Keeping kidneys

Most countries struggle to meet the demand for transplant kidneys, but a few are reaping the benefits of systems dedicated to increasing the number of organ donations after death. Ben Jones and Mireia Bes report.

On a shelf in María Jesús González’s home in Toledo, Spain, there is a small frame with a remarkable image.

It is an echogram of a freshly-transplanted kidney. Her transplanted kidney. The case of González, who had a transplant in 1992 after being diagnosed with renal failure in November 1988, is not uncommon, even if her way of reminding herself of it may seem unusual to some.

González is candid when she talks about her post-transplant life. “People who have received a transplant can teach a lot to others regarding how to live well: in general, we have a more positive attitude towards life, because we get a new reason for living. You can't be sad or get worried about everyday problems because the important thing is that you have a better quality of life, and that you are living thanks to the work of many people,” she says, referring to the time and effort not just on the part of the donor but also the surgeons, nurses and doctors, who are responsible for the success of a kidney transplant and the follow-up care.

González is one of the lucky ones. Figures released in 2010 – the latest available – by the Global Observatory on Donation and Transplantation, a collaboration between the Spanish national transplant organization (Organización Nacional de Trasplantes) and the World Health Organization (WHO), show that the number of organs – including kidneys – transplanted that year was less than 10% of what is actually needed worldwide. In 2010, that 10% represented 73,179 transplanted kidneys, well short of the estimated 800,000 actually needed.

In many countries, end-stage renal failure still leads to death. Luc Noel

Dr Luc Noel, an expert on transplantation issues at WHO, says that kidney donation is hampered by several factors. “Many people, including health professionals, do not appreciate the value of organ donation after death or how it works, and few countries have a system to allow for it,” Noel says. With regard to live kidney donation, he says that many people do not realize that the risks of health complications or death for donors is low. He cites a study published in JAMA in 2010 that found that there are 3.1 such deaths as a result of surgery for every 10,000 live donors in the United States of America, and that live donors’ long-term life expectancy does not change, when proper donor selection, care and follow-up is applied.

“In many countries end-stage renal failure still leads to death, even though some patients are on dialysis for a while,” Noel says, referring to patients with less than 10% kidney function, like González. “But we know that a transplanted kidney can give the recipient several decades of high quality life.”

“Although kidney transplantation is routine clinical practice, it needs inter-disciplinary work and follow-up, including medication, lab work and expertise in rejection treatment,” Noel says, adding that even with follow up, transplantation is cheaper than renal dialysis after the first year.

A 2011 costing report by the United Kingdom’s National Institute for Health and Clinical Excellence found that by increasing the number of kidney transplantations and, thereby, reducing the number of patients on renal dialysis, significant cost savings can be made after the first year and that these savings increase until the eighth year, when they remain steady.

One country that has tapped the potential of renal transplantation to excellent effect is Spain. The western European country is now working with WHO to improve renal transplantation worldwide via initiatives such as the Global Observatory on Donation and Transplantation.

The Spanish system deploys transplant coordinators who work in hospitals across the country to increase organ harvesting from deceased persons – often known as “deceased donors” – by identifying possible donors, mainly people who die in accidents or from stroke or heart attack, and by talking to the donors’ next of kin to gain their consent.

Spain has one of the lowest rates of family refusals. In 2011, 85% of the families asked agreed to the donation of organs after the death of a family member.

Since its creation in the 1980s, the Spanish system has focused on increasing donation after death and it is this aspect that lies at the heart of Spain’s transplant model. In recent years, Spain has achieved a kidney donation rate 33 to 35 per million population, one of the highest in the world. It is this system that González benefited from, as the kidney she received came from a deceased donor.

Nephrologist Rafael Matesanz is the founder of Spain’s national transplant organization. He explains the cost–benefit ratio: “After 20 years with this model we have calculated that doing kidney transplants instead of dialysis saves the health system every year twice the cost of transplantation.
This includes not only kidney, but also liver, heart and any other kind of transplants.”

Despite the health benefits to patients and cost–benefit advantages to health-care systems, countries are still not harvesting enough organs to help those who so badly need them. Dialysis remains the main form of treatment for kidney failure in many countries.

To increase organ supply, some experts have suggested regulating the paid provision of live donors’ kidneys – something that WHO and its Member States oppose. The Guiding Principles on Transplantation, endorsed by the World Health Assembly in May 2010, stipulate that: “Cells, tissues and organs should only be donated freely, without any monetary payment or other reward of monetary value. Purchasing, or offering to purchase, cells, tissues or organs for transplantation, or their sale by living persons or by next of kin for deceased persons, should be banned.”

While the human body and its parts should not be the source of financial gain, the Guiding Principles recognize that the costs of donation and of the transplantation process and allocation must be covered.

The shortage of donor kidneys and the over-reliance on kidney dialysis, which though life-saving can be debilitating, has led desperate patients to seek illegal means of getting a transplant.

“Unscrupulous individuals and organizations are profiteering from this situation,” Noel says. “Trafficking in human organs is not limited by national boundaries and shows the need for global governance in this area of health care.”

To address these problems, improve accountability and make donation and transplantation activities safer, WHO promotes globally consistent coding systems to track human cells, tissue and organs used for transplants following a World Health Assembly decision in 2010.

“The way forward is to establish coding systems based on the International Society of Blood Transfusion 128 global information standard for blood and cell therapy programmes, which are already widely implemented,” Noel explains.

While the trade in human organs involves primarily organs obtained from the living, the World Health Assembly also stressed the importance of increasing deceased organ donation. Noel argues that countries should do more to educate the public on these issues and apply what is known as “presumed consent” under which, people may ‘opt out’ of organ donation rather than actively opting in.

In practice most countries, including Spain and Tunisia, have legislation allowing for presumed consent but only act on this after discussing it with the family and respecting their wishes first.

Tunisia has come up with a simple way of raising its transplantation rates by imposing a small tax on dialysis to pay for the cost of the donation and transplantation system. The levy, a nominal amount of two dinars (US$1), is taken from the cost of each dialysis session and put into a budget to promote organ transplantation.

However, although this move has led to Tunisia having one of the highest rates of kidney donation in Africa – there were just under 11 transplants per million inhabitants from living donors in 2010 and about three from deceased donors, according to the Global Observatory on Donation and Transplantation – there is still work to be done.

In many countries, including Tunisia and other parts of North Africa, the consensus is broadly opposed to deceased donation, either on religious grounds or due to concerns about treatment of the corpse after death. A survey by Jalel Hmida, the former director of Tunisia’s National Centre for the Promotion of Organ Transplantation, found that only 50% of those polled would agree to donate organs after dying.

Tunisia is working hard to overcome these objections to deceased donation, again by using a network of professionals to raise the profile of kidney donation, but Dr Mohamed Salah Ben Ammar, who helped develop the system for deceased and living kidney donation in the country, points out: “The waiting list continues to grow.”

For Noel, to make progress towards meeting the demand for kidney transplants in any country, “efforts are needed to present organ donation to the public as a civic gesture and to call on their reciprocity and sense of solidarity”.

It is a long-standing problem. The cost of failing to harness the potential of kidney donation is a human one. Many thousands of people die every year waiting for transplanted kidneys, and, as transplant patient González points out, a transplanted kidney, whether from a living or deceased donor, offers another chance at life: “It was important for me to see how happy these people were. It’s a change that not only affects the transplanted person but everyone around them, because it transmits the feeling that good things can happen at any moment. Since then I decided to live my life, enjoying every single moment.”