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**KIDNEY DISEASE, DONATION, AND  
TRANSPLANTATION IN EAST AFRICA**

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Johns Hopkins Institute for Applied Economics,  
Global Health, and the Study of Business Enterprise



# **Kidney Disease, Donation, and Transplantation in East Africa**

By Peter Mpaka Ayamba

## **About the Series**

The *Studies in Applied Economics* series is under the general direction of Professor Steve H. Hanke, Founder and Co-Director of the Johns Hopkins Institute for Applied Economics, Global Health, and the Study of Business Enterprise (hanke@jhu.edu).

## **About the Author**

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## **Abstract**

The burden of kidney failure remains largely underreported in East Africa. Health systems face numerous challenges including a lack of kidney registries, shortages of trained skilled healthcare workers, a lack of diagnostic support, a lack of equipment, and underdeveloped policies to govern the provision of treatment for kidney failure. Kidney transplantation, an effective treatment option against kidney failure, is underused primarily because of its cost and the lack of laws governing it. In this paper, the author discusses the salient issues affecting kidney donation and transplantation in East Africa.

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**JEL codes:** I11, I18

## Introduction

Across the globe, End-Stage Renal Disease (ESRD), kidney failure<sup>1</sup>, a noncommunicable disease, silently devastates numerous lives. Kidney failure has had a great impact on global morbidity (being diseased) and mortality (being susceptible to death) because it increases risks associated with other major killers: heart diseases, high blood sugar (diabetes), high blood pressure (hypertension), infection with Human Immunodeficiency Virus (HIV), tuberculosis, and malaria. Kidney failure, commonly described as persistent kidney damage accompanied by a glomerular filtration rate (GFR) of less than 15 mL/min/1.73m<sup>2</sup> (compared to a normal range of 90-120 mL/min/1.73m<sup>2</sup>) and the presence of proteins in urine, is estimated to have caused 1.2 million deaths globally in 2015. Kidney failure can coexist with progressive chronic nerve damage in patients. It is associated with the inability to excrete waste, control serum minerals (electrolytes), handle daily dietary and metabolic acid load, and maintain fluid balance. It subsequently results in inadequate production of hormones by the kidneys,<sup>2</sup> deranged calcium and phosphorus metabolism, high blood pressure, and accelerated progression of heart diseases, cancers, diabetes and neurological disorders.<sup>3</sup>

Due to scanty epidemiological information, poor accessibility of laboratory and other diagnostic services, and the widespread lack of awareness, kidney failure remains a “silent killer,” especially in low-income countries where many sufferers may not receive a diagnosis. And yet, medical technology has provided an efficacious intervention: kidney transplantation. Kidney donation and transplantation, a form of renal replacement therapy (RRT), is the most valued treatment for patients with kidney failure today. The prevalence of kidney failure is such that almost every country in the world faces the daunting task in supplying an adequate number of kidneys for transplantation (Randolph, David & Rigmar 2013).

Successful kidney transplantation is common in developed countries, but rare or nonexistent in many low-income countries, including Uganda, where I live. The procedure poses severe challenges. Registries for would-be recipients and donors are non-existent. Many people have poor health habits and lack money or proximity to gain access to healthcare. Also, most sufferers from kidney disease show no symptoms at first. If kidney disease is detected, it is often in the few advanced health facilities available, and at the late stages of the disease. The true extent of kidney failure is actually unknown in most East African countries—a gap that must be filled.

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<sup>1</sup> Kidney failure in this article is used to mean End-Stage Renal Disease (ESRD).

<sup>2</sup> Hormones: erythropoietin secreted by kidneys increases the rate of production of red blood cells in response to falling levels of oxygen; calcitriol (the active form of vitamin D) increases calcium levels in body in skeletal and tissues diseases; and renin raises blood pressure.

<sup>3</sup> The following references are pertinent to the discussion in this paragraph: Murry *et al.* 2015; Jiro & Yuji 2017; Seyid, Fetimah, Shokouh & Seyid 2015; Leticia & Charlotte 2012; Jack, Corine & David 2020; Jinsoo *et al.* 2018; Rashad 2020; Geraldo *et al.* 2017; Eriksen & Ingebresten 2006; Elisabetta & Giorgina 2019; Oncohemakey, <https://oncohemakey.com/end-stage-renal-disease/>.

Babau *et al.* (2015), in a study at a national referral hospital in Uganda, indicated that up to 51% of 111 patients attending the outpatient nephrology department had kidney failure. Unfortunately, no nation-wide data are available to confirm or dispute this one-site statistic.

It is estimated that about 2.62 million people received dialysis in 2010 globally and the need is projected to double by 2030. In 2017, age-standardized incidence of kidney failure treated with dialysis increased by 43.1%, while incidence treated with transplantation increased by 34.4% (Cockwell & Fisher 2020).<sup>4</sup> Analyses indicate that the total cost of treatment of milder chronic kidney disease (CKD) is much higher than the total cost of treating kidney failure by kidney replacement therapy (Randolph, David & Rigmar 2013). This economic burden will be discussed later in this paper.

### **Brief medical background for those unfamiliar with kidney disease and transplantation**

Before the first successful kidney transplantation was performed, the choice for patients with kidney failure was either kidney dialysis or death. In 1954, Dr. Joseph Murray and his team performed the first successful kidney transplant, using identical twins (Anthony 2012).

Gradually, the transplantation procedure was established worldwide. The transplantation procedure still remained unsuccessful when an identical twin was not available, because of negative immunological reactions. Cyclosporine, a “wonder drug” discovered in the 1970s, suppressed adverse immunological reactions in patients and increased survival rates in transplant patients significantly. Kidney transplants subsequently became a much valued treatment for patients with kidney failure. In addition to increasing transplants between living related individuals, cyclosporine made transplantation between living unrelated individuals a medically successful procedure. Success increased the demand for transplantation, but the shortage of organs has emerged as a major hindrance in reaping all the benefits of these advances (Thomas 2011; Anthony 2012; Barker & Markmann 2013).

### **Risk factors for kidney failure**

Risk factors for kidney disease include diarrheal diseases, HIV infection, low birth weight, pre-term birth, and malaria. These are leading causes of disability and cover lifestyle, infection, and environmental etiologies. Identifying risk factors early and taking steps to counteract them can help prevent acute kidney injury (AKI) and chronic kidney disease. Early diagnosis can help slow the deterioration of kidney function and therefore, avert chronic kidney disease by inexpensive interventions (Neema *et al.* 2019; Murray *et al.* 2015).

*Poverty.* Poverty compounds the problems of kidney disease. Poverty-related kidney disease is associated with infections, low education, poor maternal health, inadequate access to healthcare, and strenuous or hazardous work, among other factors (Norton *et al.* 2016). Poverty is also associated with a lack of social protection, transportation, and unemployment, as well as

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<sup>4</sup> The 95% confidence intervals of these two figures are 40.5%-45.8% and 29.7%-38.9%, respectively.

poor housing. Lack of transportation alone can impede access to healthcare even in situations where treatment costs are not a major barrier. In most cases, the treatment costs are directly covered by the patients and it is an up-hill task to obtain out-of-pocket fees to cover dialysis and simultaneously pay for the monthly supply of medications required in kidney failure management, transplantation costs, and post-transplantation medications. Reducing the financial hardships faced by patients suffering from kidney failure in Uganda is paramount, and financial support is equally needed for patients preparing for transplants and those in post transplantation life. As a later section will discuss, Kenya and Tanzania have each instituted a National Health Insurance Fund (NHIF) that covers part of the cost for kidney transplants.

*Diet.* Healthy pre- and post-transplantation life requires that patients follow recommended diets. Some East Africans are malnourished, predisposing them to diarrhea, pneumonia, and other infections that are important risks for kidney disease. In adolescents, undernutrition results in underweight mothers, low-birth weight offspring, preterm births, pre-eclamptic pregnancies, gestational diabetes, and maternal obesity, all of which increase the lifetime risk of chronic kidney disease in mothers and children (Freudenberg 2016).

Adequate nutrition is key in reducing chronic kidney disease, yet communities with low incomes at times have limited access to healthy foods. Community-based strategies, which include public sensitization and education about healthy food choices, fat reduction, salt reduction, legislation (taxes on high-sugar foods and soft drinks), and regulations on the provision of public meals (say, in parties, schools, and funerals, among other places) can help improve kidney health and are a much-needed intervention to save lives.

*Sex.* Women with chronic kidney disease in East Africa face greater challenges than men do. Their involvement in childcare, housework, small-scale agriculture, and low-income manual work explains why fewer women than men receive treatment for kidney disease when compared with men. Societal gender-based issues such as child marriage, poor access to family planning, and beliefs that women may not perform marital duties after transplantation are all factors for the shortage of organs for transplantation (Cobo *et al.* 2016). Advocacy for equity aimed at betterment of women's health can decrease the burden of kidney disease.

*Drinking water.* Most of East Africa lacks access to safe drinking water. Hence, waterborne diseases that cause acute kidney injury and chronic kidney disease are far more common than in richer countries. Enteric waterborne diseases like diarrhea and non-enteric diseases caused by waterborne pathogens like schistosomiasis can cause kidney disease. Other water-related causes of kidney injury may include consumption of water contaminated with heavy metals, organic acids, or pesticides. Prolonged dehydration also contributes.

*Environmental change.* Climate change, land degradation, deforestation, degradation of biodiversity, and loss of marine life also significantly increase risk of kidney disease. These same factors also increase the risk that kidney disease will progress to a chronic condition through increasing human contact with vector borne diseases such as malaria, trypanosomiasis,

schistosomiasis, yellow fever, dengue fever, and increasing food insecurity (Johnson *et al.* 2016; Vonesch *et al.* 2016).

*Influence of urbanization.* There is limited information on the influence of urbanization in East Africa on kidney disease. However, changes in lifestyle, including a switch to high-calorie food, reduced physical activity, sodium-rich foods, higher environmental pollution, poor sanitation, poor waste management, and limited infrastructure resources all increase risks for kidney disease. Urban planning to improve hygiene and sanitation, reduce population densities, and reduce transmission of pathogens should decrease incidence of acute kidney injury and chronic kidney disease (Giles-Corti *et al.* 2016). Other urban-related risk factors like road-traffic collisions causing kidney damage, natural disasters, and armed conflicts causing crush-injury-induced acute kidney injury, rural-urban migration and immigration all contribute to the burden of chronic kidney disease in East Africa (McPhee *et al.* 2015; Sever *et al.* 2012).

### **Problems with treatment of kidney disease in East Africa**

In East Africa, there are enormous challenges in managing end-stage kidney failure. They include late diagnosis, as the condition is confirmed after worsening of kidney function, poor personal behavioral factors like physical inactivity, high salt intake, and tobacco use, improper drug therapies, lack of counseling, diabetes, and high blood pressure. When kidneys fail, kidney replacement through transplantation is the only option that allows patients to live normal lives. However, there is a great shortage of kidneys for transplantation due to the lack of legislation supported by the local community, lack of ethical and moral approval, scarcity of professional skill, lack of quality equipment, and institutions. Even where transplants occur, there are not enough kidneys for therapeutic purposes from deceased and uncompensated living donors to meet the supply. Consequently, thousands who cannot get transplants in time die.

Such circumstances have led economists, doctors, medical diagnostic scientists and other concerned personnel to call for compensating living donors to meet the supply of kidneys and other organs needed for therapeutic purposes (Frank, Phillip & Glenn 2018; Phillip *et al.* 2018; Sally 2016; Randolph, David & Rigmar 2013). However, laws established in Kenya and Tanzania stand in the way of doing so because they prohibit compensation. These laws are grounded in moral repugnance of paying organ donors and concerns that poor people will sell their organs for small sums inadequate to compensate them for the risks they are taking (Phillip *et al.* 2018). It is also worth mentioning that Uganda today has no laws to govern organs and kidney donation, transplantation, and compensation of donors.

### **Nearly global shortage of kidneys for transplantation**

A kidney shortage exists nearly in all countries of the world because many potential free-will donors do not come forward. Costs associated with evaluation and donation, the risk of dying without life insurance, concerns about long-term healthcare without health insurance, lost wages while out of work for surgery and recovery, and the cost for travel to a transplant center for evaluation and surgery all hinder altruistic donation. Compensation would increase availability of

kidneys for transplants. Transplantation remains the preferred therapy because the average total cost of kidney dialysis is considerably higher than estimates suggest would be the case if everybody who needed a transplant could obtain one. Transplantation also improves quality of life and health related outcomes compared to dialysis (Randolph, David & Rigmar 2013).

In their paper on the global organ shortage, Randolph and his colleagues performed detailed analysis of literature on both organ shortage and potential solutions, and argue that compensating organ donors, both living and cadaveric, is by far the best way of increasing supply. Their evaluation is not restricted to compensation; they also look at changes in default donor rules (such as shifting to presumed consent), improved collection procedures (the Spanish model), organ chains and swaps, demand management, etc. They argue that even if compensation would add to the costs of a transplant, it is no objection because even a modest increase in the supply of kidneys would reduce the costs of dialysis by more than enough to compensate the kidney donor. Thus, net health care costs would decline, rather than increase, with compensation.

There are some countries where some forms of compensation to donors are allowed. In these countries, compensation is not robust and direct, and although it seems to have increased the number of donors, shortages of organs remain. Some observers have argued for systems of regulated incentives to encourage kidney donation (Sally 2011, 2016). The major reason to consider incentives for living kidney donation is that transplant candidates are suffering and dying while waiting for transplants (Matas 2011). In addition, the longer the patient waits on dialysis, the worse the transplant results (David *et al.* 2018; Cosio 1998). The other reason for considering incentives is that currently unregulated black markets exist globally. Only the wealthy receive kidneys in these markets, and there is little or no oversight for donor evaluation, no long-term donor follow-up, and no protection for the donor, or the recipient. In such black market arrangements, the donor at times does not even receive what was promised. Developing a regulated system of incentives may decrease the waiting list and eliminate these unregulated black markets (Schiano & Rhodes 2010). Incentives could also be considered for donation by deceased persons, though it might be difficult to determine who would receive the incentives if family members disagree. In Uganda, for example, there is no clearly defined order for determining the next of kin. Different options for incentives could be provided. There could be a tax credit, college tuition, or a small direct payment with additional small amounts at each follow-up visit. These would minimize the risk of candidates donating for “quick cash” and help ensure long-term follow-up. Different incentives could appeal to different candidates and thus help increase availability of kidneys and save lives (Matas 2011).

### **Iran—the only exception**

There is one country where compensating kidney donors is legal: Iran, although it does not have kidney shortages. Iran began kidney transplants in 1967, but surgeries slowed down in the 1970s due to several factors. Through the 1980s, patients were allowed to travel abroad for transplants, but, because of high costs, an ever-increasing waiting list of patients, and Iran’s eight-year war

with Iraq, the country was forced to abandon the travel-abroad program. In 1988, Iran created the program it has today (Mitra 2012).

In Iran, a person needing a kidney is referred to the Dialysis and Transplant Patients Association, which matches those needing a kidney with a potential healthy adult donor. The government pays for the surgeries, while the donor receives health coverage for at least a year and reduced rates on health insurance for subsequent years from government hospitals. Those who broker the connection receive no payment. They help negotiate the financial compensation the donor receives, usually an equivalent of \$4,500, which is roughly 80% of GDP per person. They also help determine whether Iranian charities or wealthy individuals can cover the costs for those who cannot afford to pay for a kidney. Today, more than 1,480 people receive a kidney transplant from a living donor in Iran each year. Some 2,500 people undergo dialysis each year, but most do not seek transplants because they suffer other major health problems or are too old.

Iran says its system safeguards against black-market organ sales by having non-profit groups handle all arrangements and hold money in custody until after the surgery. The government's Health Department approves all surgeries, which must take place in licensed and monitored hospitals. Foreigners are largely banned from taking part, suppressing the possibility of medical tourism, though Iranians who are dual nationals can benefit from the program. This unique system has thus allowed those in need of a transplant to buy a kidney and has seen Iran's waitlist for kidneys effectively drop to zero (Mitra 2012; Samuel 2018).

East Africa has barriers to kidney donation that include lack of relevant policies and legislation, stringent cultural and religious taboos, supply shortages of essential medications, limited epidemiological data, lack of a relevant workforce capacity, lack of sufficient and standard infrastructure, poor research capacity in kidney failure, and low social economic status that cannot reliably sustain out-of-pocket payments needed for temporal management during dialysis and post-transplantation life. Despite these problems, a concerted effort by free-will advocacy groups, government leaders, researchers, educationists, politicians, and other well-wishers might help establish a kidney donation and transplantation system that alleviates the shortage of organs by ensuring that donors are compensated.

### **Treatment of kidney disease in East Africa: dialysis**

Kenya and Tanzania have many kidney dialysis centres and transplant facilities; the exact number for Kenya is unknown. In Uganda, there are few renal dialysis centres. There are no data available to estimate the number of people on renal dialysis in Uganda or the cost- a gap that needs to be filled. Most dialysis centres are located with-in Kampala (the capital city) and some others are scattered in upcountry towns. The government of Uganda has instituted one dialysis centre at the national referral hospital. It has 25 dialysis machines, which are too few to serve the whole population of 45 million Ugandans. Some patients miss out on dialysis because they have to buy the supplies for the dialysis machine and pay a service fee of about \$20 (60,000 Ugandan shillings) per session at the government-owned facility, which, for many Ugandans, is a substantial amount. Other renal dialysis centres are run under private-public collaborations or are fully



private. Under private-public arrangements, a government-run regional referral hospital can house a renal dialysis centre, but the service is entirely private and has to be paid for directly by the patient. The cost of the service under this arrangement varies across facilities, but a typical amount is \$100 (350,000 shillings) per session, a very high amount for many Ugandans. It is worthy to note that this also comes with the need to pay for drugs, the dialysis circuit, and other accessory expenses like transportation of patient and caregivers, accommodation, and feeding. The total monthly bill for patients comes to over \$2,500 (8.75 million shillings) per month, equivalent to 390% of GDP per person. About 85% of this amount goes to cover dialysis and drugs. Even for formally employed Ugandans, \$2,500 amounts to 14-16 months earnings. For peasants, it is an even higher burden.



*Figure 1: A patient undergoing dialysis at a regional referral hospital in Uganda. According to the dialysis attendant, two more patients were expected to have dialysis on this day but were unable to make it because of costs.*

To illustrate the challenges dialysis patients face, I interviewed several. Rutahira Ram is a 21 year old man who was having his first dialysis session at Mbarara Regional Referral Hospital (MRRH) with hopes his kidneys can recover back to normal function. (To protect privacy, all names of patients and family members here and in later sections have been changed.)

*“I have had to sell some of my goats and ask some family members for financial help in order to manage the dialysis sessions required this month and with the COVID-19 lockdown, transport from my village was so expensive... I can only hope that I recover so fast.”*

Rutahira Ram is a Bachelor of Laws student. He expressed discomfort with his unpredictable future because of the labourious and expensive yet compulsory dialysis he has to receive thrice every week, as he wonders whether he will be able to complete his academics.

*“I hope I could complete my bachelor’s. I only ask government to provide us more dialysis centres in our rural towns so that we do not have to cover long distances and lose a lot of time.”*

Kyobuzaire Evas is a student pursuing a Bachelor of Business Administration, a last-born child and a caregiver to her 55 year old mother, who has spent a year on renal dialysis services. She notes that renal dialysis expenses have had a great negative impact on their family as a whole.

*“The cost has been so heavy on us. We have had to sell off big parts of our family land, in order to care for our mother.”*

As a family, they have not tried to get a kidney donor because they think it is very expensive and know that a kidney transplant is not done in Uganda. She admits they are not so knowledgeable about kidney donation, compensation, and transplantation opportunities in Uganda, as they hail from one of the deep rural areas in Uganda.

*“Government of Uganda should step in to reduce the cost, equip hospitals with more dialysis equipment and create awareness in the population of existence of kidney failure. Many people are suffering and dying unknowingly, thinking they have been bewitched as they wonder why they seem not to pass out urine as usual. Many suffer a mild state of confusion which is why they call it witchcraft.”*

*“We would as a family welcome a kidney donor and proceed to do a transplant but I request government to step in up and set standard requirements and guiding laws and put up a public fund to support poor kidney failure patients,”* she asserts, with a frown on her face.

### **Treatment of kidney disease in East Africa: transplantation**

Uganda currently refers all patients who require kidney transplants abroad. This practice continues even though Uganda has acquired the requisite high-tech equipment and teams of experts (Ministry of Health 2017). There is no kidney donation or transplantation in Uganda because laws to govern the procedures have not been developed. However, neighboring Tanzania and Kenya have developed this capacity. Transplants occur at two hospitals in Tanzania (Muhimbili National Hospital in Dar es Salaam and Benjamin Mkapa Hospital in Dodoma) and seven hospitals in Kenya (including Kenyatta National Hospital, Aga Khan Hospital and M.P. Shah Hospital in Nairobi, while Moi Teaching and Referral Hospital and St. Luke Orthopedic and Trauma

Hospital are located in Eldoret, western Kenya). In 2019, Kenyan hospitals conducted about 163 kidney transplants. Kenya does not have cadaveric organ donation and only uses living donors. Most donors (84.5%) are first-degree relatives such as mothers and brothers, while a further 14.3% are second-degree relatives such as cousins and nephews (Korir 2020).

According to Kisanga *et al.* (2017), in Tanzania, most kidney donors were living donors (97.7%). Among the donors for the 44 transplants the authors studied, first-degree relatives (59.1%) of donors and second-degree relatives were a further 25%. Tanzania currently has the capacity to conduct 200-240 transplants in a year.

Uganda refers about 20 patients per year to other countries for kidney transplants after thorough preparation of patients. Most referrals are to India; a few are to Kenya. The preparation process involves routine dialysis and monitoring, screening of the donor for kidney and blood compatibility, screening the donor and recipient for other secondary conditions like diabetes, hypertension, routine counseling, and referral to the Uganda Medical Council for authorization to leave the country for transplantation.

### **Cost of treatment of kidney disease in East Africa**

In Uganda, pre-transplantation tests and activities cost \$3,500-\$5,750 (12 million-20 million Ugandan shillings). That figure does not include routine dialysis costs.

The costs of kidney transplant depend on the facility. Patients can be referred to hospitals in Tanzania at a total cost of \$18,920 (about 66 million Ugandan shillings), while in Kenya the cost would be \$21,530-27,000 (75 million-94 million Ugandan shillings). In India, the total cost of transplantation is \$27,000-32,435 (94 million-113 million Uganda shillings), which is roughly 4,000-5,000% of GDP per person. It is estimated that transplants in Uganda would cost \$5,000-6,000 (17 million-21 million Ugandan shillings), roughly 800-900% of GDP per person. In Uganda, the cost of dialysis and transplantation is entirely and directly the responsibility of the patient; the country has no National Health Insurance Fund.<sup>5</sup>

Kenya and Tanzania each have a National Health Insurance Fund (NHIF) that helps cover part of the costs for their citizens. Kenya's NHIF covers the costs of dialysis and the initial transplant surgery. However, the patient has to cover the costs of the post-transplant essential medicines (immunosuppressant drugs) that pacify the body's immune system's reaction to the new organ, reducing the chances of it being rejected (Thuo & Riro 2019).

Funding for dialysis in Tanzania is through its NHIF, which was initially established to cover public servants but now enrolls members from the private sector. Tanzania's NHIF provides full reimbursements for dialysis services for its members. Tanzanians not covered by the NHIF must

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<sup>5</sup> Costs in this paragraph are rough estimates obtained by interviews of participants. It is not clear why the Uganda referral system prefers India, where costs are rather higher than in some other countries.

pay out of pocket for dialysis services. Thus, only members of this fund have guaranteed access to dialysis (Furia *et al.* 2019).

Mrs. Kinyi Mbabali has been a widow for over ten years having lost her husband to kidney failure in 2009.

*“We got to know that my late husband had kidney failure when it was too late. The doctors told us about the operations, but we could not raise the money to have him taken for a transplant. It was such a hopeless situation. We lost our only ‘bread winner’ to kidney failure, and I had to be courageous and fend for our children. Some dropped out of school; they could not go far with their studies”* says the 65 year old matriarch, who I found at her village home.



*Mrs. Mbabali seated on a traditional bench at her ancestral home during the interview*

It was unfortunate for her in her situation and she represents a great number of people who painfully lose their loved ones without their voices being heard.

Different patients set up different strategies to raise the funds needed to cover the cost, as expressed by Mrs. Kanye Naomi.



*“My husband decided to list 100 close friends of his who could willfully contribute \$150 (500,000 Ugandan shillings), he listed institutions to which he was a board member, he contacted all the schools where our children were at the time both primary and secondary schools, and also informed all the staffs he was working with. We also put up an advert in a daily newspaper to solicit for well-wishers’ support, and luckily we were able to get all the money for the transplant in India.”*

She is grateful that she has been given a second chance at life after a successful kidney transplant.

*“I thank my husband. I also appreciate my donor. I ask the Government of Uganda to sensitize communities about donor safety because there are so many communal based myths that had discouraged my donor and she almost backed out on me. They should tell people that kidney donation is less risky than people think, and both the recipient and the donor live normal lives after the process. Also the government should step in to fully cover or help cover part of the costs of kidney transplantation and revamp the effort to institute a functional kidney transplant facility in Uganda because the patients suffer too much in the foreign countries where they are referred. Lastly, let there be an effort to institute a facility where we can get post transplantation medicines at a subsidized price because private pharmacies balloon the prices of the drugs.”*

Although other East African countries have fully implemented a kidney donation system and transplantation program, the issue of compensation to kidney donors remains silent, limited, and largely restricted and is an out-of-hospital agreement between the kidney recipient and the donor. Mrs. Kanye, the kidney failure survivor, notes this on kidney compensation:

*“There should be no sales for the kidneys or any other body organ. The government should maintain the current standing statutes or laws. However, compensation in kind should be allowed. In my case, we offered three in-kind helps to our donor and her family. After the transplant, I and my husband helped our donor start a small hotel business in the town where she lives and we also helped her husband get more markets for his coffee sales. Their son was at that time going into secondary school, we have since sponsored that child’s education. He is at the University now. We treat the boy as our own child.”*

There remains a great desire to institute transparent kidney registries and allow a legally acceptable and public kidney donation and compensation program in most of the countries. Uganda has fallen behind other East African countries, though there is evidence of some gains towards this novel cause.

### **East African law concerning transplants**

Tanzania, despite having a kidney transplantation program at two hospitals, still lacks a strong legal framework for organ donation. There is no legislation on the subject. Kidney transplantation services are offered in observation of the Istanbul declaration on organ trafficking and transplant

tourism and the special guidelines in the Muhimbili National Hospital Establishment Act (Furia *et al.* 2019). The lack of a stronger framework may limit the ability to carry out more transplants in Tanzania.

Uganda's Mulago National Referral Hospital by October 2018 had acquired high-tech equipment and teams of expert nephrologists, physicians, surgeons and nurses to carry out the numerous tests before conducting kidney transplants. The greatest hindrance to the big leap forward has been the absence of an enabling law to facilitate kidney transplantation in the country. The enabling law still remains a policy (bill) paper, though, as of October 2020, the bill has been approved by the Cabinet and now awaits review and approval by the Parliament. The principles of this bill include:

- Establishing a legal framework for human organ, cell, and tissue transplants in Uganda by enacting the Uganda Human Organ Transplant Bill.
- Regulating donations and trade in human organs, cells, and tissues.
- Reducing government expenditure on referrals abroad for organ transplant procedures.

For the bill to become law, it needs approval by Parliament and then obtain Presidential assent. Once the bill is an act of law, it will enable and regulate the performance of organ transplants, donations, harvesting, exportation, and importation.

Kenya already has a functional and fully enacted law that governs organ transplantation. The law is part of the larger Health Bill 2016 and builds on the Human Tissue Act, which was reviewed in 2012. It allows Kenyans, either in a written will or an oral statement before witnesses, to donate their bodies or body parts to persons or institutions of their choice upon death. In the absence of a will, however, the law states that "the spouse or spouses, elder child, parent, guardian, eldest brother or sister of that person, in the specific order mentioned, may, after that person's death, donate the body or any specific tissue of that body to an institution or a person contemplated in this subsection." According to the law, the Cabinet Secretary for Health can also step in and donate an individual's organs in the event that the relatives of the deceased person cannot be traced and no will is left behind. Donations may be made for training medical students in learning institutions, for research or advancement of health services, or for healing purposes, including the use of tissue in any living person.

The Kenyan law further provides that any transplant of tissues must be done in a duly authorized health facility after approval from a medical practitioner in charge of clinical services in that facility. The law ensures that doctors and other health professionals do not coerce patients into untimely removal of organs. It stipulates that a doctor who authorizes such a procedure shall not play a leading role in the transplantation to the other party. The law also comes with a hefty fine of up to \$92,500 (10 million Kenyan shillings), about 5,400% of GDP per person in Kenya, or ten years in jail or both for anyone found selling life-saving organs for cash. The law in Kenya opens a way for a legal and regulated mechanism for donations from non-relatives (Thuo & Riro 2019; Merab 2017).

Kenya and Tanzania have made strides in instituting organ donations and transplantation laws. Other East African countries, including Uganda, Rwanda, Burundi, and South Sudan<sup>6</sup> lag behind in enacting laws and instituting transplantation services. Compensation to kidney (or organ) donors remains an omission of focus and largely a silent issue in all countries.

**Table 1: Summary of kidney disease data in East Africa**

No.	Key	Kenya	Tanzania	Uganda
01	People with kidney disease	4 million	Not available	Not available
02	Annual deaths from KD	About 10,000	4,704 patients <sup>7</sup>	Not available
03	Number of dialysis centres	Not available	17 centres	2 public hospitals
04	Number of dialysis machines	Not available	104 machines	45 machines
05	Number of dialysis patients	Not available	600 patients	Not available
06	Estimated cost of dialysis <sup>8</sup>	9,500=	250,000=	350,000=
07	Transplant hospitals	7 hospitals	2 hospitals	None
08	Annual transplants, latest	163 transplants	56 transplants <sup>9</sup>	None
09	Living / deceased donors	All living	All living	None
10	Cost of local transplant <sup>10</sup>	0.25-3 million=	21 million=	Not applicable
11	Cost out of country	Not applicable	Not applicable	100-150 million
12	Who pays for the transplant	NHIF, patient	NHIF	Patient
13	Government law on donation	Available	Not available <sup>11</sup>	Not available
14	Professional expertise	Available	Available	Available <sup>12</sup>

### Current efforts to improve treatment for kidney diseases in East Africa

In Uganda, the general perception is that, where it exists, the effort to improve treatment for kidney disease is not institutional, but individual. It arises mainly from key leading urologists who set up private dialysis centers and personally give counsel to their patients. The government has made minimal effort, setting up only one public centre for dialysis in the capital. At this public centre, the patients are charged a service fee per session and have to provide the dialysis circuit supplies themselves. In the future, the national referral hospital may start kidney transplants, but the fear remains that patients needing the service may have to first solicit large sums of money to pay for it.

<sup>6</sup> Rwanda, Burundi and South Sudan are East African Community member states but are omitted from the discussion in the rest of the paper.

<sup>7</sup> As of 2014; no recent data available.

<sup>8</sup> Cost of dialysis per session, in units of local currency (Kenyan, Tanzanian, or Ugandan shillings).

<sup>9</sup> As of 2017; no recent data available. In some parts of this paper, I indicate 200-240 transplants. The reader must understand that this estimate demonstrates that Tanzania has developed capacity to conduct 200-240 transplants in a single year; this is not the number of transplants in the latest year.

<sup>10</sup> Expressed in units of local currency. Cost of transplant depends on facility ownership; government or private, and whether patient has NHIF coverage or not.

<sup>11</sup> Though Tanzania has no law, transplantation is conducted following the Istanbul declaration and the Muhimbili National Hospital establishment act.

<sup>12</sup> In Uganda, though professional resources are available, more training might be required.

In Kenya and Tanzania it is evident that gains have occurred regarding kidney transplantation. Tanzania has worked with the Tokushukai Medical Group, Tokyo Women's Medical University, and Nipro Laboratory Co. (Osaka, Japan) to institute kidney transplantation at Benjamin Mkapa Hospital in Dodoma. The effort included donating 161 dialysis machines with reverse osmosis and demineralization water clean systems to 15 Sub-Saharan countries, initiating kidney transplantation in Tanzania, educating medical staffs, and providing modern specialties in diagnostic and curative services (Shuzo & Shumi 2020). After overcoming difficulties including poor electricity and water supply systems, bureaucratic delays over procurement procedures, constructing a state-of-the-art kidney transplant theater, training, and getting medical staffs accustomed to medical equipment, the Tanzanian team conducted a kidney transplant on 22 March 2018. It was the first kidney transplant by a Tanzanian staff, for a Tanzanian patient. This success was followed by another seven kidney transplants later that year at Benjamin Mkapa Hospital. This complimented kidney transplant gains made at Muhimbili National Hospital in Dar es Salaam.

It is desirable to initiate similar efforts elsewhere in East Africa so that patients with kidney failure are not ignored, and to satisfy the goal expressed by the 2015 World Congress of Nephrology in Cape Town that "No one should die of untreated acute kidney injury by 2025" (Etienne *et al.* 2019).

### **Ideas for steps for the near future**

Great gaps of information exist concerning kidney donation, transplantation, and compensation to kidney donors in East Africa. I hope that this paper will encourage other researchers to gather and publish data. Some of the outstanding questions include:

- How many people officially die of kidney disease in East African countries per year?
- How many patients are on renal dialysis in individual East African countries?
- What is the agreeable and affordable cost of dialysis and kidney transplants, and how many people can comfortably and privately afford this cost? If people cannot afford the cost of transplants, how do governments of countries without health insurance policies step in to support patients?
- How can costs to patients be reduced so as to improve accessibility to dialysis and transplantation services and thus improve the quality of life?
- Are living donors in East Africa at a high risk of developing complications after transplantation compared to nondonors?
- Why is the issue of compensating kidney (or organ) donors a serious omission of focus, yet one that could solve the grinding scarcity of kidney (or organ) shortage?
- Are there peculiar medical characteristics of the East African population that would affect the question of compensation for organ donors, and how can compensation be legalized to achieve availability of organs to save lives?



In developing a kidney transplant system in Uganda and other East Africa Community states, major areas still require public sensitization and education. They include ethical, religious, and cultural perspectives on organ donation and compensation. Laws should apply to organ transplants from living and deceased donors alike. Proper sensitization is also required in dealing with the contentious issues of who are “the rightful heirs,” appropriate authorities to make decisions in the absence of a will, and the government’s role in the case of unclaimed bodies. Governments also need to develop positions on how much of the cost of transplants they are willing to pay, negotiations for compensating kidney donors, and how they will punish organ traffickers or other law breakers. Physicians, medical laboratory scientists, biomedical engineers, nurses, and counselors all need appropriate training.

To evaluate the anticipated contribution of kidney transplants in Uganda, there needs to be a database for donors and recipients, greater capacity to offer dialysis and perform kidney transplants, and clarity about offering donor compensation. Taking those steps would reduce deaths from kidney disease and improve the quality of life for survivors. The healthcare system should monitor immunosuppressive protocols and follow up with donors and recipients to provide emotional, medical, and psychological support. It should not only be the patients’ responsibility. All these are gaps that require thorough examination so as to reap the best outcomes. A survey to estimate the extent of kidney disease and assess public knowledge and attitudes towards it would provide the basis for more precise estimates of the costs of kidney diseases and the benefits of compensating organ donors, and would provide answers to other important questions.

## **Abbreviations and synonyms**

AKI: Acute Kidney Injury

BMH: Benjamin Mkapa Hospital

CKD: Chronic Kidney Disease

ESRD: End-Stage Renal Disease

GDP: Growth Domestic Product

GFR: Glomerular Filtration Rate

HIV: Human Immunodeficiency Virus

NCD: Non-Communicable Disease

NHIF: National Health Insurance Fund

NR: Normal Range

RRT: Renal Replacement Therapy

## **Operational definitions**

Acute kidney injury (AKI): Abrupt decrease in kidney function, resulting in the retention of urea and other waste, and in dysregulation of extracellular volume and electrolytes.

Chronic kidney disease (CKD): A kidney disease that has lasted a long time.

Comorbidity: The coexistence of multiple disorders in the same patient.

Glomerular Filtration Rate (GFR): A calculation that determines how well the blood is filtered by the kidneys, which is one of the ways to measure remaining kidney function.

Hemodialysis: The process of purifying the blood of a person whose kidneys are not working properly.

Kidney failure: Used to mean End-Stage Renal Disease (ESRD) in this article.

Metabolic acid load: Metabolic balance of acid-inducing foods and base-inducing foods.

Metabolism: Chemical processes that occur within a living organism in order to maintain life.

Morbidity: Having a disease or a symptom of a disease, or the amount of disease within a population.

Mortality: The state of being susceptible to death.

Neuropathy: A disease or dysfunction of one or more nerves, typically causing weakness, numbness, and pain.

Noncommunicable Disease: A noninfectious health condition (no person to person spread).

Normal Range (NR): A range of values deemed normal for physiologic measurement in health.

Risk factor: Something that increases a person's chances of developing a disease.

Serum electrolytes: Minerals present in the blood and body tissues, and essential for metabolism.

Transplant tourism: Overseas transplantation in which a patient obtains an organ through organ trade or other forms the organ trade may take.

Travel for transplantation: The movement of organs, donors, recipients, professionals across borders for transplant purposes.

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## Appendix: Major laws affecting kidney donation and transplantation in East Africa

Tanzania		
Description		Important messages
<b>Name of law</b>	Istanbul Declaration on Organ Trafficking and Transplant Tourism	<p>Organ trafficking and transplant tourism should be prohibited; they violate principles of equity, justice and respect for human dignity.</p> <p>Transplant commercialization targets poor and vulnerable donors, leads to injustice and inequity, and should be prohibited.</p> <p>Distinguishes transplant tourism from travel for transplantation.</p>
<b>Place within legal code</b>	Calls legal and professional framework in each country to govern organ donation and transplantation	
<b>Year</b>	30 April to 1 May, 2008	
<b>Responsible bodies</b>	The Transplantation Society and the International Society of Nephrology (ISN)	
<b>Venue</b>	Istanbul, Turkey	
<b>Name of law</b>	Muhimbili National Hospital Act	<p>Make Muhimbili National Hospital (MNH) a centre of excellence for hospital care in Africa.</p> <p>Improve the quality, efficiency, and affordability of patient care, teaching and research, as well as the income-generating capacity of the hospital.</p> <p>Promote the aims of the health sector reform and strengthen hospital links with other levels of care in the referral system.</p> <p>Provide advisory and consultancy services to the government and others on health related matters.</p>
<b>Place within legal code</b>	Act No.5 of 2000	
<b>Year</b>	2000	
<b>Responsible body</b>	Parliament of Tanzania	
<b>Venue</b>	Dar es Salaam, Tanzania	

<b>Kenya</b>		
<b>Description</b>		<b>Important messages</b>
<b>Name of the law</b>	Human Organs, Human Blood, Blood Products, Other tissues and Gametes Act	<p>No person shall remove tissue or gametes for transplantation or carry out transplantation except in a duly authorized health facility and on written authority of the medical practitioner in charge of services at the health facility.</p> <p>The practitioner should not lead the transplantation he authorized.</p> <p>The Cabinet Secretary shall prescribe the criteria for approval of organ transplant facilities.</p>
<b>Place within legal code</b>	Kenya Gazette Supplement No. 101 (Acts No. 21)	
<b>Year</b>	2015	
<b>Responsible body</b>	Kenya National Assembly	
<b>Venue</b>	Nairobi, Kenya	

<b>Uganda (Bill proposed to parliament but not yet passed, as of October 2020)</b>		
<b>Description</b>		<b>Important messages</b>
<b>Name of the bill</b>	Uganda Human Organ Transplant bill	<p>Establish a legal framework for human organs, cells, and tissues transplants in Uganda.</p> <p>Regulate donations and trade in human organs, cells, and tissues.</p> <p>Reduce government expenditure on referrals abroad for transplant procedures.</p>
<b>Place within legal code</b>	Unspecified	
<b>Year</b>	Unspecified	
<b>Responsible body</b>	Parliament of Uganda	
<b>Venue</b>	Kampala, Uganda	