

Transplant news

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Editorial

Professor Jerome Loveland
Editor

I read 2 horrendous pieces of news over the last 2 weeks, both disturbing with respect to humanity.

The first bombshell was that every single rhinoceros in the Mozambiquan sector of the Great Limpopo National Park, which straddles Mozambique, Zimbabwe and South Africa (Kruger), has been slaughtered for the medicinal use of their horn – a practice that has no scientific basis. 300 rhino inhabited this region of the park when it was declared open in 2002. Today they are extinct in the region, courtesy of the very people empowered with protecting them, the park rangers.

On the flip side, the positive impact of organ transplantation is immeasurable from a social and economic perspective, reducing preventable mortality, and increasing productivity. What a travesty then that only 0.1 percent of South Africans are registered organ donors! This equates to only 50 000 people from a population of over 50 million! The Organ Donor Foundation's goal is to increase this 10-fold, to 1 percent, by the end of 2017. In stark contrast, consented donation rates in the USA and Australia are 37 and 24 percent respectively. As South Africans, it seems that in both cases, we are doing too little, too late!

Also common to both themes is where the effort comes from. Although perhaps generalising, it seems to me that the driving force to combat poaching and to educate around the need and importance of organ donation, comes from NGOs and the private sector, an obviously noble effort. However, where are our government stakeholders in these forums?

They should be the driving force behind these projects!

Whilst we have focused on the importance of organs previously, and what a scarce resource they are, I would like to use this opportunity to underline the issue again. This issue of Transplant News is the last one prior to the World Transplant Games and South African Transplantation Society Congress, which run back to back in Durban from 28 July to 4 August.

Never before have these two events run concurrently, and it provides the unique scenario where two groups of people are brought together: those that have received the "gift of life", and embracing the opportunity, live their lives to the full, and those of us that strive to care for current and future patients, sharing knowledge and forging new transplant solutions into the future.

I would encourage everyone, patients, relatives, the general public, and our healthcare professionals to support transplantation at these two vital events, thereby increasing awareness of this vital aspect of medical care.



Production Editors:

Ann Lake Publications:
Ann Lake/Helen Gonçalves
Jane Gouveia
Astellas Pharma
Ann Lake Publications
Tel: (011) 802 8847
Fax: 086 671 9397
Email: lakeann@mweb.co.za;
www.annlakepublications.co.za

Design:
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Cardiovascular Disease – A leading cause of death after liver transplantation



Professor Ernest Song FCP(SA); FRCP (London)
Hepatology
Wits Donald Gordon Medical Centre
Johannesburg

With advances in surgical techniques and in immunosuppressive drug treatment, which effectively controls the rejection process, the expected survival after liver transplantation (LTx) exceeds 90% at 1 year and 70% at 5 years. However, it is increasingly becoming evident that cardiovascular disease (CVD) is emerging as the major cause of disability and death after LTx and threatens the advances already made.

These **cardiovascular events (CE)** consist of:

- Acute coronary syndrome (any condition bringing about sudden reduction of blood flow to the heart often leading to a heart attack)
- Congestive heart failure
- Stroke
- Heart rhythm disturbances (arrhythmia)
- Disease of the peripheral arteries

The risk factors

The **metabolic syndrome (MS)** has been identified as a major risk factor.

The common components of the MS include:

- Diabetes mellitus
- High blood pressure (hypertension)
- High blood fat concentrations (hyperlipidaemia)
- Low high density lipoprotein (HDL) concentration
- Obesity

The enhanced risk of MS for CVD is highlighted in a recent study where the prevalence of MS among LTx patients who had a CE was 61% versus 37% among those who did not. In several other studies, the overall prevalence of MS after LTx ranged from 43% to 58% and is higher than that among the adult population at large. It has been estimated that LTx patients with MS are about 2 to 3 times more likely to have a

CE than those who did not have MS and that these occurred within 3 years of transplantation.

Other risk factors have also been identified, namely:

- Older age
- Male sex
- The immunosuppressive regimen used is also an important contributor to the heightened CE risk such as among patients who receive tacrolimus and cyclosporin A.

These drugs also cause hypertension, diabetes, hyperlipidaemia and kidney dysfunction. The latter is, in itself, an independent risk factor for CVD. Prednisone is yet another prominent risk contributor by also increasing the prevalence of hypertension, diabetes and hyperlipidaemia.

- Active smoking dramatically increases the all-cause death rates. Thus the 1-, 5- and 10 year survival rates of 94%, 83% and 77% respectively among non-smokers drop dramatically to 94%, 68% and 54% among smokers in a recent Scottish study which demonstrated that smokers were not only more likely to die from CVD, but also from infection.
- The cause of the liver disease leading to LTx such as non-alcoholic steatohepatitis (NASH); these patients already have several components of MS before transplantation and chronic hepatitis C infection among whom an increased prevalence of diabetes exists.

Because of the increased cardiovascular risk, it is most important that all patients who will likely receive a liver

transplant undergo stringent cardiovascular evaluation and stratification before transplantation to enable identification of those requiring interventional treatment and also assist the transplant team in the appropriate and equitable distribution of the scarce resource of donor organs.



All patients who will likely receive a liver transplant should undergo stringent cardiovascular evaluation and stratification before transplantation to enable identification of those requiring interventional treatment.

Reducing the risk

About a fifth of late deaths following LTx are attributable to CVD. There are risk factors that cannot be modified such as pre-existing heart disease, male gender, family history of heart disease and age, but those that can, such as hypertension, hyperlipidaemia, diabetes and cessation of smoking should be vigorously addressed.

Hypertension is encountered in 40% to 75% of LTx recipients. Decreasing the doses of anti-rejection drugs and the addition of antihypertensive medication(s) frequently improves the blood pressure profile.

Hyperlipidaemia/obesity. These problems may affect as many as half of patients. Factors that contribute to both disorders include anti-rejection drugs, enhanced appetite, diabetes and hyperlipidaemia. Lifestyle modifications, such as

diet and exercise, are prescribed. If these measures fail, drugs such as simvastatin are introduced. Treatment of obesity likewise emphasises lifestyle changes, but refractory cases might call for empiric bariatric surgery or other measures.

Glucose Intolerance and Diabetes. Treatment of post-transplant diabetes is similar to that for any patient. Reduction in anti-rejection drugs and insulin or oral anti-diabetic drugs may be necessary. Once again, weight reduction is crucial and often greatly facilitates blood sugar control. Long-term monitoring for other target organ damage (eyes, kidneys and peripheral nerves) is also a priority for these patients.

Smoking cessation. All supportive efforts including behavioural counseling and drug therapy which produce the best results should be brought to bear on this most difficult and hazardous habit.

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Paediatric Living Donor Liver Transplantation



Dr Jean Botha
Transplant Surgeon
Liver Transplantation
Donald Gordon Medical Centre
Parktown
Johannesburg

Paediatric liver transplantation is a highly effective therapy for children with end-stage liver disease, one-year survival rates now exceed 90% and long-term survivors enjoy an almost normal quality of life. Key to the success of paediatric liver transplantation has been the refinement of technical issues in order to provide a child with a suitable sized graft. Adult to paediatric living donor liver transplantation highlights that success and has been instrumental in decreasing waiting list mortality to less than 5%.

Liver transplantation is the definitive treatment for children with end-stage liver disease (ESLD). The greatest limitation for liver transplantation is scarcity of deceased donor organs for transplantation. This limitation is particularly critical for the smaller children (less than 10 kg). Living donor liver transplantation (LDLT) has emerged over the last two decades as a viable option to offer children definitive treatment, and consequently reducing their mortality while on the waiting list as well as adequate long-term graft and patient survival. Compared with the whole liver deceased donor graft, LDLT for children presents a greater technical challenge with a greater chance of complications. The shorter vascular pedicles, the orientation and the size mismatch between the vessels of graft and recipient can lead to multiple forms of vascular complications. The size of the graft can further increase the technical challenge and even compromise abdominal wall closure. The presence of a cut surface can lead to bleeding and or bile leakage and the size of the bile duct along with its blood supply can compromise adequate biliary drainage.

Who is a potential candidate for living donor liver transplant?

Indications for liver transplantation in children are generally grouped into the following:

1. Extrahepatic cholestasis e.g. Biliary atresia
2. Intrahepatic cholestasis e.g. Alagille syndrome, PFIC syndromes
3. Metabolic diseases such as Wilson's disease, alpha 1 antitrypsin deficiency, Crigler-Najjar syndrome and the inborn errors of metabolism (tyrosinemia, hyperoxaluria, organic acidemias)
4. Fulminant hepatic failure
5. Primary liver tumors e.g. Hepatoblastoma and HCC

Cholestatic liver diseases

Biliary atresia is the commonest indication for liver transplantation in children. Typically most of these children will have undergone a Kasai procedure that has failed to re-establish bile flow and secondary biliary cirrhosis develops necessitating transplantation.

Metabolic Diseases

These account for the second commonest indications for liver transplantation as a group. The metabolic diseases are divided into those that are associated with structural damage to the liver (Wilson's, Alpha 1 Antitrypsin) and those in which the liver is structurally normal and liver transplantation is required to replace a life threatening enzyme deficiency (Crigler-Najjar, Ornithine transcarbamylase deficiency, hyperoxaluria Type 1)

Liver Tumours

Non-resectable hepatoblastoma is effectively treated with total hepatectomy and transplantation. Hepatocellular carcinoma is often secondary to other metabolic conditions e.g. tyrosinemia, and if contained within the liver is also effectively treated with total hepatectomy and transplantation.

Who is a suitable donor?

A healthy parent with a compatible blood type and suitable vascular and biliary anatomy usually volunteers to be a living donor, however donors do not necessarily need to be blood relatives and most healthy adults with an emotional relationship to the child are considered as potential donors. Suitable potential donors undergo detailed evaluation in order to determine their physical, psychological and social fitness in order to be a donor. Living liver donation is not without risk and donor safety is the overriding concern during this procedure. While being very low (less than 0.05%), the risk of death is not zero and this remains a sobering fact when discussing the ethical issues surrounding living donor liver transplantation.

Conclusion

Living donor liver transplantation has been widely debated from a societal and ethical point of view and has become an accepted procedure worldwide especially for paediatric recipients. Donor mortality and morbidity rates are low following left lateral segment donation and recipient survival rates are between 80-90% at one year in experienced centres. The good survival rates after living donor liver transplantation allow transplantation to take place before the onset of life threatening complications and severe nutritional failure.

7 Steps to success after transplant



Sr. Marlize de Jager
Organ Transplant Information System (OTIS) educator
Donald Gordon
Medical Centre
Johannesburg

A new organ is a precious gift. You have been fortunate enough to receive one. It's now up to YOU to take excellent care of yourself.

1 Take your anti-rejection medication exactly as prescribed

You will need to take medication for the rest of your life to prevent your body from rejecting your new organ and to treat other medical problems.

You must know:

- The names of your medications.
- What they look like.
- What they are used for.
- The dosage (how much to take and how often).
- What time of day to take them.

Take your medication at the same time every day. Never stop or change your medication, or take ANY over-the-counter or alternative-herbal therapies without talking to your doctor first. Never run out of medication. If you are not sure, ask.

2 Prevent infections

The same medications that help prevent rejection also place you at risk for infection. Certain viruses, fungus or bacteria which are normally harmless can cause you to become very sick.

Take prescribed medication, to prevent or control infections. Wash your hands thoroughly and often. Follow good dental care. Take action to prevent infection by avoiding people who have colds and flu. It's best to avoid crowded places for the first 3 months. Know the symptoms of infection and when to call your doctor.

3 Remember rejection

When your body tries to get rid of the transplanted organ or tissue it's called rejection. Rejection must be identified and treated quickly by your transplant doctor.

Know the warning signs and symptoms of infection and rejection. Do not ignore these, attempt to treat them yourself or wait until the following week. Do call your transplant doctor or co-ordinator.

4 Follow a healthy diet

Good nutrition is an important part of healing. You will need to follow a healthy, well-balanced diet that includes a variety of healthy foods to help you heal and stay healthy. If you don't know or are unsure about your specific diet guidelines, ask. Know what foods to avoid. Drink plenty of fluids (unless you are restricted by your doctor). Safe, clean water will always win first prize.

5 Live a healthy lifestyle

In order to have a healthy lifestyle it's important to follow a proper diet, be active, begin a lifelong exercise program, and avoid alcohol, cigarettes and drugs.

6 Follow-up visits are extremely important

Never skip a follow-up appointment with your transplant doctor. These visits are very important to monitor your progress, adapt your treatment programme accordingly as well as identifying rejection. He/she will inform you how frequent these visits must be. Feel free to be honest and discuss any concerns you may have. There are no stupid questions. Rather be safe than sorry.

7 Make every day count

The purpose of having an organ transplant was to make you feel better and to live a full life again.

Someone agreed to organ donation. YOU were fortunate enough to receive a new organ, a precious gift. Look after your new organ and make every day count.



The Organ Donor Foundation



Taryn Gingell
Gauteng Project Manager
Organ Donor Foundation SA



2013 is a very special year for the Organ Donor Foundation. We aim to sign on 50,000 new organ donors in 2013. Did you know: In South Africa we have less than 0.2% of the population who are registered organ donors? If compared to other countries such as the USA, who have 37% of their population as registered organ donors and Australia who have 24% of their population as registered organ donors – we must admit that this is a shockingly low statistic for South Africa.

Help us in 2013 to reach our target of 50,000 donors. Encourage family members, friends, work colleagues and everyone you know to become organ donors. Our long term goal is to have 500,000 registered organ donors by the end of 2017 – this will translate to 1% of the SA population.

Visit our website – www.odf.org.za, where you can fill in seven friends or family members email addresses. We will invite seven of your friends to become organ donors on your behalf. By making use of this special referral tool, you can be instrumental in increasing your contribution seven fold. Just a few minutes of your time will guarantee an amazing impact!

So please help us. By doing so, the Organ Donor Foundation will easily reach many more potential organ donors in a very cost effective way.

Clayton Duckworth takes on the world's toughest mountain bike stage race for a good cause



Final Day: Owen Hannie, Clayton Duckworth, Janez Vermeiren and Joel Stransky of Team ABSA.

Clayton Duckworth, aka 'The Flying Duck', recently completed the gruelling ABSA Cape Epic for a second time. He rode once again on behalf of the title sponsor, ABSA, together with a group of select individuals referred to as 'Team ABSA'.

Born and bred in Johannesburg, Gauteng, Clayton is an engineer at NIC Instruments & Engineering. He is a dedicated family man and enjoys spending time with his wife Megan, and 2 daughters, Kyla (4) and Ella (5 months). Every other spare minute he gets, you will find him on his mountain bike!

As a former pro motocross rider, Clayton used cycling as a form of cross training so it was a natural progression into the sport of mountain

He unknowingly helped 17 different people and I would not have my Mom around today if it wasn't for him.

biking (MTB). Duckworth raced as an elite cyclist during his time at university and completed all the major tours and races around South Africa.

As a rider for Team ABSA, Clayton passionately dedicated his participation in the race to The Organ Donor Foundation (ODF). A total of R18 000 was donated to the ODF on completion of the race.

"I decided to support the ODF because I was directly impacted by an organ donation," Clayton explains. "My mother was diagnosed with stage 5 kidney failure in 2006. After 4 difficult years, including a few near-death episodes, we were finally thrown a help line by the ODF.

Sadly, a young man who had been in a car accident was given no chance of survival and his family donated his organs. Our family got the call one Saturday morning and that evening my Mom received her kidney transplant. Thanks to that young man, she is now able to lead a near normal life again. He unknowingly helped 17 different people and I would not have my Mom around today if it wasn't for him."

Clayton's heart-warming story is the reason he chose to create awareness of the ODF through the Absa Cape Epic and get as many people listed as organ donors as possible.

In accordance with the unique 2-rider team format of the race, Clayton pedalled alongside his ABSA teammate, Janez Vermeiren, presenter on Top Billing. Other riders who rode for Team ABSA included TV Presenter Michael Mol and model and actress Vanessa Haywood and rugby legends Joel Stransky, Cornè Krige and Tiaan Strauss.



Janez Vermeiren (Clayton's riding partner), with Clayton's mom, Rita Duckworth and Clayton on the right.



Clayton at the finish: Crossing the final finish line at Lourensford Wine Estate in Somerset West with his partner Janez Vermeiren.

Patient interview with Talenta Mhlanga



Annamarie Wagner
Trust Manager
KidneyBeanz
Morningside Medi-Clinic
Morningside
Johannesburg

Occupation:

Scholar

Family:

Talenta's mom and dad live in Bushbuckridge. She has been living with her aunts Zanele, Goodness and uncle, Vincent in Thembisa for 2 years to be closer to hospital. She had been on dialysis for just over 2 years before her transplantation.

Talenta's hobbies:

Music – singing, dancing and playing guitar. She received a guitar from The KidneyBeanz Trust on Christmas 2011 and it has become one of her best friends.

Talenta's interests:

R and B music and her favourite artist is Justin Bieber.

Talenta's likes:

Chicken, spaghetti, clothes, adventure games, computer games and friends. One of the people she likes best is her doctor, Dr Gottlich as he always helps her and is so kind.

Talenta's dislikes:

Needles and drips, She hates the fact that she has to live so far from her parents.

When did Talenta have a kidney transplant?

She had a kidney transplant on 13 June 2012.

How did Talenta come to have a kidney transplant?

She was diagnosed with FSGS Nephrotic at the age of 5 and went into renal failure in 2010. Her life on dialysis started at the age of 10. She had to move closer to the hospital and remained as a permanent in-patient for almost a year. She became well known to The KidneyBeanz Trust where she started formal schooling in the unit and took part in her weekly occupational and physiotherapy treatment as well as play therapy for psychological support. She was also on strict food and fluid restrictions. It was a very difficult time for her.

How has having a transplant changed Talenta's life?

She can now eat and drink pretty much anything she likes. She can visit her parents and go to school and have friends. She still comes to hospital for check ups once a month.

Have you found an improvement in Talenta's quality of life?

Complete change in quality of life. She is happy and full of energy.

What are the challenges of Talenta's lifestyle as a transplant patient?

She has to take medication for the rest of her life. Sometimes she still misses a bit of school due to the check ups. She gets sick more



Don't be scared, have the transplant and trust God. You will have your life back. Never give up hope if something gets tough.

often than other kids, for example colds or tummy bugs. She has to go to the doctor whenever she gets sick, otherwise her body might reject her kidney.

What advice would you give to those who have recently undergone transplantation?

To never give up hope! Take your medication and do all the things your doctor tells you to do.

What resources have helped Talenta cope with transplantation (books, websites, and support groups etc)?

The KidneyBeanz Trust! Also her favourite teddy, "Lovie" that is always with her.

Inspiration from a brave little girl

"Don't be scared, have the transplant and trust God. You will have your life back. I will never give up hope even if something gets tough. I feel I can help and encourage other people even more now."

The KidneyBeanz Trust has done so much for me. The support was so big when I was lonely and I had a family when I was in hospital. Teacher Megan, Annamarie and Orli became my mothers in hospital. Morena, Livia, Chane, Kura and Michelle became my sisters and brother in hospital and I actually miss them now that I'm not there all the time.

Although I didn't go to school for 3 years, I had schooling and therapy at the hospital so after my transplant I was good enough to go to Grade 7 and I started high school this year which made me very happy. I am now in the same class with all my old friends."