

Transplant news

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South African Transplant Society

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Editorial

Professor Jerome Loveland
Editor

Relatively pressurised to get this Editorial onto paper, I battled to get my thoughts into a version that made any type of sense. Like any great novelist, perhaps I can put this down to writer's block! Not! Be that as it may, it has only taken a review of the contents of this edition of Transplant News to find inspiration!

As a constant background to the field of transplantation, one is always well aware that without the availability of organs, patients would not receive their "gift of life" and waiting list deaths would escalate significantly. Samantha Volschenk from the Organ Donor Foundation once again motivates strongly for both deceased and living donation, in the process clearing up many misconceptions around the donation process.

Despite these constant pleas, I think that members of the healthcare team do sometimes lose sight of the enormity of the impact that a successful transplant has on the life of the recipient. Enter Ethelwyn Rebelo, herself a Clinical Psychologist from Johannesburg. Ethelwyn has written a superb article, providing real insights into the trials and tribulations that face any transplant candidate, pre- and post-procedure.

Interestingly, Tina Sideris, another psychologist, provides her insights into the mental effects of end-stage liver

disease, although this from the perspective of a member of the transplant team.

Finally, as alluded to in numerous editorials previously, there is a need for equitable access to organs for all members of society, irrespective of age or background. In this vein, Cecil Levy provides sobering insights into the provision of paediatric kidney transplantation in the Government sector. There is little more for me to say – enjoy this wonderful edition!



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Leading Light for Life

Kidney transplantation - public sector paediatric nephrologist's perspective



Dr Cecil Levy
Head of the Division of Paediatric Nephrology
Charlotte Maxeke Academic Hospital
Johannesburg

When I was asked to write a short article on "a public service doctor's perspective of paediatric transplantation" a number of emotions immediately sprang to mind. Frustrating, challenging, rewarding, humbling.

The paediatric nephrology unit at Charlotte Maxeke Johannesburg Academic Hospital (CMJAH) provides a comprehensive paediatric nephrology service to children referred from Gauteng and its surrounding provinces. Over the past 4 years we have dialysed, on average, 18 new patients a year, of which about half ended up requiring long term dialysis. The vast majority of these children are from a very poor social circumstance, often from far away and often from a fractured home environment.

Coping with the triad of a young child, poor social circumstance and chronic kidney disease is hard enough for the families without the other challenges that are common in caring for these children.

Many of our patient's parents have a very basic education and the concept, and the implication, of having a child with an often seemingly 'invisible' and potentially fatal disease is commonly difficult to grasp. Many families are living close to the poverty line and the cost burden of multiple hospital visits can be overwhelming but, inspiring, none of these families are prepared to give up on the opportunity to give their child a chance at life.

The decision to exclude a child from a chronic program solely because their parents have limited financial resources, or live far away, raises many ethical issues and so we do our best to try to give each child a fair chance at receiving life

sustaining dialysis and ultimately a transplant. Due to the long waiting list for a transplant, the number of patients cared for by our unit slowly builds up and so we, on average, care for around 30 chronic dialysis patients at any one time, evenly split between haemo and peritoneal dialysis (PD).

Many of the patients we see present late, often having been through a range of traditional and conventional medical practitioners before they arrive on our doorstep, and as such they are often more ill than they would have been had they been referred earlier. Our advice is that if patients

are unhappy with a diagnosis they have been given that they continue to get "second opinions" until they are satisfied.

The shortage of deceased donor organs, and better results from live donor organs, has resulted in most units, including ours, encouraging an active live donor program. Between 1995 and 1999 only 24% of all transplants done in our unit were from live donors but this rate steadily improved so that by 2000 – 2008 just over half of the transplants performed were from live donors. Unfortunately, this promising trend appears to be reversing with only 30% of the transplants we performed between 2010 and 2013 now coming from a live donor.

One of the main reasons for our inability to increase the number of live donor transplants is the poor health of our potential donors which is directly related to their poor social circumstance. Close

to half of our potential live donors are turned down due to medical conditions, the most common being hypertension, obesity and undiagnosed HIV infection. This, combined with the fact that many of our patients have only one parent, has resulted in fewer and fewer potential live donor organs being available for our patients.

Survival on the transplant list is another big issue facing our patients. There is a limit to how long a child from a poor social background can remain event free on peritoneal



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dialysis and a high percentage of our chronic patients experience failure of PD after a number of years and need conversion to haemodialysis. A long wait on dialysis is often accompanied by a slow deterioration in the child's medical condition and this, along with vascular access issues, may eventually negate a child being eligible for a transplant. Of our current group of 27 patients on chronic dialysis only 9 are still healthy enough to remain on the transplant list. Regular clinic visits, keeping to dietary and fluid intake recommendations and presenting timeously when ill all help in slowing this process.

Issues such as schooling, normal childhood activities and taking part in sport are often significantly curtailed as, year after year, many days are spent at the hospital either being dialysed or being admitted for periods of illness rather than being in school.

Our patients who have eventually received a transplant have, on the whole, been remarkably good at keeping to their medication and clinic visit schedules. They have gone on to do well at school, win medals at the transplant games, graduate from colleges, get jobs and even start families. Problems we have had with adherence usually have arisen in the teen years, especially with the boys. The teenager's experimental behaviour reaches its natural peak just as their parents start trying to get them to take responsibility for themselves. This clash of wills has resulted in the loss of at least two of our working kidneys over the past few years. Our recommendation is that parents retain control over the medication and clinic visits until their children are well into their late teens to prevent this happening.

It can be frustrating having to deal with the many social issues our patients have, through no fault of their own, without a full time social work/psychology team attached to a unit.

It can be challenging to provide long term medical care to a large group of children, who are slowly deteriorating, while still keeping up the hope, year after year, that the phone call that we have been allocated another kidney will eventually come.

But it is so rewarding when the call does finally come and we get a good result. It is wonderful when the only complaint the parents come with is that, now that the transplant is working, the child has so much energy that the parents don't know what to do with them. It is very rewarding to

see a child thrive and grow with a working graft and very humbling to see how families with a difficult social background cope with a difficult disease with dignity.

We believe that all children deserve a chance to beat chronic kidney disease with a transplant and we are grateful that we still have access to a dialysis/transplant programme for our patients. We view it as an honour to care for these children and we hope that our transplant numbers improve from the current rate of around 4 per year back to the numbers that they were at in the late 1990's when we were doing around 10 -12 per year.

Paediatric transplantation is a team effort and I would like to acknowledge the amazing work that our team of doctors, nurses, social workers and ancillary ward staff put

in. The job is often thankless and as such I would like to say "thank you" to all of them.

One thing our patients have taught us is to never give up hope and we try to adhere to that adage every day.

With acknowledgement to Drs Moonsamy, Khumalo, Mudi, Obiagwu and Rugamba for helping to get the data together for this article.



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Cognitive Deficits in End Stage Liver Disease



Dr Tina Sideris
Clinical Psychologist
Wits Donald Gordon Medical Centre
Parktown

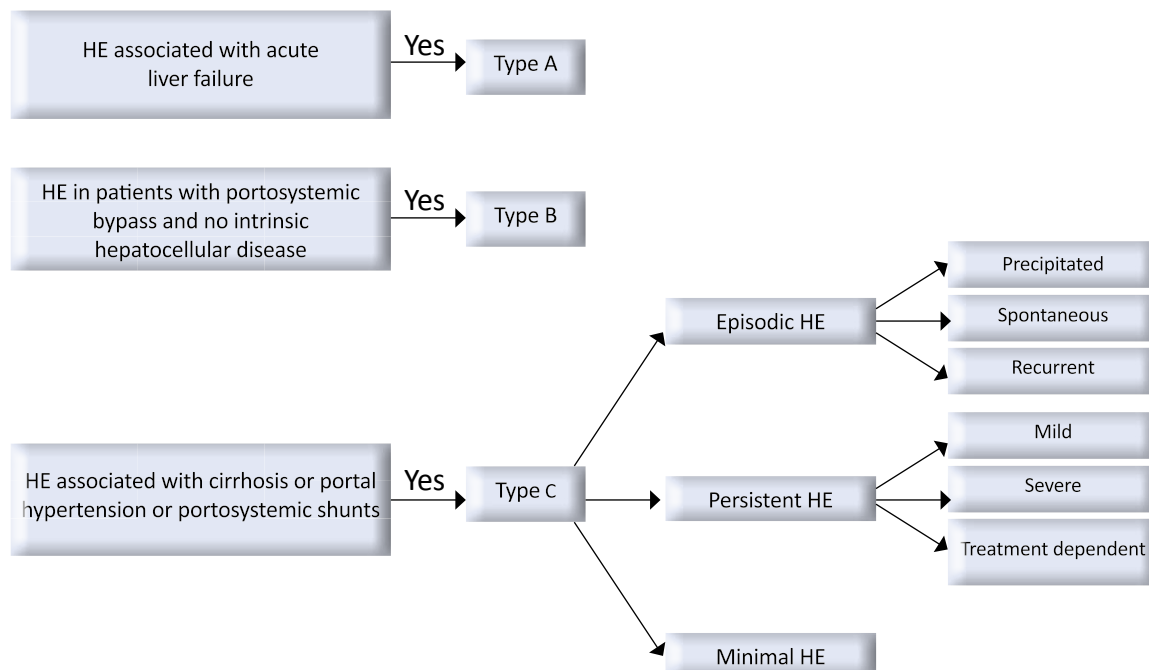
Cognition refers to the mental processing of information and includes the processes and actions of attention, concentration, memory, language interpretation, visuo-spatial perception and interpretation, recognising patterns, problem recognition, problem solving, planning and carrying out a task. Cognition is NOT the same as intelligence.

Neuropsychology examines how parts of the brain or brain pathways carry out these information processing activities by the use of standardised exercises or tests that assess multiple cognitive domains. The scores of

individuals are compared to normative scores based on the testing of a large number of people. The scores are usually normed according to age and educational level. We can say that neuropsychological tests assess the brain behaviour relationship and detect deficits in cognitive processing.

There is a large body of international literature showing that cognitive deficits are a common complication of liver disease due to hepatic encephalopathy (HE) which by definition affects brain functioning. The following provides a classification of HE.

Figure 1:
Classification of hepatic encephalopathy (HE) proposed by the Working Party at the 1998 World Congress of Gastroenterology, Vienna, Austria



Prakash, R. & Mullen, K.D. (2010) Mechanisms, diagnosis and management of hepatic encephalopathy *Nat. Rev. Gastroenterol. Hepatol.* doi:10.1038/nrgastro.2010.116

(Source: Nature Reviews Gastroenterology and Hepatology)

Hepatic encephalopathy (HE) is also classified according to Grades:

Grade 1:

Mild lack of awareness, euphoria or anxiety, impaired attention, impaired arithmetical calculation

Grade 2:

Lethargy, disorientation to time and place, personality changes, disinhibited behaviour

Grade 3:

Somnolence, stupor, confusion, gross disorientation, decreased gag reflexes, flapping tremor of the hand (asterixis)

Grade 4:

Coma

Minimal hepatic encephalopathy (MHE) is proposed as a distinct type and is best detected by neuropsychological testing. By definition MHE does not display the clinical signs outlined above under Grades.

MHE is defined as follows:

- No clinical signs of hepatic encephalopathy
- Subtle deficits in:
 - Attention
 - Visuo-spatial processing and physical orientation in space
 - Interpretation of perceptual information
 - Interpretation of the demands of a task
 - Planning and implementing tasks
 - Psychomotor speed

In general people with **MHE** do not show deficits in the cognitive domains of language and long term memory. Therefore they present as if the liver disease has not affected their cognition. Neuropsychological testing reveals subtle deficits.

These subtle deficits **can have a negative effect on activities of life and on work.**

The above-noted subtle deficits affect the following activities and do cause frustration and agitation:

- Driving
- Operating machinery
- Household activities including in the kitchen
- Operating a computer or word processor
- Problem solving
- Planning and finishing tasks

South African Data

Between September 2011 and November 2013, ninety three (93) patients with end stage liver disease, referred by the Wits Donald Gordon Medical Centre Transplant Clinic were assessed. As part of their assessment they completed neuropsychological screening tests.

The test results are consistent with international findings. 40%-50% of patients showed subtle cognitive deficits in:

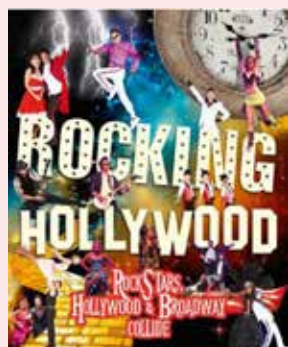
- Attention
- Visuo-spatial processing
- Orientation in space
- Psychomotor speed
- Executive functioning (interpreting, planning, organising and implementing tasks)

The test results of the patients assessed show that language and long term memory functions are preserved.

In patients whose liver disease is related to alcohol cirrhosis there may be brain damage related to alcohol use that negatively affects memory and language expression.

Hepatic encephalopathy is reversed by liver transplantation. Minimal hepatic encephalopathy (MHE) is reversed or improved by liver transplantation.

Memory and language dysfunctions associated with alcohol related damage will not necessarily be reversed by liver transplantation.



CKA at 'Rocking Hollywood'

Join the Cape Kidney Association for an afternoon of fun and laughter!

'Rocking in Hollywood' is a musical journey where rock Stars and Hollywood collide in a party of music, song and dance. So get ready to experience the awesomeness of mind blowing dance routines from Saturday Night Fever, Grease, Fame, Footloose, Dirty Dancing and many more.

- Venue: Barnyard Theatre Willowbridge
- Time: 2pm, Sunday 30th November
- Tickets: R135 per person
- For more information or to make bookings, please call Tel: (021) 761 1326 or Cell: 083 265 7490.

Please say yes to organ donation and save lives!



Samantha Volschenk
Executive Director
Organ Donor Foundation
Cape Town

ationally there are over 4,300 South Africans awaiting an organ and cornea transplant. Less than 600 transplants are performed each year and many adults and children die waiting for a life-saving transplant.

How can we address this issue and encourage more South Africans to become organ donors? Through continued education aimed at the public and medical professionals.

Did you know:

In South Africa there are 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 an extremely shocking and low statistic for South Africa.

The Organ Donor Foundation (ODF) would like to encourage members of the public to become organ donors. It is an extremely simple process and costs nothing – you can visit our website at www.odf.org.za or register via our Toll Free Line: 0800 22 66 11. We then ask you to discuss the decision with your family – this is very important. In South Africa we have a system of required consent. This means that your family will need to give consent for your organs to be removed, at the time of your death.

One person can 'Save Seven Lives' when they become an organ donor – this includes the use of 1 heart, 2 lungs, 2 kidneys, 1 liver and 1 pancreas. One donor can also improve the quality of life of up to 50 more people by donating their tissue – their skin, bone, heart valves and corneas.

A few important facts about organ donation:

It costs nothing to become an organ donor

There is no cost or fee to register as well as at the time of your death. The hospital or state will cover all medical expenses from the moment of diagnosis of brain death, and your family has given consent for the removal of organs/tissue.

Fears and misconceptions

• How do doctors know I am really dead?

Two doctors, who are completely independent of the transplant team, have to perform detailed tests before a person can be declared brain dead. The criteria for brain death are very strictly adhered to and accepted medically, legally and ethically in South Africa and internationally.

• Does being a donor delay the funeral?

No. As soon as the donated organs / tissue has been removed, the body is returned to the family to bury or cremate.

• Does organ/tissue donation leave my body disfigured?

No. The utmost respect and dignity is given to the donor at all times. The recovery of organs and tissue are carried out with great care by surgeons and trained staff and the process does not change the way the body looks.

• YOU CANNOT BUY OR SELL ORGANS IN SOUTH AFRICA - THIS IS ILLEGAL.

• Religious objections to transplantation:

Most religions support organ and tissue donation, as it is consistent with life preservation. If you are unsure, we ask individuals to speak to their religious or spiritual leader.

• Specific illnesses or chronic diseases:

Anyone who is in good health and does not have cancer, Type 1 diabetes (taking insulin as this affects the organs and corneas), is HIV positive or has hepatitis can be a donor. Individuals CAN be donors if they have had hepatitis A commonly known as jaundice and Type 2 diabetes. If you are unsure about an illness, please note that all tests are done at the time of your death. The doctors will determine then if the organs can be used.

• You can change your mind about being an organ donor – simply tear up your organ donor card and inform your family that you no longer wish to be an organ donor

What are the benefits of being a living donor?

It is important to mention that you can donate one kidney or a part of your liver while you are alive. A living donor may be a blood relative, spouse or a friend. **In South Africa, you cannot donate an organ, while alive, to a complete stranger.**

To consider donating one of your kidneys to a friend or family member is an unselfish act that could result in changing the life of someone with kidney failure. Were it not for living donors, many patients awaiting a kidney transplant would never receive a kidney as there is a very long waiting list. For most donors there is a personal reward that results from the act of giving the precious gift of good health to someone with kidney failure.

For the recipient there are many benefits, including a high success rate, a low complication rate, the ability to plan for

One person can save seven lives when they become an organ donor and can also improve the quality of life of up to 50 more people by donating their tissue – their skin, bone, heart valves and corneas.

the transplant procedure, and most importantly the opportunity for a healthier, happier life with their new kidney.

You can also donate blood and bone marrow while alive. Contact the Blood Transfusion service in your area or the Sunflower fund for bone marrow donation on 0800 12 1082.

To sign up as an organ donor please visit www.odf.org.za or call Toll Free: 0800 22 66 11

please say
YES
to organ
donation

If you needed an organ transplant, would you accept an organ from a donor?

Please say yes to organ donation. Many families said yes and saved the lives of mothers, children and fathers. Your child might need a life-saving transplant one day. If we are not prepared to be organ donors, is it fair for us to ask for a life-saving organ transplant if we need one from someone else?

It is possible that a medical professional might ask you to consider organ donation. Your decision will make a life-saving difference.

Please say yes to organ donation.

Tell your family today
SAVE SEVEN LIVES

**One Organ Donor
can save seven lives
You can save seven lives
Register now - it's easy**
0800 22 66 11 (toll free)
www.odf.org.za

ORGAN DONOR
FOUNDATION



Fighting the dragon - Thinking about my transplant



Ethelwyn Rebelo
Clinical Psychologist
Highlands North and Bryanston
Johannesburg

Like last year I was lucky enough to get a liver transplant after my liver and spleen had been damaged by a blood disorder and what immense change this operation has brought to my way of life. There is nothing like organ damage to put one in touch with one's anxieties about personal death and to inspire one to find new and better manners of surviving.

Choosing to protect myself

In my case, I had to come to the difficult decision that the position I worked in for so many years was no longer the healthiest space for me to be in. I was employed as a clinical psychologist in a large state hospital and while I enjoyed the nature of my work, the reality was that I was coming into contact with too many people suffering from various infections. It is not a good idea for a psychotherapist to wear a mask or to distance her body from those she is trying to assist. It conveys disconnection and disrupts an important aspect of therapy known as the 'therapeutic alliance', the bond between therapist and her patient for successful therapy. I was not comfortable wearing a mask, but I was getting ill too frequently. My physical fragility made me want to withdraw. I was being infected with viruses, bacteria and unhappiness.

It has been a difficult journey, both emotionally and physically. I have had numerous admissions to hospital and I suspect my physician dreads my number coming up on his cell phone. But I see myself as a knight fighting a potentially annihilating dragon who breathes the fire of rejection into me.

My weaponry

In this fight, I have several swords at my disposal. Some are called 'Medications'. They are accompanied by my clever hepatologist sorcerer and while very useful, they do occasionally cut me with their side-effects. The names of the others are: 'Diet', 'Exercise' and 'Emotional Support'.

Most importantly, I carry within me a magic amulet, buried deep within my body by the wizard surgeons. It is the liver of a woman who must have had enough goodness, value for life and appreciation of the importance of giving to others, to donate her organs. Like the other body parts that are a part of me, it may not function forever, but while it works, it gives me hope.

My benefactor

I have thought a great deal about this woman and I have wept for her: while I was in hospital after the transplant, I looked through my file and found a page with the details of a nineteen year old girl. Was this my donor, or was the page there accidentally? Do I have the liver of a young woman whose life was so tragically shortened that she hardly knew adulthood?

Throughout our lives we have all ingested aspects of other people in terms of their thoughts, their ideas, their emotions and their responses to us.

I have tried visualising this alien liver within me, urging the rest of my body to accept it and be at peace with it. If I were to say that this has protected me from episodes of rejection, it would be a lie. But it has helped me to adjust myself to the notion that a section of someone else is now a part of me and helped to view this part as good and potentially transformative. Throughout our lives we have all ingested aspects of other people in terms of their thoughts, their ideas, their emotions and their responses to us. Some of these ingestions or introjects may have been poisonous, but usually there have been enough good ones to help us build our strengths.

Examples that come to mind are my own dear father's frequent statements that the world is a dangerous place, that I should remember 'it is a jungle out there' and that I should not be quick to trust. In many instances, these words, replayed in my memory, have cautioned me to be careful and this vigilance has been self-protective. In others, it has caused me to fear unnecessarily and even to panic. At such times I have struggled to challenge this internalization of my dad's perspective, reminding myself that yes, the world is bad and yes, often others cannot be trusted. But there is also goodness and beauty and there are people with compassion and generosity.

A major contradiction of my father's one-sided view is the liver I carry within and the message from my donor that is implicit in this gift. It conveys to me the conviction of this woman that other people have value and so do other lives: I can imagine her saying: 'if I have to die, why shouldn't I help others live?' With her liver and the inner goodwill and hope it represents, with my medications, my improved diet, exercise, support of family and friends and my physician's harassed ear and cell phone, my thoughts can let out a scary growl and shout out: 'Dragon of death, I will defeat you.' For now.