused, while the rest continue to be followed up locally, as they do not yet need transplantation. Tuberculosis, with its high prevalence in the community, is a particular danger to infants and toddlers with chronic liver disease, leading to malnutrition, impaired immunity and susceptibility to infection. At one point during 2008, 4 of the 5 children on the RXH liver transplant waiting list were suspended from the list as they were being treated for active tuberculosis. The other reality is the poor socioeconomic circumstances of many of the indigent patients referred for assessment. Access to running water, a local health care centre with some resources (at least enough to supply the appropriate medication), a local health professional who will take responsibility for ongoing care, and an understanding by parents of what caring for a transplant recipient involves, are essential for long-term success. Relocation of the family close to a major centre has been one way of dealing with these issues. Nevertheless, we have frequently been impressed by how well parents cope under very difficult personal circumstances.

Sixty-three of the 91 patients who underwent transplants at RXH are alive and well 1 month to 18 years after transplantation and, of the former, 28 are being followed up by the RXH and Groote Schuur Hospital liver units, and are being seen and supplied with medication on a monthly basis. The other 35 survivors are being followed up locally all around the country by private paediatricians or family doctors who refer to RXH or the Johannesburg Hospital transplant unit for advice if queries about medical care transpire.

The WDGMC has by now performed transplants on 20 children aged  $\leq 18$  years (all but 2 of those in the Cape Town programme were  $< 12$  years). Eighteen survive and are being

followed up locally. Three of these were indigent children, 2 of whom received money raised by public appeal; the remainder had medical aid support. Extensive appeals and representations to all levels of government have been made by WDGMC to financially support indigent children onto this programme, but to no avail. Plans are progressing to develop an integrated system of staffing, both private and provincial, under the 'Wits' banner, rather than any particular clinic or hospital (personal communication, Russell Britz, Head of Liver Transplantation at WDGMC).

The average cost of a relatively uncomplicated liver transplant at Board of Healthcare Funders (BOHCF) medical aid rates is around R450 000, with an exponential increase if complications arise. The cost of medication for at least the first year can range from R5 000 to R20 000 per month, or more, depending on the dose of tacrolimus and other medications required. These costs are currently being taken on by RXH for all local patients who are not on medical aid. Likewise, those referred from afar have to be sure that their local referring hospital or their medical aid will take on this post-transplant cost. Although the need for immunosuppression is lifelong, the dose may gradually be reduced to a low maintenance level provided that no breakthrough rejection episodes occur and the patients are well monitored.

It has been estimated that the need for liver transplants in children is around 2 - 5 per million of the population per year, depending on local disease prevalence. With the more timely earlier referral for operation of infants with biliary atresia and a near 70 - 80% clearance of jaundice after a Kasai portoenterostomy, the need has indeed decreased in the UK in recent years and the indication has changed, with intestinal failure-associated liver disease coming to the fore, either as an isolated liver transplant for infants with short-bowel syndrome or as part of a composite liver and bowel transplant.

In South Africa, the reasons for transplantation have changed little, with biliary atresia still being the most frequent, followed by metabolic disease and acute liver failure. It seems that the total number of transplants being done has not changed substantially, but there has been a shift for medical aid-funded patients to be operated on in Johannesburg, and the indigent in Cape Town.

There is still an unacceptable waiting list mortality of around 30% as a result of a severe paucity of donors. This could be addressed by splitting livers (dividing one adult donor liver into two functioning units, the larger part going to an adult and the smaller to a child), but this would require considerable logistic endeavour and an expansion of resources, especially if the two centres (Cape Town and Johannesburg) were to share donors. Most livers transplanted into children are those reduced in size from an adult donor, which implies



less chance of an adult receiving a liver graft. Living-related transplantation is one other way of alleviating the problem of donor scarcity, and has been very successful in the Far East, the USA and Europe. The Cape Town group performed one such transplant successfully in 2002 but, although several more have been prepared for living donation, up to 80% of potential donors were unsuitable for anatomical or health reasons, and in the others cadaver donors were used.

The current focus in transplantation, while not losing sight of the importance of the basics, has moved towards quality of life and long-term care issues. Many of our children have now gone through adolescence and are mature young men and women who look forward to life's challenges. Career decisions, sexual health, contraception and the desire for children are very relevant factors. In fact, four female patients from the Cape Town unit have now successfully gone through pregnancy and childbirth; one of them had a second child recently. This prospect of a long and productive life is after all what we were hoping to achieve from the beginning. It has indeed been a wonderful privilege to see this maturation over

the last 21 years, from hope at the beginning to the reality today; this could only have been achieved by a team effort of dedicated health professionals and very brave parents and their children who put their faith in us.

The clear need persists for, at the very least, centralised funding of liver transplantation, particularly for children without medical aid; with a new Health Minister, perhaps now is the time to act.

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1. Millar AJW, Kahn D, Terblanche J, Robson S, Spearman W, Cywes S. Liver transplantation for children in South Africa (letter to the editor). *S Afr Med J* 1993; 83: 293.