

Transplant news

Official newsletter of the
South African Transplant Society

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Editorial

Professor Jerome Loveland
Editor

Towards the end of this edition of Transplant News, one will come across an advert for "The Heart of Cape Town Museum", which pays tribute to the world's first heart transplant, performed on Louis Washkansky by Chris Barnard 46 years ago. What a privilege that the history of transplantation has such a strong South African foundation.

In the early days of transplantation, all of this work occurred in our world-class provincial/government facilities, which at the time were pillars of excellence in healthcare, not only with respect to transplantation, but all aspects of medicine.

Today, an ever decreasing percentage of end-stage organ failure and transplantation occurs in these hospitals, with many patients not being afforded access to this care or being forced to the private healthcare sector to seek it. It is an absolute travesty that the Department of Health has allowed this situation to develop and enormous emphasis needs to be placed on restoring these services to the previous high levels of clinical excellence.

As a result of this global collapse in many disciplines of state healthcare in South Africa, an enormous necessity for private healthcare and consequently private health insurance has emerged. Whilst playing a pivotal role in funding transplantation in the private sector, this has two significant disadvantages.

First of all, it is an absolute disincentive for the state sector to improve their service, and secondly, fiscal control of the entire process becomes driven by the insurer, not the insured.

Consequently, those patients that are fortunate enough to have access to private health insurance are then entirely at the mercy of the healthcare funders and the confusing terms and conditions of their contracts.

To answer many of these questions, and clarify some on the uncertainty, Elsabe Klinck has written a superbly informative piece on the ethical and financial issues facing transplant patients, particularly those funded in the private sector, which I would encourage all patients, administrators and healthcare providers to read. I personally found it most beneficial. It demystifies the cost of healthcare in this environment and enlightens one on the rights of the patient.

The tragedy lies in the fact that this article is necessary in the first instance!



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Corneal transplants: The gift of sight



Dr Eduard Sevenster
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Blindness secondary to corneal pathology is a major cause of visual disability worldwide, affecting at least ten million people. Most of these patients can be successfully treated and can regain useful or even normal vision after corneal transplantation.

Approximately 150 000 corneal transplants (keratoplasty) are performed annually worldwide, and there are several million people alive today who can see and lead better quality and more productive lives.

The first successful corneal transplant was performed in Germany in 1904 by Dr Eduard Zirm. New technologies in microsurgery and new drugs to counter rejection transformed keratoplasty and made the procedure safer and more effective.

It is the cheapest and most cost effective transplant in medicine in terms of quality-adjusted life years gained. New techniques, procedures, materials and medicines are constantly improving.

A major step has been the development of lamellar keratoplasty, where only either the anterior or posterior layers



It is the cheapest and most cost effective transplant in medicine in terms of quality-adjusted life years gained.

are transplanted, thereby significantly enhancing safety, improving the quality of vision and shortening the recovery time.

Unfortunately these techniques are extremely costly and dependent on many factors, including the skill and training of eye bank technicians, as well as corneal surgeons.

80% of transplants are still functional after twenty years – making it by far the most successful transplant procedure. Approximately 10% of keratoplasties undergo rejection.

There is a great need for more donor corneas, especially in developing countries. These shortages are due to financial constraints, insufficient eye bank resources and inadequate numbers of trained eye bank personnel. However, as with all other organs, the ultimate factor limiting corneal transplantation is insufficient

numbers of organ donors. Ignorance, cultural differences, religious taboos, and political ineptitude are the reasons why people with treatable corneal blindness are not being helped in sufficient numbers.

In South Africa there are tens of thousands of potential donors annually, yet our society places numerous obstacles in the way of utilising this precious resource. Currently, about 800 corneal transplant procedures are performed in South Africa per year, but by far the majority of donors are imported from developed countries with enlightened legislation and regulations, which promote rather than hinder transplantation of donor human cells, tissues and organs.

The enemies we have to conquer in our battle to enhance the “quality” and “quantity” of life of our fellow human beings are ignorance, apathy, prejudice and fear. The weapons we have at our disposal are empathy, skill, dedication and perseverance. Fortunately these attributes are available in abundance in the whole community of transplant medicine.



Dr Eduard Zirm, an Austrian surgeon, performed the first semi-successful corneal transplant - and the first successful human organ transplant in 1905.

Giving of yourself



Joanne Lillie
Health Journalist

Source: www.discovery.co.za

There is a critical shortage of all donor organs for desperately ill patients, particularly kidneys, in South Africa. It's the one organ you can donate while you're still alive.

High school friends Duane Galloway and Clayton Powell (both 38) hope to share more than a few old memories and class photographs. They are making preparations for Duane to become a live kidney donor for Clayton later this year.

"We remained a close group of friends after school and several of us offered Clayton a kidney. He never wanted to take one, but at some point he had no choice," says Duane. "I was a blood group and tissue match."

Clayton and his brother were both diagnosed with end-stage renal failure at the age of 21. He has already had two kidney transplants and since the last one failed in 2003 Clayton, a keen poker player, has been on dialysis. "I go to the clinic three times a week for four hours at a time. My biggest problem at the moment is my heart condition; ten years of dialysis has taken a toll. Due to my history of transplants and blood transfusions, I have built up antibodies, which means my body will reject any transplanted organ at this point," he says. For this reason, Clayton's last hope is a live donor.

"Clayton is currently undergoing desensitisation procedures, which he does once a month for five months, to trick his blood into liking mine," says Duane. Desensitisation aims to reduce the number of antibodies in Clayton's blood and match it with Duane's. After the last session, Duane will be tested again and all going well, the transplant will be scheduled shortly after that. Discovery Health has approved the desensitisation medication (which costs R60 000 per month) and given the go-ahead for the transplant to be fully funded. In the meantime, the Department of Health needs to approve the procedure, as it's fairly rare as the transplant is between two people who are not related.

Live donations are almost always between close relatives, often from a parent to a child, or between siblings, because they are more likely to be a blood and tissue type match. About 40% of transplanted kidneys in SA come from living donors. This is comparatively high and based on the need in this country.

Kidneys are by far the most in-demand organ in South Africa. The diseases that contribute to the great need for kidneys in SA are essential (genetic) hypertension, especially in the black population, diabetes (especially in white and Asian population), glomerulonephritis and pyelonephritis (inflammation of the kidneys) and inherited diseases such as polycystic kidneys.

When disease causes kidney failure, dialysis treatment can take over the function of the kidneys, but transplantation is the ultimate aim for all end-stage kidney failure patients.

Many more people are probably eligible for kidney transplant, but experts don't have an accurate picture of the numbers as people are turned away from dialysis centres in the state system daily as there are just not enough machines.

One year after transplantation, about 90% of transplanted kidneys are still functioning well. After five years, over 60% are still healthy and overcoming the need for dialysis. Some kidney transplant patients have survived for more than 30 years.

How to register to become an organ donor

You can save 7 lives by becoming an organ donor (heart, liver, pancreas, lungs, kidneys) and 50 lives by donating tissues, such as corneas, bone and skin. (No organ or tissue donations from deceased donors leave the body disfigured.)

Register online at: <http://www.odf.org.za/> or toll free by phone: 0800 22 66 11 or email: info@organdonor.org.za. You will receive an information brochure, a donor card for your wallet and organ donor stickers to put on your ID and driver's licence.

Don't forget to discuss your decision with your family, so when the time comes, they can act on your wish.

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The funding of healthcare by medical schemes: What the law says



Elsabe Klinck
Legal Consultant and Business Owner
Elsabé Klinck Consulting CC

Funding for healthcare is a controversial issue and can lead to friction between healthcare funding companies (medical schemes or insurers), providers (doctors, hospitals) and patients. Because no person chooses to be ill, the buying of healthcare services is rarely done on a purely voluntary basis and mostly begrudgingly. Add to this the aspect that some healthcare interventions are life-saving and the moral arguments on equal access to healthcare and a conflict-free discussion appear virtually out of the question!

The legal frameworks do, however, provide some guidance as to how one is to deal with the various interests and rights, some of which may be conflicting. It is therefore always important to refer to these frameworks in order to de-personalise the debate.

Funding for healthcare services (doctors' fees, hospitalisation, etc.) and goods (medicines, etc.) can be provided:

- By persons out of their own pocket (often these patients are called "private patients").
- By their medical scheme, subject to the provisions of the medical schemes law and the scheme rules.
- By third party insurers, which sometimes provides a lump sum cover for "dread disease" and/or "hospitalisation" or "gap cover", which pays the difference between what another funder pays and what is owed.

Where it all starts: informed consent

Healthcare should always, unless the patient is unconscious, be preceded by a process of informed consent. This process is a legal requirement set by the National Health Act and is also an ethical rule applicable to all healthcare professionals.

This means that, before treatment is started, the following must happen:

- The patient must be informed about his/her health status. This means knowing how ill one is and what exactly the

diagnosis or problem is and any other relevant aspects, such as whether one also has other conditions that has an influence on one's healthcare.

- The patient must know what the generally available treatment options are for the condition. This will include the specific treatment option (e.g. is an operation necessary, or only medicines, or both and if so, what are the option within those broad approaches).
- The patient must know what the benefits, risks and implications of the various options are. Some options may pose a larger risk, but may have a larger benefit for the patient, some options may be more complex, but could solve the health problem for a longer time, etc. Once a patient has chosen a particular option it means she/he is also accepting the risks and implications of that treatment option. The Consumer Protection Act states that a patient should consent in writing to any risk that is serious, unusual or that could pose a risk to one's 'life or limb'.
- The patient should know what the costs of the various options are. Patients should know that what their medical scheme says it would fund may not be what is the best, or what is clinically appropriate. In such cases the medical scheme law protects patients. Sometimes patients are willing to make a co-payment so as to access more "state of the art" care. If a patient chooses a cost-effective option, they should still be aware of what the other options were.
- The patient has the right to refuse healthcare, but she/he must understand what the implications of the refusal are. Sometimes the risks and complications may sound very bad, but the risk of not going for the treatment may be worse!

There should also be time for the patient to consider the options, enough time to ask questions and the right to have them answered to one's satisfaction, and not to be pressurised by anyone.

The above means that there must be discussion with the patient, not only on the treatment options, but also on the risks and costs and the patient must formally agree to these. There should also be time for the patient to consider the options, enough time to ask questions and the right to have them answered to one's satisfaction and not to be pressurised by anyone.

Paying for care

Medical schemes have to, by law, pay for all conditions that are listed in the law as “prescribed minimum benefit” (PMB) conditions. There are 271 conditions listed in the law and 25 chronic conditions (such as “chronic renal disease” and “cardiac failure”).

Patients should ask their doctors if their conditions are PMBs. The law says that this treatment must be funded “in full and without co-payment” (regulation 8, Medical Schemes Act). The law generally describes the type of treatment that the scheme must pay for “in full”. For example:

- Liver failure, hepatic vascular obstruction, inborn errors of liver metabolism, biliary atresia: liver transplant, other surgery, medical management.
- End-stage renal disease regardless of cause: Dialysis and renal transplant where Department of Health criteria are met only.

This, in short, means that the scheme must pay for the transplant and for medicines in the case of a liver transplant and in the case of kidney failure for the dialysis and transplant within what the Department of Health sets as its conditions.

Where a medical scheme limits the various aspects of healthcare, such as the way in which the transplant is done, or the medicine it would pay for, these limitations have to take place within what the law allows.

The law says that the scheme must set these limitations on what is called “evidence-based medicine”. This means that the scheme must be sure that, within the limitations that they set, the patient can be treated appropriately and meaningfully. If that is not possible, the scheme must create exceptions so as to make sure that a patient can be treated according to what scientific guidelines require. The specific treatment must be “clinically indicated”, i.e. it must be the right treatment for the right patient. Sometimes there is

only one option for a patient to ensure that their condition is addressed.

Exceptions where co-payments cannot be levied

The law also states that, in certain situations the scheme must make exceptions. In these exceptions they are prohibited from imposing co-payments on patients in these circumstances. The circumstances are:

- Where the treatment or medication that scheme is willing to pay for, did not work for the patient (this is called “treatment failure”)
- Where the scheme-recommended treatment causes or would cause harm, or, in the case of a medicine, caused or would cause a negative reaction.

If a patient falls within the categories of requiring treatment that is clinically appropriate for him/her, but which is different from the general or standard treatment, or where previous treatments did not work, such a patient must still have their PMB treatment funded in full and they cannot be required to make a co-payment. The same applies if there is a risk of harm, or even if there had already been harm (such as an allergic reaction to a medicine).

Conclusion

Patients should be aware of their entitlements in terms of the law. These entitlements override the medical scheme rules, if there is a conflict between the rules and the law.

In interactions with medical schemes, whether the condition is a PMB or not must always be indicated, as well as why certain treatments would be clinically appropriate.

In cases of treatment failure or (likely) harm, it must be made clear that the law requires these exceptional circumstances to be accommodated and that no copayments may be levied for the patient to access alternatives to the scheme-recommended treatment.

Medical schemes have to, by law, pay for all conditions that are listed in the law as “prescribed minimum benefit” (PMB) conditions. There are 271 conditions listed in the law and 25 chronic conditions (such as “chronic renal disease” and “cardiac failure”).

The importance of being involved in the global community of transplantation and what it means for South Africa



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Transplantation is a field with many clinical as well as ethical and moral dilemmas. It brings together a group of professionals from a wide background of disciplines: physicians, surgeons, psychologist, social workers, coordinators and nursing staff. In this context people have different roles and responsibilities, but also different backgrounds and ideas. In the ever growing

transplant community, where patients are constantly exposed to new treatment options, new drugs and new procedures, we need to make sure that we all come together under one umbrella and that we drive a common interest and shared responsibility to serve patients and their needs.

It is in this regard that The Transplantation Society (TTS) and the World Health Organisation play an important role in South Africa. Unlike the USA and Europe, who abide by guidelines set by the European Union and UNOS (United Network of Organ Sharing in the USA), we have very little professional and patient regulations specifically pertaining to transplantation in SA. The Department of Health provides a basic legal framework for transplantation and has a small committee of renal physicians (Ministerial Advisory Committee) advising them. This is certainly not enough, as the role of the Department of Health and the Ministerial Advisory Committee are not to provide guidelines for the day-to-day practice of people with a wide range of specialities and backgrounds working in the field of transplantation.

The World Health Organisation provides several guidelines to clinicians and patients. Some guidelines are for specific regions and some are more general. In the field of transplantation there are many documents on transplantation safety, transplant tourism, consensus statements on living donor work-up, harmonisation of data related to deceased donation

and bulletins on organ sharing. These guidelines provide a major structure to the South African transplantation field. Furthermore there are downloadable documents related to, for instance, HIV testing in donors. Using these documents helps us not to re-invent the wheel. By using these guidelines we have access to a high standard and easily reproducible set of rules, often specific to the region we work in.



Prof Francis Delmonico and Dr Luc Noel at a meal in Durban during congress



Dr Bappa Adamu - winner best paper award at SATS congress and African workshop

The Transplantation Society (TTS) is a professional worldwide society consisting of about 7500 members all over the world. It provides governance to professionals working in the field of transplantation and includes people from many different specialities. Furthermore the TTS has the objective to train and educate and provide scientific communication to its members. This allows practitioners throughout the world to be in line with the newest and most effective treatments and drugs available today. With the Internet the world has become a small place and the TTS website (www.tts.org) is a major source of information for professionals and patients.

The TTS also has a regional structure to try and address regional issues all in a friendly but effective manner. It is strictly a professional organisation, but many of the outreach projects of the TTS interact with policy makers, ministers of health and legislative issues throughout the world. A highlight for Africa in the last few years was a workshop for African countries starting off in the field of transplantation, which was held in July 2013 in Durban. At this meeting a total of 50 African physicians and surgeons attended a 2-day workshop specifically focusing on centres that are new in the field. It was a wonderful opportunity to establish new relationships and drive transplant projects in Africa.

TTS also provides certain guidelines downloadable through the TTS website. This includes the Amsterdam and Vancou-

ver Forum on the care of the living donors, ethical guidelines to the members as well as interesting facts around areas in the world where the transplantation practices still fall outside the margins of the society's ethical standpoint, for instance China.

It is the goal of TTS to unite many professionals under the single umbrella of the society. One might ask why this is important for patients? The truth is that this helps patients to be treated in a safe and respectable way and makes sure they get access to the best available treatment for their conditions.

The TTS has interesting material on the website, for instance a section on pioneers in the field, a "historical" library and a list of previous congresses and speakers. There are



Sisters from E12 transplant unit at Groote Schuur at African Workshop

participate at international congresses, to serve as chairs and to do invited presentations.

We hope that there will continue to be positive initiatives from TTS to South Africa but also back from South Africa to the international community to ensure a collaborative effort and to reach more people in need of transplantation in the future.

important educational updates to members as well as some links to patient educational resources. All these things are available to South African doctors and their patients.

The South African Transplantation Society has grown in the last few years and our members have welcomed the fact that we are now officially affiliated with The Transplantation Society. More and more of our members are invited to participate

Paying tribute to the 'firsts'

On the 3rd of December, 1967, the world's first successful human heart transplant was performed at Groote Schuur Hospital in Cape Town. The operation was a medical milestone that paved the way to the successful transplantation practices we have today.

Today, The Heart of Cape Town Museum honours the skill and wisdom of that first heart transplant team, the courage of the recipient, Louis Washkansky, the generosity of the donor's father, Edward Darvall and the memory of the young donor, Denise Darvall.

A fully guided 2-hour tour describes the electrifying events of that night, after which, visitors are free to browse on their own.

Guided tours begin at: 9:00, 11:00, 13:00 and 15:00 and the museum is open 7 days a week.

For more information, contact the museum at:
Tel/Fax: 021 404 1967
Email: info@heartofcapetown.co.za
Web: www.heartofcapetown.co.za



Mother Kay saves her son's life with a living organ donation of a liver transplant



Kay Pietersen
Living organ donor and
mother of Kayvin, liver transplant recipient

Name: Kay Pietersen

Occupation: Receptionist

Family: Kay, Vivian and Kayvin Du Preez

Child Likes: He likes riding his bicycle, playing with friends and watching cartoons.

Child Dislikes: He dislikes sleeping during the day and eating his fruit and veggies.

When did your child have his liver transplant?

My son had his transplant on the 27 September 2013.

Please tell us how your child came to have a liver transplant:

My son was diagnosed with Hepatitis A and his liver failed completely. His eyes and skin were yellow. He would vomit everything he ate. When his liver would not recover, he was transferred from Glynnwood Hospital to Wits Donald Gordon Medical Centre on the 25 September 2013. The following day the doctors decided that, as he only had 48 hours to live, they needed to do the liver transplant as soon as possible.

How has having a transplant changed your child's life?

It changed his life completely. He has gone from being a very shy, moody boy to being more of a people's person.

Have you found an improvement in your child's quality of lifestyle?

Yes. He has gained weight and now is fond of going to school.

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

He likes to play outdoors which he never did before, so we have to be cautious about how much sun he is exposed to. We have to make sure he takes his medication 12 hourly and so we have to wake him up in the morning for the morning dose.

What advice would you give to those who have been newly transplanted?

My advice to newly transplanted patients would be to take good care of themselves and live healthy lifestyles to avoid



Kayvin is 6 years old and likes to ride his bicycle. He is the recipient of a liver transplant from his living donor mother, Kay.

any complications and to take their medication on time and as prescribed.

What resources have helped you cope (books, websites, and support groups etc)?

Support groups and websites.

What advice would you give to other potential donors?

My advice to potential donors would be to just think about it as saving someone else's life. I think it is a gift from God to be able to save someone's life.

When did you find out that you could become a living donor?

I only found out the day before the operation that I could become living donor.

What were your reservations about making this decision?

In our situation, everything happened very fast. We were desperate to save his life, so we had to make a decision immediately.

How has your lifestyle changed and what precautions do you take since donating part of your liver to your child?

I no longer take medication, just eat healthily. I've been diagnosed with a hyperthyroid so I just take care of my health.

Anything else you would like to add?

I would like to thank all the doctors and staff at Wits Donald Gordon Medical Centre for what they did for both me and my son, Kayvin. He is a totally different boy. I am very proud that I could save my son's life.

A big thanks to the Lord, our God, who gave the knowledge and direction to the doctors during the transplant. Keep on with praying to the Almighty. Thanks to all our friends and family who kept us in their prayers!