



Transplant News

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Editorial Board



Professor Jerome Loveland
Academic Head
Department of Paediatric Surgery
University of the Witwatersrand
Transplant Surgeon
Wits Donald Gordon Medical Centre
Johannesburg



Professor Russell Britz
General Vascular
Surgeon
Wits Donald Gordon
Medical Centre
Johannesburg

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

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Editorial

Professor Jerome Loveland
Editor

This edition opens a new chapter for Transplant News with Novartis joining the editorial board and Ann lake Publications, facilitating the publication of this wonderful newsletter into the foreseeable future.

I guess as a publication house, one tends to be biased towards the success of one's endeavours. Fortunately, however, our readership shares our opinion, underlining the importance of this patient orientated newsletter.

That said, on behalf of all of the staff and readers, I would like to extend a warm welcome to Novartis, and thank them for ensuring that Transplant News continues to provide the superb quality of education to our patients that they are accustomed to and deserve.

With a clean new layout, this edition is superb, with exceptional content on a wide range of topics. South Africa has a remarkable reputation for producing world-class doctors, and we are privileged to have Professor Elmi Muller writing for us in this edition. We are all too familiar with the horrendous impact that HIV has on our population, none more so than with end stage renal disease as a consequence. With the limited availability of dialysis slots in our state health care facilities, these patients were often denied access to dialysis, dying from their disease. Professor Muller has challenged this dictum, and initiated a programme of transplanting kidneys from HIV positive donors into HIV positive recipients, previously denied a basic standard

of care. Leading the field in this work internationally, the programme's results have been remarkable, revolutionising the treatment of this group of patients.

The stories that always endorse the reality of transplantation are those from a patient perspective. As a surgeon, one often views the transplant experience very much as a technical exercise, and whilst one clearly sees the amazing turnaround that a new organ gives to the recipient, it is the recipient themselves that provide the true insights into the impact that these operations have on their lives. I have yet to read an article that describes this experience better than that written by Tersia Smit in this edition. It is truly inspirational!

Complicating things further still, transplantation impacts not only the patient, but other members of the family and social circle. Once again, these nuances often fall outside the immediate scope of practice of the physicians and it is the broader members of our multidisciplinary team that are key to supporting the patient and their family through these challenges. Alexia Michaelides is one of the most experienced transplant coordinators in the country, and as usual provides superb insights into these challenges.

These are but three of the articles in this edition, the others of equally high standard, providing critical education around diet in transplantation and the impact and treatment of common viral infections in our paediatric patients.

Enjoy the read!!!!

Transplantation in resource limited setting: using HIV positive donors for HIV positive patients

Professor E M Muller
Consultant Surgeon
Groote Schuur Hospital
University of Cape Town
South Africa



South Africa currently offers dialysis and transplantation as a treatment option for patients with End Stage Renal Disease (ESRD). However, dialysis is not freely available to everyone, but severely limited and only available to a selected group of patients. This means that patients get assessed when they present with ESRD and they only get accepted onto a dialysis programme if they fulfil certain criteria. These criteria are used to assess the patient's medical fitness in general as well as whether the patient will be compliant with follow-up from a social perspective. In most state hospitals, patients will only be accepted onto a dialysis programme if they are also fit to receive a transplant in the long run. The idea is that dialysis programmes should naturally feed into transplant programmes. Therefore a patient who is not a suitable transplant candidate will normally be turned down for dialysis.

In 2008, when the HIV positive-to-positive programme started, patients with ESRD and HIV would be turned down for dialysis. The reason was that they were seen as unfit for transplantation and therefore not suitable dialysis patients. This meant that anybody with HIV and ESRD was doomed to die. This situation remained unchallenged for a number of years, especially as the rollout of antiretroviral therapy was quite slow in the state sector.

The HIV population with ESRD started to grow dramatically in South Africa in 2008. A major problem with having HIV is that a large percentage of these people will develop HIV associated nephropathy (HIVAN).

Modelling the incidence of End Stage Kidney Disease (ESKD) and HIV in Sub Sahara Africa we know that we have at least 20.9 million people over the age of 15 years with HIV-related chronic kidney disease (CKD), according to UNAIDS prevalence statistics. It is estimated that about 60% of these people are treated with anti retroviral therapy.

Whether or not an individual is receiving treatment influences the rate of mortality in the HIV-Chronic Kidney Disease (HIV-CKD) population, and also affects the rate of progression to ESRD in the population with HIVAN. Although the proportion of HIV-CKD that is attributable to HIVAN is variable, biopsy studies have reported that approximately 30% of CKD in the HIV positive South African population is attributable to HIVAN, and that treatment reduces the risk of developing ESKD in HIVAN by about 60%.



In South Africa we have a unique situation in that we have low antiretroviral therapy resistance rates. Most patients who failed second-line ART in South Africa, have wild-type virus and resistance rates remain less than 5% in our HIV population.

Because of very high HIV rates in the country, more and more HIV positive brain-dead donors presented to the Groote Schuur Hospital Transplant team. These donors were brain-dead people who were worked up for organ donation (after consent was obtained from the family) and who then turned out to be HIV positive. In 2008 it made sense to try and marry this supply of donors with the group of HIV positive patients without any treatment options in the country.

Concerns about a second viral strain of HIV remained a problem. In the literature the outcomes and reports of HIV positive patients with superinfections are difficult to interpret as there are a lot of methodological difficulties which often yield conflicting results. When a patient with low viral load gets exposed to a second viral strain, a superinfecting strain may be detectable for only a short period of time. Viral fitness and the ability of a viral strain to replicate effectively in a given environment, may play a role to determine whether the two different strains will eventually become undetectable in standard resistance tests or whether outgrowth of a different virus from the baseline or whether a novel recombinant virus will become detectable.

In South Africa we have a unique situation in that we have low antiretroviral therapy resistance rates. Most patients who failed second-line ART in South Africa, have wild-type virus and resistance rates remain less than 5% in our HIV population. So in our setting, the issues pertaining to transplanting HIV positive patients are mostly that they have very high rejection rates, that they need powerful and

expensive immunosuppression as these patients have a dysregulated immunosystem rather than a suppressed one. They also have a high infection risk as opportunistic infections are more common in immunosuppressed and HIV positive patients and in Africa opportunistic infections remain a major reason why transplant patients might run into trouble.

The HIV positive-to-positive programme in Cape Town is a deceased donor programme where the donors are HIV positive and selected according to the following criteria:

- ART naïve donor
- If on ART – must be on first line treatment with no resistance
- Normal serum creatinine
- No proteinuria
- Protocol Biopsy on reperfusion of kidney

No donor with the following problems are used:

- Active viral/fungal/parasitic infection
- Malignancies
- Sepsis
- Possible HIVAN present

Recipients are selected to have undetectable plasma HIV type 1 RNA levels and be on a stable antiretroviral regimen. CD4+ T-cell counts of at least 200 per cubic millimeter in last 6 months prior to transplant, with no previous serious opportunistic infections. If a patient had previous tuberculosis infection, it must be fully treated.

In the study we have enrolled 32 patients over the last five years. Five patients died after transplant. The reasons for death were myocardial infarction, lung squamous cell cancer, pancreatitis with a duodenal perforation, disseminated *Aspergillosis* and *Klebsiella Pneumonia* sepsis. Two patients lost their grafts in the first week after transplantation: one with venous thrombosis of the graft and one with acute severe rejection within one week of transplantation. A third patient lost her graft with chronic vascular rejection and fibrosis of the graft 2 years after her transplant. The risk of rejection in this patient population group is higher than that expected in HIV negative patients. In the Cape Town study rejection took place on 8 occasions in 5 of the patients, which gives an acute rejection rate of 18%. This happened despite induction therapy with Thymoglobuline. A dysregulated immune response might be the reason for high rejection rates despite potent immunosuppression and similar high rejection episodes were reported in the NIH study using HIV negative donors for HIV positive recipients.

Using HIV positive donors might resolve some of the problems we are experiencing in getting enough donors for our patients with ESRD. In the USA the HOPE act was accepted in 2014 and this might now also impact on the use of HIV positive donors elsewhere in the world.

References available on request.



Devastating news that turned into a miracle

Tersia Smit
Liver transplant recipient and
World Transplant Games athlete



I will never forget the day I was told that there was nothing anyone could do for me anymore, besides to consider a Liver Transplant as soon as possible. I was already at the very critical end stage of Chronic Liver Failure Disease.

Since childhood I suffered with a liver disease. Ironically, we all thought I had outgrown my liver problem in my late teens, but unfortunately my symptoms came back twofold in my early twenties with each pregnancy. As I grew older the more severe and serious my condition became.

At the age of 49 I felt as though my life had come to an end. After many weeks of minimal health and no energy, I received a phone call informing me about a potential donor. I was admitted into theatre and ten hours later, I received my 'Gift of Life'!

It remains such an incredible miracle – to think... my donor, a 16yr old girl, saved my life. My utmost praise goes to my donor family, the medical team and my husband for his unconditional love, hope and support. "Thank you" is too small a word to express a recipient's sincerest gratitude!

Quality of life

Today, at the age of 59, I not only have quality of life, but a positive outlook that one must never give up hope and appreciate every day as though it is your last. I never thought I could participate in sports again, but thanks to my new liver I can.

As an active member of SATSA, I was privileged to participate with my swimming in the 18th and 19th World Transplant Games in Gothenburg, Sweden and in Durban last year. I was incredibly blessed to win 3 silver medals in Gothenburg and 3 silver and 1 gold in Durban – I broke a new world record in the 50m Backstroke. I qualified again last year in October at the Nationals in Stellenbosch. If all

goes well and I can keep my qualification standard, there's a chance that I might be chosen to represent SA in the 20th World Transplant Games (WTG) in Mar del Platte Argentina in October this year.

Goals to strive for

- To spread the word and raise awareness for the desperate need for donors.
- To be a continuous ambassador for the Organ Donor Foundation.
- To stay an active member of SATSA as long as I can.
- To promote the Organ Donor Foundation, to talk about it and to ask people to register as donors.
- To be an example through sport and be chosen again for the next WTG.



Today, at the age of 59, I not only have quality of life, but a positive outlook that one must never give up hope and appreciate every day as though it is your last

I would love to participate in the 2015 WTG not only to celebrate quality of life, but also mainly to create awareness for organ donation and transplantation. To take part in sport and to be a member of SATSA remain such an honor and privilege, a goal to strive and work for.

The WTG is a wonderful opportunity to meet and make new friends in similar situations and to be inspired by all their miracle and success stories.

I hope that, by telling my story, I will inspire more people to register as organ donors, to give hope to other chronically ill patients still waiting for an organ.

Madiba once said:

"What counts in life is not the fact that we have lived – it is what difference we have made to the lives of others"



Every transplant candidate has a dream of what life will be like on the day after transplant surgery. Those dreams can be both thrilling and frightening, so it helps to know what you might expect. Transplant recipients will tell you two truths: no two transplants are alike and immunosuppression brings new challenges. Even after your transplant, you may still have a serious chronic illness that must be closely managed.

Immediately after Transplant

After dealing with the effects of long-term illness (lack of energy, shortness of breath, etc) you may feel euphoric when you awake after surgery to find those symptoms gone. Anaesthesia often protects you from post-surgical pain for a short time.

Transplant is major surgery. It may take time to get back to eating normally, moving around, and managing your own care. Don't be discouraged. Most recipients report feeling much better just after transplant, others take longer to feel better. Remember that you now have a functioning organ which gives you a new lease on life.

Going home

There is no set time when people go home after transplant. Various factors can affect how soon you will be able to go home such as your overall health status, lab results, other chronic health problems and availability of support at home.

Medications

Immunosuppressants, or anti-rejection medications, "hide" your new transplanted organ from your body's immune system to protect it from being attacked and destroyed. Take these and other medications just as your doctor prescribes.

You may also take other medications for other chronic health problems and in the beginning it seems like you are taking lots of tablets, but this will likely change as you recover.

In the first few months you will visit with your transplant team frequently to be sure that your new organ is functioning well and to help you develop good health habits.

Lifestyle changes

Every person is different. The amount and type of activity you can handle after your transplant depends on your age and health. You may be able to return to activities that you gave up because of your illness. Many people return to playing sports, gardening or hiking. Remember, don't start or resume any activity without getting approval from your doctor first. After transplant, you may need to change your diet. You may need to drink more water, get lab tests done frequently and if you are a kidney recipient, you won't go to dialysis anymore. Most people go back to their jobs or studies after transplant.

After dealing with the effects of long-term illness (lack of energy, shortness of breath, etc) you may feel euphoric when you awake after surgery to find those symptoms gone.

It is common to have at least one episode of rejection, when your body attacks the newly transplanted organ. "Rejection" is a very scary word, but it doesn't always mean you are losing your transplanted organ. Your transplant team knows how to manage rejection with medication. After treatment, most people live normally with their transplanted organ. Other complications may require re-hospitalisation. Going back to the hospital allows you to be properly monitored and treated so that you can get healthy quickly.

Relationship changes

While you were ill, family members and friends may have managed many things for you or helped you with your care. After your transplant, you may be able to handle more of these issues on your own. As you change and feel better, everyone will have to adapt their thoughts and behaviour to a new you. Open communication will be important to maintaining good relationships.

It may be difficult to absorb all that has happened. If you received an organ from a deceased donor, you may feel sad or guilty because someone else died so that you could have a chance at a healthier life. Take advantage of emotional and spiritual supports to help you understand how you feel about your transplant. If you received your organ from an unknown deceased donor, you should write a letter to the donor family thanking them for their decision. Your co-ordinator will be able to assist you with this.

Your transplant is an awesome gift. You can never truly repay your donor, but you can honour the gift that was made by taking good care of yourself and your new organ. Get involved in promoting organ donation in your community, so that someone else can receive the same wonderful gift.

Colds and flu in paediatric transplant patients

Dr Priya Walabh MBChB (UCT), DCH(SA), FCPAEDS(SA), CERTPAEDS Gastro(SA)
Paediatric Gastroenterologist
Charlotte Maxeke Johannesburg Academic Hospital
Johannesburg



Children who have received organ transplants are usually on immunosuppressive medication. The medication protects the body's immune system from rejecting the organ and allows the body to live in relative harmony with the new organ. Unfortunately, in doing this, the medication also lowers the body's natural defense mechanisms, making transplant patients more susceptible to infections.

The winter months are the main times of the year when colds and flu due to bacterial and viral infections are rife. Extra precautions need to be taken during these times.



Talk to your doctor before taking any over-the-counter medications for treating symptoms as sometimes they can interact with the immunosuppressive medication.

You should contact your doctor when you have any of the following signs and symptoms:

- Sore throat
- Fever
- Malaise
- Cough
- Muscle and body aches
- Coryzal symptoms
- Shortness of breath

Talk to your doctor before taking any over-the-counter medications for treating the above symptoms as sometimes they can interact with the immunosuppressive medication. Most of the time antibiotics would be required, as in our setting in South Africa even viral infections have superadded bacterial infections.

Precautions to prevent colds and flu

- In children correct nutrition, rest and exercise are important.
- Administer flu vaccines annually to both the transplant patient and their family members.
- Regular handwashing reduces exposure to germs. Alcohol based hand disinfectant is vital in households of transplant recipients.
- Avoid people who are ill especially if they are highly infectious e.g. measles or chicken pox. If exposure/contact with these diseases has occurred, contact your doctor immediately as the transplant patient may require immunoglobulin. If close family members are ill, they should wear a facemask when coming into contact with the transplant patient.
- Avoid overcrowded areas e.g. concerts, shopping malls etc.
- In the first 3 – 6 months post transplantation a facemask should be worn to prevent exposure to respiratory/airborne bacteria and viruses, as early on the immune system is extremely suppressed.
- Brush and floss teeth regularly.
- Take recommended antibiotics before and after dental work or any invasive medical procedures are performed. Contact your doctor before the procedures.
- Avoid compost piles, construction sites, damp hay and decaying plants, fruits and vegetables.
- Wear shoes when walking outside to prevent exposure to microorganisms.
- Avoid all live vaccinations post transplant.
- Avoid café food, and especially junk food from unreliable sources.

Winter (cold and flu season) is a challenging time for everyone and especially transplant patients who already have a predisposition for all sorts of infection. Anticipate this and gear up by eating healthy, getting your vaccines and taking the required precautions.

A guide to eating well while being on dialysis

Marike Bauermeister
Registered Dietitian
Wits Donald Gordon Medical Centre
Parktown



When you have kidney failure your kidneys are no longer able to control the level of waste products in your blood, causing them to rise. Waste products (urea and creatinine) and minerals (potassium and phosphate) can build up in your blood in between your dialysis sessions. Following a well balanced yet suitably restricted diet will help reduce this build up. A balanced diet is also important to prevent nutrient deficiencies and to optimise your health.

You will need to:

- follow a diet low in sodium, potassium and phosphate
- include adequate amounts of protein and calories in your diet
- restrict fluids

Salt/Sodium

Too much sodium can cause water retention and an increase in your blood pressure.

Sodium is a mineral found in foods and is found in large amounts in salt. A pinch of salt can be used in cooking if necessary, to increase palatability. It is even better to use herbs instead e.g. garlic, parsley, mixed herbs, ginger, onions, pepper, rosemary, lemon juice. Do not use salt substitutes, these are high in potassium.

Salt is often added to foods during processing. Cut down on sausages, bacon, cured meat e.g. biltong, crisps, sauces and condiments. Salty foods tend to make you more thirsty, which can make it difficult to stick to your fluid restriction.

Potassium

Potassium is found mainly in fruit and vegetables. However, these provide other essential vitamins so you should eat some fruit and vegetables daily. A high level of potassium in your blood will cause your muscles, including your heart muscle, to become weak. Avoiding foods that are high in potassium will help to prevent this.

Potatoes, sweet potatoes and pumpkin are high potassium vegetables but can be soaked in water before cooking. This will remove some of the potassium. They should be peeled and cut into small pieces and left to soak prior to cooking for 2-3 hours.

Other examples of high potassium fruit and vegetables include: melons, oranges, grapes, kiwifruit, peaches, avocado, figs, spinach, mushrooms and gem squash.

Phosphate

Phosphate is a mineral found in certain foods. When your kidneys are not functioning properly, phosphate builds up in your blood which draws calcium from your bones and may lead to weak bones. High phosphate levels in your blood may also lead to crystallisation in your joints and vessels which can cause poor blood circulation, damage to your heart and other organs and pain. Avoiding foods high in phosphate, taking your phosphate binders with meals and snacks, and dialysis work together to control your phosphate levels.



Examples of high potassium fruit and vegetables include: melons, oranges, grapes, kiwifruit, peaches, avocado, figs, spinach, mushrooms and gem squash.

Certain processed foods are preserved with phosphate salts and are therefore high in phosphate. Read the food label and look for the word phosphorus or "phos" in the ingredients list. Avoid processed meat such as polony, viennas, cold meats. These are generally also high in sodium, just another reason why they should rather be avoided. Rather choose fresh protein options like fresh chicken or fish. Other foods high in phosphate include: cola drinks, chocolates, liver and organ meats, shellfish, hard cheeses and bran products (e.g. bran cereal, bran muffins).

Meat, chicken, fish, eggs, dairy products, beans and pulses and nuts are also high in phosphate but cannot be avoided completely since these are a valuable source of protein and calcium. Dairy products are often limited to one cup per day (for example 1/2 cup of milk and 1/2 cup of yoghurt for the day). Eat more chicken and fish than red meat and limit eggs to three eggs per week.

Calories and Protein

Calories are provided by all the food you eat and gives you energy and helps you to maintain a healthy weight. The amount of calories you need to consume each day depends on your body's individual needs. If you struggle to eat enough food (calories) you may start losing weight.

Because you are on dialysis, you require more protein in your diet than before you started dialysis. This is necessary because some protein is lost during dialysis. An adequate protein intake is important to preserve muscle mass and help with wound healing and fighting infections. Many high protein foods (meat, chicken, fish, eggs, dairy products, beans and pulses) contain phosphate. A dietitian will be able to give you advice on the right amount and right type of protein.

A healthy weight

A dietitian will be able to determine a healthy weight for you. If you are losing weight you might need advice on increasing the

calories in your diet. If you are slowly gaining too much weight suggestions on safely reducing your calorie intake might be necessary. If there is a sudden increase in your weight along with swelling you might be retaining too much fluid.

Fluid restriction

Your doctor will determine your fluid allowance. Fluid is any food or beverage that is liquid at room temperature. This includes ice, jelly, ice cream, custard or soup. It might be useful to use a smaller cup or glass for your drinks, not to fill your cup to the top and to spread your fluid allowance throughout the day. Ice cubes are thirst quenching, but must be counted as part of your allowance.

It is important to remember that we are all individuals with different dietary requirements, different bodies, different cultures and different needs. A dietitian can help you to adapt to your new diet, and ensure that you still follow a healthy, balanced and interesting diet.



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

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