DEPARTMENT OF SURGERY

Master of Medicine in Surgery

Research Report

FACTORS INFLUENCING THE DEVELOPMENT OF TRANSPLANTATION IN AFRICA

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DECLARATION

I, Ferhana Gool, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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DEDICATION

To David Thomson & Amarah Thomson for being my constant support.

To my parents, Gamza & Zorina Gool, for always believing in me.

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To the Transplantation Society and the Global Alliance for Transplantation whose initiative to improve access to transplantation across the world led to the conference this work is based on and helped to bring together African delegates to help further organ donation and transplantation.

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ABBREVIATIONS AND DEFINITIONS

GAT	Global Alliance for Transplantation
TTS	The Transplantation Society
WHO	World Health Organization
ISN	International Society of Nephrology
CKD	chronic kidney disease
ESRD	end stage renal disease
ESKD	end stage kidney disease
CRF	chronic renal failure
GFR	glomerular filtration rate
HPT	hypertension
DM	diabetes mellitus
HbA1C	glycosylated haemoglobin
mmol/l	millimoles per litre
g/dl	grams per decilitre
WORTH	world organization of renal therapies
TLC	transplant links
IgA	immunoglobulin A
HIV	human immunodeficiency virus
RRT	renal replacement therapy

TABLE OF CONTENTS

ABSTRACT

Background

Access to dialysis and transplantation in Africa is very limited. The challenges vary in different countries across the continent from legislative, to political, to financial.

Aim

To assess factors influencing the development of organ donation and transplantation in the African context.

Methods

A structured interview was held with African delegates attending the 25th Southern African Transplantation Society Congress and Global Alliance for Transplantation Workshop in Durban from the 28th July to 2nd of August 2013. Data from workshop working group presentations for each African country were additionally analysed.

Results

30 delegates from 10 African countries (Cameroon, Ethiopia, Ghana, Kenya, Malawi, Nigeria, Rwanda, Tunisia, Sudan and Zambia) participated in the working groups. Twenty-eight questionnaires were completed. The burden of disease and challenges were large and varied. With marked disparity between countries where kidney transplantation is paid for entirely out-of-pocket—such as Ghana, Kenya, and Nigeria (kidney transplant rates in 2012 of 0.1, 1.4 and 0.1 per million population respectively)—and countries where costs are covered by the government or by insurance schemes—such as Sudan and Tunisia (kidney transplant rates of 5.3, and

11.5 per million population, respectively). For most countries, the cost of immunosuppressive drugs and the ability to perform adequate matching of donors and recipients were the main infrastructure concerns. Five countries (Cameroon, Nigeria, Ghana, Ethiopia, Zambia) did not have legislation governing organ transplantation.

Conclusion

There is need for major political transform which will to ensure that African populations achieve access to transplantation. This would allow international collaboration and willing local clinicians a framework within which to develop sustainable transplant systems.

LITERATURE REVIEW

INTRODUCTION

Transplantation is an unavailable therapeutic option for millions of African patients with end stage organ failure.

An effective transplant program requires legal and government backing, financial support and effective healthcare infrastructure which includes medical personnel, laboratory and hospital facilities. The WHO and various international societies advocate that each country develop a national strategy for organ donation and transplantation.(1, 2) Apart from helping the local population, this self-sufficiency in organ transplantation helps to combat organ trafficking and transplant commercialism.(3)

Transplantation in Africa is limited to a few countries. Only Morocco, Tunisia, Egypt and Sudan in North Africa and South Africa in sub-Saharan Africa have established transplant programs. Deceased donation is only practiced in South Africa.

The burden of non-communicable diseases in Africa is increasing.(4) End stage kidney disease has been identified as a public health concern.(5) In Sub-Saharan Africa chronic kidney disease primarily affects young adults in their economically productive years unlike in the developed world where it typically affects middle-aged and elderly populations.(6)

Renal failure is the most common type of end organ failure that can benefit from transplantation. Renal transplantation is the treatment modality that offers the best quality of life and is in most contexts more cost-effective than long-term dialysis. Living kidney donation is an established donor source and the kidney is the most accommodating organ in terms of warm and cold ischaemia from deceased donors.

End stage kidney disease alone can be estimated through modelling studies to affect 400 cases per million population in sub-Saharan Africa.(7-9) The prevalence of HIV associated kidney disease, particularly in sub-Saharan Africa, also adds to the burden of ESKD. HIV associated kidney disease is reported at 6% in South Africa, 24% in Kenya, 34% in Zambia and 38% in Nigeria.(10) HIV also leads to exclusion of living organ donors and deceased donors. Except in South Africa, where an HIV+ to HIV+ program is in place for deceased donors who test positive.(11) Governmental action is required to treat what is a public health threat on all levels: from prevention, to access to dialysis and transplantation.(12) There is however a paucity of renal registry data to inform health policy which has been identified as an area desperately requiring address by numerous authors.(13, 14)

While various efforts have been made to help develop transplantation in Africa it has been limited by various factors in different countries.(15) Training opportunities and outreach from large international societies such as the International Society of Nephrology (ISN) have helped increase awareness to some degree in sub-Saharan Africa.(4) Despite efforts such as this the fact remains that vast majority of ESKD patients in sub-Saharan Africa discontinue treatment and die.(16)

The Global Alliance for Transplantation (GAT) is a partnership between The Transplantation Society (TTS) and the World Health Organization (WHO) aimed to help countries develop transplantation through the support of the international community.

COUNTRY SPECIFIC TRANSPLANT LITERATURE REVIEW

CAMEROON

There have been no reports of successful solid organ transplants in Cameroon. There are no reports of public or health care worker views towards organ donation and transplantation.

Renal replacement therapies have been available since the 1980s with successful ambulatory peritoneal dialysis reported in Cameroon in 1985.(17) Haemodialysis was also started with twice weekly dialysis sessions for 54 patients in 2008 with 12 dialysis machines.(18) This was for a population of 18 million people. The burden of end stage kidney disease has grown and a series of 518 AV fistulas over 7 years was reported in 2010.(19) Currently peritoneal dialysis is no longer available in Cameroon. A nutritional study of 113 patients undergoing haemodialysis over a 6 month period highlighted that 28% were underweight, 21% had objective muscle wasting, 31% had a low albumin and 83% were anaemic.(20) The same author has reported on mortality rates over a 10 year period from 2002 to 2012. In this study 88.8% of patients had an unplanned initiation of dialysis with 25% dying within the first year. Median survival was 3 years with 66% of patients being male

with a median age of 47 years at the start of dialysis.(21) In 2017 a multicentre study prospective cohort study published over a 15 month period showed a median survival of only 8 months and concluded that in a country where 95% of dialysis patients receive a government subsidy to start dialysis improvements were necessary.(22)

ETHIOPIA

There have been no reports of successful solid organ transplants in Ethiopia. There are no reports of public or health care worker views towards organ donation and transplantation. There have been some reports on corneal donation with 37% in a single study reporting a willingness to donate their eyes. This was correlated with a religious belief of Christianity and a higher education level of high school.(23) In a similar study looking at attitudes towards corneal donation in health science students religion, be it “church going” or Muslim, was seen as a significant influence to not donate.(24)

The first published report of dialysis in Ethiopia was in 1994 with 118 cases of acute renal failure requiring renal support. Septic abortion (71 patients) and malaria (29 patients) were the leading causes of renal failure.(25)

The next available report is of a dialysis service started at Bethel Hospital in 2008 funded through international support and a non-profit foundation.(26) Dialysis had been available in the private sector since the early 2000s. The cost was estimated to be $100 per session, this in a country with a per capita GDP of $161 in 2005. A more

recent publication put the cost of a year of dialysis at $10 680 with a renal transplant estimated to cost $ 20 000.(27) In a study from a private centre, Saint Gabriel General Hospital, a total of 191 patients were offered dialysis over an 8 year period from 2002 to 2010. Of the 91 patients analysed from this cohort only 42% of patients survived longer than a year. Transplantation was sought by 9 patients, who all travelled abroad. Ten patients left the country to continue treatment and 7 patients transferred to other centres in Ethiopia during the study period.(28) In August 2013 a public dialysis unit was opened in Saint Paul's Hospital Millennium Medical College in Addis Ababa but this services only acute kidney injury patients. This study did not report any patients going on to end-stage kidney disease requiring maintenance dialysis.(29)

GHANA

Dialysis has been available in Ghana since 1972 with a report of 92 patients dialysed over a 7 year period from 1972 to 1979.(30) In a 20 year review published in 1996 from the same centre the authors argued for expanding dialysis support in view of their 68% survival rate.(31)

That patients travel from Ghana for transplantation is evident from a report published in 1998 of a heart transplant in a Ghanaian man who developed Kaposi’s sarcoma 3 months after a heart transplant.(32)

There have been strong links with Ghanaian centres from the developing world in an effort to improve healthcare since the mid-1980s. This began initially in haematology

in 1986 between the School of Medical Sciences, Kwame Nkrumah University of Science and Technology in Kumasi and St George's Hospital Medical School in London followed by Infectious diseases, microbiology, paediatrics and ultimately nephrology in 1995. In 1999 there was no haemodialysis available at this centre and this international collaboration resulted in 4 nurses being trained in haemodialysis at St George's Hospital and their returning to work at Komfo Anokye Teaching Hospital.(33)

In 2009 a study from Kumasi reported 40 patients who underwent dialysis from October 2006 to December 2007. The 1000 bed (2nd biggest) hospital had 5 dialysis machines. A 36% mortality was reported. Only 50% of patients were able to afford 20 sessions of dialysis.(34) Peritoneal dialysis is offered for acute renal failure in Kumasi since 2010 and in Accra since 2014. The first $216 of treatment is covered by the government and thereafter by the patient or their family. An outreach program by Saving Young Lives program, a partnership between the international Society of Nephrology (ISN), International Paediatric Nephrology Association (IPNA), International Society for Peritoneal Dialysis (ISPD) and Sustainable Kidney Care Foundation (SKCF) continues to support the development of peritoneal dialysis in West Africa. Limited referral of patients was seen as a limitation on the program to develop peritoneal dialysis.(35) A review of dialysis services in 2015 reported 3 public and 3 private dialysis centres all located in the south of the country (in the north 2/3 are not covered) with the author commenting that expanding peritoneal dialysis would help to counter an erratic electricity supply.(36)

Some studies have looked at attitudes towards donation in Ghana. Although 60% of the respondents (who were primarily commuters) had a tertiary level education only 50% had heard of organ donation. Only 60 % indicated a willingness to receive/donate an organ. Reasons given for non-acceptance of organs was cost (19%), religious beliefs (30%), medication side effects (21%) and personal feelings (26%).(37) In a study of eye clinic patients in Accra 8% were aware of eye donation with 60% of respondents indicating a willingness to donate.(38) In 2017 Boima looked at 480 respondents from sub-urban Ghana to assess their views on organ donation and transplantation. The respondents were from the general public in a major city and well educated. Although 71% were willing to donate their kidneys after death when they were questioned about the method of determination of death only 41% were willing to donate after brain death and 60% after cardiac death. A higher number (85%) were willing to accept a kidney.(39) In a paper exploring cultural aspects of donation the importance of “ancestorship” was explored in the Ghanain setting as a way in which cultural support for organ donation could be achieved if it was handled in a culturally sensitive manner.(40)

“Ancestorship is a reputational issue of great cultural and existential importance in the Ghanaian socio-cultural setting. As such it imposes a unique obligation on families at custom that cannot cavalierly be dismissed as non-person affecting and may pose a challenge to conscription of deceased organs in that socio-legal context. However, crafting a socio-culturally sensitive regulatory framework does not necessarily preclude the donation of (deceased) human biomaterials for transplant and science research. Indeed, when the contextual issues are explored with open-

mindedness and sensitivity it can be shown that such donation can form part of the important customs of some communities in this jurisdiction."(40)

Transplantation Links, a UK based charity supporting transplantation in the developing world, has supported the development of living related renal transplantation in Ghana since 2007. This has taken the form of 1 scoping visit, 5 transplantation visits and a Ghanaian surgeon work placement at University Hospital Birmingham for 6 months. Transplantation visits involve performing live donor transplants, both adult and paediatric. One year survival across all centres is reported at 90%.(15) Longer term data is not available from any African centre (includes Nigeria, Kenya and Zambia) involved with this group. The data is held locally and although "encouraged to publish" there is no peer reviewed publication of the outcomes of any transplants from these countries. Specialist skills transferred include transplantation surgery (adult), nephrology (adult), anaesthesia, adult renal nursing, operating theatre practitioners, transplantation program management.

A total of 17 living related kidney transplants have been performed in Ghana since 2008.(36)

With a view to assessing the need for liver transplantation a 7-year review from 2007 – 2013 looked at all patients diagnosed with hepatocellular cancer and their treatment options as per the Barcelona Clinic Liver Cancer algorithm. Of 465 patients 206 charts were available for review and 118 had enough information to complete BCLC staging. Of 465 patients 50% died on the admission HCC was diagnosed. Only 8% were eligible for resection, transplantation or ablation.(41)

KENYA

The first report of a renal transplant in Kenya was in 1980.(42) In a 2 year period from 1984 to 1986, 77 patients were offered haemodialysis with a view to transplantation. The mean age was 29 years and the mean duration of dialysis was 2.9 months. Of 4 patients transplanted 2 were successful with the other 2 patients dying. Only 14 patients were still on dialysis at the end of the study period.(43) When a 5 year review was performed of 20 patients transplanted only 12 were alive 1 year post transplant.(44)

By 1996 results had improved with Kayima et al. reporting one year graft and patient survival rates were 93% and 86.6% respectively. The second year graft survival rates remained at 93% and the patient survival rate was 80%. Complications were primarily bacterial (69%) and 7 patients had acute rejection. The majority of donors were siblings.(45) In 2003 there were 100 patients on haemodialysis at Kenyatta National Hospital.(46)

Attitudes towards xenotransplantation in Kenya were reported in 2001 as part of a 3 centre study. Of note 83% of Kenyan students were religiously active (compared to Sweden 10% and Texas, USA 59%) and this was associated with a lower acceptance rate of xenotransplantation. Vegetarians were also less accepting.(47)

In a 2007 study looking at attitudes towards donation of umbilical cord blood amongst recent mothers only 66% felt they could make the decision to donate alone

despite 81% being in favour of donating and 78% prepared to have their child receive a transfusion. 90% of women were prepared to undergo HIV testing if they were to donate.

MALAWI

Dialysis (haemodialysis and peritoneal) was available in Malawi in the 1980s but results were poor due to an inability to purify tap water to dialysis water. By 1994 dialysis was no longer available with patients travelling to South Africa for dialysis. In1998, 4 machines and a water –purifying system were purchased and staff sent to South Africa for a 1 week training course. In 2 years, 29 patients (58% male) were dialysed. 8 of these were chronic renal failure patients. There were 10 deaths (2 in the chronic renal failure group).(48)

Malawi is rated 165 out of 177 in the human development index and as such is one of the poorest countries in the world. A paper in 2007 looked at the laboratory costs involved for Malawi to adopt the WHO endorsed system of voluntary unpaid blood donation. In sub-saharan Africa the lack of such services means that 80% of blood donors are sourced from families at local hospitals. Of 1729 donors only 1104 resulted in blood collection; 275 were excluded for being anaemic, 175 were HIV positive, 38 were VDRL positive, 21 had Hep B and 102 had malaria smear positive (35.4% were rejected). The laboratory cost was $56 per unit of blood in a country with a per capita GDP of $320.(49) A year of dialysis is estimated in 2016 to cost $20 000 in Malawi.(50)

In correspondence to the Lancet in 2015 Bates et al, note that while dialysis is offered to 60 patients at two different centres in Malawi the reality of the situation is that the inclusion of the palliative care team for these patients is the major treatment pathway given that so many will not access dialysis after their diagnosis.(51)

In 2016, a look at health-related quality of life of haemodialysis patients was published because standard laboratory monitoring of dialysis effectiveness is not done. The Kidney Disease Quality of Life Instrument was used with the physical health scores reported as particularly low (59.9 out of 100) which was postulated to affect income generating capacity.(50) A further study looked qualitatively at 10 patients with end stage renal failure not able to be dialysed for “health systems issues”. The major issues for these patients were functional decline, financial challenges, loss of role in the family and spiritual and cultural beliefs. A sense of the health care system letting the patients down was not reported.(52)

Evans et al reported in 2017 on a pragmatic cohort of all medical admissions over a 2 months period. Of 892 patients screened 153 had AKI. 58.8% of whom had HIV. A total of 21 patients (13.7%) had an indication for acute dialysis. 8 patients received dialysis with renal recovery in 6 patients after a median of 4 sessions of dialysis. 1 patient died on active treatment and another had treatment withdrawn. Long term follow-up of these patients was not available and although 68 patients had some recovery of renal function 43 of these had persistent kidney injury at the time of discharge. A total of 128 patients were discharged with abnormal creatinine levels and no further record is noted.(53)

Worldwide pooled mortality from AKI is 21% and in SSA is 32%.

In a study on traumatic brain injuries over a 3 year period from 2012 to 2015 the authors looked at the outcomes of exploratory burrholes necessitated by a lack of available CT scanning resources. The authors report a mortality rate of 6.8% but do not comment on brain death legislation.(54)

NIGERIA

The first publication related to transplantation in Nigeria was in 1992 which was a case study of a 40 year old patient who had received his transplant in the United Kingdom and presented with repeated episodes of chronic allograft rejection. This patient during admission for one such episode.(55) The first report of haemodialysis in Nigeria was of the first 100 sessions at University College Hospital, Ibidan. Of the 9 patients 6 discontinued therapy due to financial constraints after less than 10 sessions. There were also multiple technical challenges highlighted with 8 septic episodes reported.(56) A subsequent report from the same institution 5 years later reported on 158 patients (141 for chronic renal failure) and noted 70.8% were unable to afford dialysis for more than a month. Between 1 to 10 new patients presented each month to the service and the authors concluded that haemodialysis in a developing economy like Nigeria would be subject to “adequate health planning”.(57)

In a study looking at attitudes towards living kidney donation 62% of health workers would be willing to donate. This compared to 52.1% of first degree relatives of patients with ESRD and 27.1% of people from rural areas who were surveyed. The

most commonly cited reason for refusal to donate was fear of adverse health consequences.(58) In a subsequent study looking only at 205 health care workers (55% of whom were doctors) only 59.3% were willing to donate an organ. “Fear of complications” (44.9%) and “mistrust of health sector” (20.6%) were the most common reasons for unwillingness to donate.(59) In the largest such study looking at public attitudes across Nigeria of 1300 respondents (with 53.2% Muslim) 66% were willing to donate a kidney, 25% were not willing and 8.9% were undecided. Respondents were asked if incentivization would change their opinion and 99.4% said that it would not.(60) A lack of awareness related to religious precepts and trust in the health care workers handling the organs was demonstrated in one study looking at attitudes towards deceased donation in northern Nigeria.(61) A lack of awareness of kidney transplantation was highlighted in another study of health care workers and care givers where on 60% were aware that kidney donation existed.(62) In a study in 2011 looking at cadavers used for teaching, at over half of the medical schools in Nigeria, not one body was bequeathed to scientific research with 90% being traumatic deaths and 10% were unclaimed bodies.(63)

Nigeria has been chronically under resourced in terms of dialysis machinery. In 2000 with a population of 120 million it was estimated that Nigeria had 80 haemodialysis machines. The absence of government funding or subsidy was highlighted as a problem as well as staff migration to the Middle East and Western world.(64) In a 7 year review of 320 consecutive renal dialysis patients done in 2012 80% of patients funded their dialysis treatment directly out of pocket. The average duration of dialysis was 5.2 weeks with the majority (98.1%) unable to sustain dialysis longer than 12 weeks. One hundred and twenty eight patients died within 90 days of entry into

dialysis care leading the authors to conclude that opportunities for kidney transplantation would be low.(65)

In 2005 the first series of renal transplants in Nigeria was published. The first patient died 6 months after from sepsis while the other 2 patients were well 35 months post transplant. The authors commented on major difficulties procuring and monitoring immunosuppressive drugs.(66) In a survey of family members of neurosurgical patients 22.2% had heard of brainstem death however almost all (98.4%) believed that death only occurs when both breathing and heartbeat stop. Although 66.9% would donate an organ, and 76.4% would accept an organ 59.8% would not allow an organ to be taken from a deceased relative.(67)

Ethical concerns related to the commodification (commercialization) of organ transplants are discussed in the Nigerian academic literature with another major area of focus being that of truly informed consent for donors and recipients based on local outcomes.(68) The lack of legislation regarding deceased donation and transplantation as well as the lack of a renal registry was highlighted by Bakari et al. in the Nigerian Journal of Surgery in 2012 and by Ajayi et al. in 2016.(14, 69) Patients in Nigeria do travel for transplant primarily to India with 54% being living unrelated transplants. Over an 8 year period 26 patients travelled abroad for transplantation and were then followed up in Nigeria. Short term graft and patient survival were poorer than values recommended for living kidney transplants.(70)

RWANDA

In Rwanda there are 4 dialysis centres. Three are in the capital city, Kigali and one in a rural area in the south of the country. In Rwanda 84% of the 11 million population lives in the rural areas. For those undergoing dialysis only 51% (21 patients) were adherent to their dialysis regimen. Financial limitations were a major factor to non-adherence. Transplant was not considered a treatment option for the patients in this study even though 12 patients had been on dialysis more than 5 years. (71) Technical surgical success rates of arterio-venous fistula (AVF) creation in 31 of 37 patients assessed for AVF were good at 90% in a study from Rwanda.(72) Blood transfusion alone has been noted to be in need of assistance in Francophone countries in Africa (which includes Cameroon and Rwanda) with poor levels of organization, insufficient supply of blood products, limited financial resources and cultural obstacles.(73)

SUDAN

The first renal transplant in Sudan was between 1978 and 1985. In that same period 39 transplants for Sudanese patients were performed in other countries primarily in the United Kingdom (21) and Kuwait (11). Survival at 2 years was 90%.(74) The impact of Immunosuppression with cyclosporine (CsA) in 78 Sudanese renal transplant patients was published in 2009. Patients had a mean age of 42.1 years and had been transplanted a mean of 3.8 years with increased CsA levels in hypertensive and female patients and 62.8% of patients having lipid abnormalities.(75)

In a case report of two Sudanese refugees resettled in the United States who underwent liver transplantation the infectious disease considerations were highlighted as requiring specialized input. Evidence of exposure to malaria, intestinal parasites and tuberculosis were identified in these patients with treatment and preventative strategies tailored for the individual patient.(76) The need for malaria prophylaxis in transplant recipients has been looked at in a study from Sudan where 55 renal transplant recipients were followed up and compared to 55 controls. There were 25 and 26 malaria attacks diagnosed in each arm in one year of follow-up.

Cost of renal transplantation for both the first (US $14 825.04) and second (US $10 651.00) year post transplant was higher than a year of haemodialysis (US $6 847.00) in Sudan.(77) The authors do note that the haemodialysis regime employed in Sudan of 2 sessions per week is not adequate as per the National Kidney Foundation Dialysis Outcomes Quality Initiative recommendations(78, 79) and the National Cooperative Dialysis Study(80) and as such the difference may be less.

The genetic polymorphism of the 3 major tribal groups in Sudan was looked at in 250 renal transplant donors. There was considerable polymorphism at each locus for Gaalia, Johyna and Nile Nubian population groups which the authors commenting that the considerable heterogeneity in Class I and II polymorphisms reflects recent admixture of these groups with local Arab and African populations.(81)

A report on Sudanese victims of organ trafficking in Egypt is available online with video testimonies from 12 individuals. 57 Sudanese refugees and asylum seekers were reported to be the victims of illegal removal of a kidney. In 9 of the 57 cases they were simultaneously trafficked for sex. In depth interviews were conducted with 12 victims. In 3 of these cases the organ traffickers had assisted in smuggling the victims into Egypt.(82)

TUNISIA

Tunisia has a long history of providing renal transplantation with the first case in 1962. A national registry was formed in 1962. In 1968 a comprehensive dialysis program was setup. A renal failure association was setup in 1982 and a national society of nephrologists in 1983. A national registry in 1986. The incidence of renal replacement therapy increased from 13 per million population (pmp) in 1986 to 133 per million population in 2008. There are five nephrology departments across university hospitals and strict government criteria regulating dialysis centres.(83)

Tunisia reports data to Middle Eastern Society of Organ Transplantation (MESOT). This organization collects data on transplant activity from Middle Eastern countries since 2002. Tunisia has both a deceased donor and a living related program. Through the end of 2003, 155 cadaveric and 350 living-related kidney transplants had been performed in Tunisia. Thirty of these kidney transplants had been performed outside the country. Limited numbers of liver (16), heart (14) and bone marrow transplants (196) had been performed.(84) In 2014 is was estimated that Tunisia spends 7% of the gross national product on health.(85)

The first transplant was performed in 1986 with that centre recently publishing its 30 year experience in 702 renal transplants. Before that time it is estimated that 120 Tunisians had travelled abroad for transplants covered by the government and social funding. The mean age of recipients was 32.7 +/- 11.5 (rage 6 – 65 years) with a gender ratio of 2.2: 1 in favour of males. The majority of donors were living (78.8%) with deceased donors accounting for 21.2% of kidneys. In a subset analysis the authors noted that deceased donation fell from 27.4% of donor kidneys in 2006 – 2010 to 12.9% in the period 2011 – 2015. Outcomes were good from this single centre with patient survival rates at 1, 5, 10 and 20 years being 96%, 89.3%, 79.5% and 65.4%. This centre conducts 42% of all renal transplants in Tunisia.(86) This centre published the outcomes from the first 144 donors in 1997 and reported some intraoperative challenges, no deaths and minor morbidities that were commented to be slightly higher than United States rates at the time.(87)

Tunisia is predominantly a Sunni Muslim country with deceased donor corneal transplants allowed by religious leaders since 1959 in Tunisia. The International Islamic Jurist Council recognized brain death in October 1986. This was followed by the International Islamic Fiqh Academy and the Islamic Fiqh Academy issuing important fatwas on organ transplantation in 1990 and 2003.(88) In Tunisia transplants occurred without legal statute as brain death and transplantation legislation was only passed in 1991. In 1995 Tunisia formed a national coordination body responsible for overseeing organ donation and transplantation.(89) Subsequent to this the Tunisian Islamic authority now supports donation and public hospitals are exclusively authorized to perform transplants with financial compensation for organ

donation strictly prohibited.(86) Tunisia is the only Islamic country in North Africa with a deceased donor transplant program.(90)

Two papers have covered tuberculosis in transplant recipeints. In the first 5 renal transplants recipients were diagnosed with TB over a 22 year period. In one case this was disseminated disease leading to the death of the patient and in 3 patients it recurred. The incidence however was no greater than the 1% recorded in the general population.(91) In another series over 25 years an incidence of 3.2% was reported. Mortality was 12.5% (2 of 16 patients).(92)

There is a good body of published research from Tunisia looking at impact of multiple arteries in the donor kidney(93), vasculitis(94), polycystic kidney disease, re-hospitalization rate(95), factors influencing long term (>15 years) outcomes(96), organ trafficking(78), and post-transplant diabetes(97). In the study looking at re-hospitalization rate in the first year after transplant was 45.5% with infections accounting for 55% of admissions and renal dysfunction 26% with an median length of stay around 15 days.(95) In the study looking at organ trafficking 20 patients had travelled to Iraq (14), Egypt (3) and Pakistan (3) with a high incidence of surgical complications reported.(78) The short-term and long-term outcome of living kidney donors has been looked at with minimal procedural complications reported and no deaths and good long term outcomes with 52% follow-up. In this 30 year retrospective review 20.4% of donors had become hypertensive and 8.4% had become diabetic although renal function was preserved and the authors stressed the need for good follow-up.(98)

ZAMBIA

There have been no reports of successful solid organ transplants in Zambia. There are no reports of public or health care worker views towards organ donation and transplantation. There are no published reports of dialysis facilities in Zambia.

INTERNATIONAL COLLABORATION PROJECTS

Transplant Links, founded in 2006, is a UK based charity with volunteers primarily from University of Birmingham, who together with African colleagues aim to perform between 2 – 4 renal transplants in a one-week period in the local country. The largest amount of work has been done in Ghana but this group has also performed outreach to Nigeria and to Trinidad.(99)

In Cameroon a dialysis unit is maintained through the World Organization of Renal Therapies (WORTH) with plans for further expansion.(100)

SUMMARY OF LITERATURE REVIEW

The level of health care infrastructure varies markedly between the countries reviewed. In some countries (Cameroon and Ghana) despite dialysis being available for some time there has been very limited progress towards establishing transplant programs. Financial limitations are a repeated concern in accessing dialysis services across the continent. In countries where the dialysis service has grown to service sufficient numbers of patients transplantation has been more actively pursued.

Overall there are relatively few publications from African countries on issues related to dialysis and transplantation. The quality of data reported is poor with research being driven by isolated research projects rather than coming as a spin-off from large national registries informing health care practice.

Public awareness of organ donation is limited even amongst families members of patients with organ failure and healthcare professionals. In Zambia there is no published literature related to dialysis, organ donation or transplantation.

AIM

To assess factors influencing the development of organ donation and transplantation within the African context.

METHODS

A structured interview was held with African delegates attending the 25th Southern African Transplantation Society Congress and Global Alliance for Transplantation Workshop in Durban. Interviews were performed by a single interviewer for 30 minutes over a 4-day period from 29 July - 2 August 2013 with a standardized questionnaire completed (Appendix 1).

Delegates for the conference were selected on the basis that they were from English speaking countries identified to benefit the most from forming partnerships with the International Society of Nephrology (ISN) and the Transplantation Society (TTS). A list of 31 interested clinicians from 10 countries was compiled based on discussions held at the 12th Congress of the African Association of Nephrology in Accra, Ghana on 20th - 23rd February 2013. Clinicians with previous nephrology training through ISN and surgeons tasked with performing transplants were selected.

The questionnaire covered respondent details, their local staffing infrastructure, hospital infrastructure, drug availability, financial support and views on international collaboration and training. Perceived country specific barriers to living donor transplantation, deceased donor transplantation, successful transplant outcomes and

transplantation in general were assessed on a 10 point Likert scale, with 1 being of least important and 10 being the most important.

Working group presentations presented during the Global Alliance for Transplantation Workshop - by representatives of each country - were prepared following small group sessions according to a template (Appendix 2) and aimed to assess activity in each country and identify key aspects to improving transplantation in each country. The presentations covered transplantation and dialysis activity, number of transplant centres, infrastructure, waiting lists and laws and legal regulations for each country represented.

Verbal consent was taken from each delegate taking part in the interview and completion of a questionnaire, and participation was on a voluntary basis. That the questionnaire was part of a research project was expressly stated. Presentations during the Global Alliance for Transplantation Workshop were for the purpose of compiling information to help further develop transplantation in Africa in country specific terms and consent was given for such information to be published.

The study was approved by the University of Cape Town, Department of Surgery Research Committee project number 2013/132 and by the Human Research Ethics Committee of the University of Cape Town 594/2014.

Descriptive statistics were used to present the data. Continuous variables were summarized as means and standard deviation (SD) or median with interquartile

range if data is not normally distributed. Categorical variables were summarized as frequencies and percentages.

Data were entered into Microsoft Excel spreadsheet and variables analyzed on an individual and a country basis. For countries with multiple delegates completing interviews the Likert scale answers for barriers to living donation, deceased donation, transplant outcome monitoring and national transplant programs were summarized as means and standard deviations in order to draw comparisons between countries. All analysis was conducted in Stata statistical software version 15.1 (Stata Corp, College Station, TX).

RESULTS

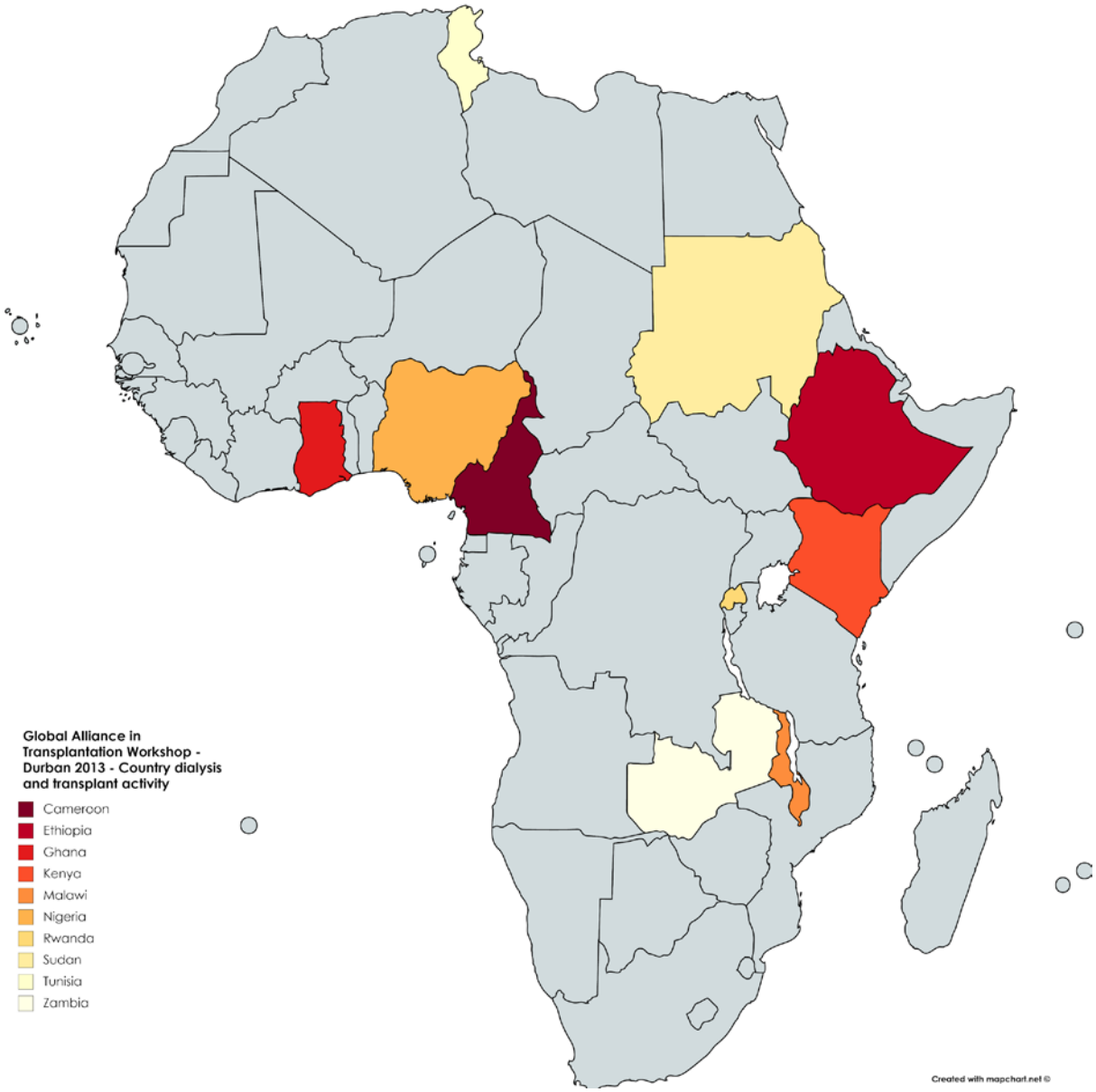
30 delegates from 10 African countries attended the Global Alliance for Transplantation Workshop and South African Transplant Society Meeting from the 28th July to 2nd of August 2013.

African countries represented were Cameroon, Ethiopia, Ghana, Kenya, Malawi, Nigeria, Rwanda, Sudan, Tunisia and Zambia with a total of 20 different hospitals represented. (Figure 1: African Countries Participating in Global Alliance in Transplantation Workshop – Dialysis and Transplantation Activity 2012)

All 30 delegates participated in compiling the working group presentations specific to their country and 28 delegates completed a 30 minute structured interview with the researcher.

Delegates completing the questionnaire were majority male (25) with only 3 female doctors represented. Twenty-two were physicians or nephrologists (78.5%), 2 were urologists (7%), 1 cardiothoracic surgeon (3.5%), 2 surgical trainees (7%) and 1 immunologist (3.5%). The majority of delegates were from Nigeria (12) followed by Kenya (4) and Zambia (3), there were 2 delegates from Ethiopia and Ghana and 1 each from Cameroon, Malawi, Rwanda, Sudan and Tunisia.

Figure 1: African Countries Participating in Global Alliance in Transplantation Workshop – Dialysis and Transplantation Activity 2012



There were no more than 3 delegates from a single institution from the total of 20 institutions represented. (Table 1: Institutions and countries represented at the Global Alliance for Transplantation workshop)

Table 1: Institutions and countries represented at the Global Alliance for Transplantation workshop

Institution	Country	Number of delegates
Yaounde General Hospital	Cameroon	1
Black Lion Hospital	Ethiopia	1
School of Medicine, Addis Ababa	Ethiopia	1
Korle Bu Teaching Hospital	Ghana	1
University of Ghana	Ghana	1
Kenyatta National Hospital	Kenya	2
Maseno University	Kenya	1
Moi Teaching and Referral Hospital	Kenya	1
QE Central Hospital	Malawi	1
Aminu Kano Teaching Hospital	Nigeria	2
Obafeni Arolomo University	Nigeria	1
St Nicholas Hospital	Nigeria	1
University College Hospital, Ibadan	Nigeria	2
University of Ilorin Teaching Hospital	Nigeria	3
University of Nigeria Teaching Hospital	Nigeria	2
Yariman Bakura Specialist Hospital	Nigeria	1
King Faisal Hospital	Rwanda	1
Dr Salma Centre for Kidney Disease	Sudan	1
Charles Nicolle Hospital	Tunisia	1
University Teaching Hospital, Lusaka	Zambia	3

Half of respondents had worked for 10 years or less at their current institution, but the majority had completed their undergraduate medical training locally (22 / 78.5%), 3 people (10.7%) had trained elsewhere in Africa and 3 people (10.7%) had trained overseas. All but 1 delegate had completed postgraduate training with 24 of these being locally trained (85.7%), 2 (7.1%) had specialized elsewhere in Africa and 2 (7.1%) had specialized overseas. Most (23 / 82.1%) of the delegates had travelled abroad for some form of further training. The primary salary source for the respondents was from the national government (22 / 78.5%) with 2 (7.1%) being university employees and 4 (14.2%) primarily privately funded. The monthly salary was under $1500 for over half (60.7%) of respondents. Twelve (42.8%) supplemented their salary with additional private work and for 3 delegates this made up over half their monthly income. (Table 2: Respondent information)

Table 2: Respondent details

Total respondents	28
Gender	
Male	25
Female	3
Undergraduate training	
Locally trained	22 (78.5%)
Trained elsewhere in Africa	3 (10.7%)
Overseas	3 (10.7%)
Postgraduate training	
Yes	27 (96.4%)
No	1 (3.5%)
Postgraduate training institution	

Locally trained	24 (85.7%)
Trained elsewhere in Africa	2 (7.1%)
Overseas	2 (7.1%)
Other training abroad	
Yes	23 (82.1%)
No	5 (17.8%)
Years at current institution	
0 - 10	14 (50%)
11 -15	2 (7.1%)
16 - 20	7 (25%)
21 - 25	3 (10.7%)
> 25	2 (7.1%)
Teaching role at institution	
Yes	26 (92.9%)
No	2 (7.1%)
Salary source	
Government	22 (78.5%)
Private	4 (14.3%)
University	2 (7.1%)
Salary level (monthly)	
$ 1000 -1500	17 (60.7%)
$ 1500 - 2500	7 (25%)
Unsure	4 (14.3%)
Percentage of income from private work	
None	16 (57.1%)
0-25%	6 (21.4%)
25-50%	3 (10.7%)
>50%	3 (10.7%)

Staffing Support

All respondents reported that surgeons, nephrologists and anaesthetists were available at their centre. The absolute number did vary but most respondents had between 2 - 4 surgeons (n = 19), 2 - 4 nephrologists (n = 15) and 2 - 4 anaesthetists (n = 11) able to support transplantation. Four respondents would have to rely on less than 2 surgeons and 2 respondents would have to rely on less than 2 anaesthetists.

Specialized nursing support was available in the form of ICU nurse specialization according to 10 respondents. Most (n = 23) reported that nephrology was available as a specialization for nurses as well as transplant coordinators (n = 18). (Table 3: Staffing support for transplant services)

Table 3: **Staffing support for transplant services**

Doctors	
Surgeons able to support transplantation - < 2 - 2 - 4 - > 5	 4 19 5
Nephrologists - < 2 - 2 - 4 - > 5	 5 15 8
Anaesthetists - < 2 - 2 - 4 - 5 - 9 - > 10	 2 11 7 6

Nursing	
ICU Specialization - Yes - No	 10 18
Nephrology specialization - Yes - No	 23 5
Transplant coordinator - Yes - No	 18 10

Hospital Infrastructure

Respondents reported on laboratory support, pathology services, radiological services, operative and peri-operative support, infection prevention and the ability to mechanically ventilate brain dead donors.

Most basic laboratory services required by transplantation were available. However over 25% of respondents did not have access to laboratory microalbuminuria testing, 24-hr ambulatory BP monitoring and CMV viral load monitoring. Just over half (53.6%) had pharmacology services available for therapeutic drug level monitoring.

All but 2 respondents reported the capability to perform renal biopsies, however 28.6% were worried about the ability to interpret acute rejection at their centre.
CT Scanning was widely available. Only 1 centre in Malawi did not have a CT scanner available. They were of varying resolution. Radiological interventions for treating potential transplant complications such as percutaneous nephrostomy and

cystoscopy and stenting were available to most respondents. Nuclear medicine studies were only available to 53.6% of respondents.

Theatre availability was 24 hours at all centres. Epidural anaesthesia was available in all but 1 centre. Laparoscopic surgery was available to 72.4% of respondents with just under half (46.4%) already performing nephrectomies laparoscopically. Most (92.3%) of respondents would have availability of isolation rooms for transplant recipients.

Infection prevention committees were active for 85.7% of respondents. And although Hepatitis B and Yellow fever vaccines were widely available (96.4% and 89.3% respectively) pneumovac was less available with only 57.1% of respondents having access.

While 23 (82.1%) of respondents reported the ability to ventilate a brain dead patient for 24 hours ICU resource limitations meant that only 19 (67.9%) would be able to extend that period to 48 hours.

Basic internet access was available in all but 1 centre although 25% reported that their internet access was not of sufficient quality to support video calling. (Table 4: Hospital Infrastructure)

Table 4: Hospital infrastructure for transplant services

Laboratory services	Available	Not available
Daily creatinine	27 (96.4%)	1 (3.4%)
GFR estimations	27 (96.4%)	1 (3.4%)
Microalbuminuria	21 (75%)	7 (25%)
24 hr BP monitoring	19 (67.9%)	9 (32.1%)
HIV	27 (96.4%)	1 (3.4%)
Hep B sAg	28 (100%)	0 (0%)
Syphilis	27 (96.4%)	1 (3.4%)
CMV viral load	21 (75%)	7 (25%)
Infective blood screening results in 24 hrs	22 (78.6%)	6 (21.4%)
Blood bank	27 (96.4%)	1 (3.4%)
Pharmacology lab	15 (53.6%)	13 (46.4%)
Pathology services		
Renal biopsy	26 (92.9%)	2 (7.1%)
Able to diagnose acute rejection	20 (71.4%)	8 (28.6%)
Radiology		
CT scanner	27 (96.4%)	1 (3.6%)
Resolution of CT Scanner (No. of slices) - 8 - 16 - 32 - 64 - unsure	 - 2 (7.1%) - 6 (21.4%) - 3 (10.7%) - 7 (25%) - 9 (32.1%)	
Ultrasound	28 (100%)	0 (0%)
Nuclear medicine studies	15 (53.6%)	13 (46.4%)
Percutaneous nephrostomy	25 (89.3%)	2 (7.1%)
Cystoscopy & stenting	26 (92.9%)	2 (7.1%)
Operative & perioperative care		

24 hour operating rooms available		
Epidural anaesthesia	27 (96.4%)	1 (3.6%)
Laparoscopic surgery	20 (72.4%)	8 (28.6%)
Level of laparoscopic operations - Cholecystectomy - Colectomy - Nephrectomy	 18 (64.3%) 4 (14.3%) 13 (46.4%)	 6 (21.4%) 17 (60.7%) 12 (42.9%)
Isolation rooms	26 (92.3%)	2 (7.1%)
Infection prevention		
Infection control committee	24 (85.7%)	4 (14.3%)
Vaccinations available - Hepatitis B - Yellow fever - Pneumovac	 - 27 (96.4%) - 25 (89.3%) - 16 (57.1%)	 - 1 (3.6%) - 3 (10.7%) - 12 (42.9%)
Mechanical ventilation for donors		
Ability to ventilate brain dead patient for 24 hrs	23 (82.1%)	5 (17.9%)
Ability to ventilate brain dead patient for 48 hrs	19 (67.9%)	9 (32.1%)
Internet access		
Basic internet access	27 (96.4%)	1 (3.6%)
Bandwidth to support video calls	21 (75%)	7 (25%)

Drug availability

Immunosuppressive drugs were not available to all respondents. The most commonly available drugs were methylprednisolone, cyclosporin, mycophenolate mofetil and azathioprine. Tacrolimus was available to 64.3% of respondents. Other immunosuppressives such as anti-thymocyte globulin, thymoglobulin and rituximab were not readily available, with less than 14.3% of respondents having these drugs available. Seventeen (60.7%) of respondents had immunosuppression protocols in

place with 9 of these (52.9%) using tacrolimus and 8 (47.1%) cyclosporin as their primary calcineurin inhibitor. Plasmapheresis was available to 92.9% of respondents. The cost of 1 years' worth of immunosuppression was not known to 82.1% of respondents. The cost was thought to be > $20 000 per year amongst those (17.9%) who did estimate the cost. Antivirals in the form of antiretrovirals (92.3%) and acyclovir (89.3%) were widely available however valganciclovir (46.4%) was available to less than half of the respondents. (Table 5: Drug availability to support transplantation)

Table 5: Drug availability to support transplantation

Immunosuppression	**Available**	**Not available**
Methylprednisolone	22 (78.6%)	5 (17.9%)
Cyclosporin	21 (75%)	6 (21.4%)
Tacrolimus	18 (64.3%)	9 (32.1%)
Azathioprine	20 (71.4%)	7 (25%)
Mycophenolate mofetil	21 (75%)	6 (21.4%)
Mycophenolic acid	11 (39.3%)	16 (57.1%)
Anti-thymocyte globulin	4 (14.3%)	23 (82.1%)
Thymoglobulin	2 (7.1%)	25 (89.3%)
Rituximab	3 (10.7%)	24 (85.7%)
Antivirals		
Antiretrovirals (HIV)	26 (92.3%)	1 (3.6%)
Acyclovir	25 (89.3%)	2 (7.1%)
Valganciclovir	13 (46.4%)	14 (50%)
Donor specific antibody management		
Plasmapheresis	26 (92.9%)	1 (3.6%)

Protocols		
Immunosuppression protocols in place	17 (60.7%)	9 (32.1%)
- Cyclosporin predominant - Tacrolimus predominant	8 (28.6%) 9 (32.1%)	
Cost of immunosuppression	Known	Unknown
For 1 year	5 (17.9%) Between $ 20 - 30 000	23 (82.1%)

International support and collaboration

Half of respondents reported a deficiency in surgeons, infrastructure and government support. While 14.3% reported that surgeons alone were the greatest need, 7.1% cited infrastructure support alone, and 28.6% said only government support was lacking. Respondents were split as the preferred method of international collaboration, between visiting foreign experts (42.9%) and travelling abroad for training (46.4%). Three (10.7%) of respondents were in favour of completing a foreign specialization. (Table 6: Needs and preferred method of international collaboration)

Table 6: **Needs and preferred method of international collaboration**

Perceived Deficiency in System	
Surgeons	4 (14.3%) Total 18
Infrastructure	2 (7.1%) Total 16
Government support	8 (28.6%) Total 22
All of the above deficient	14 (50%)

Preferred method of collaboration	
Visiting experts	12 (42.9%)
Training at a foreign centre	13 (46.43%)
Foreign specialization	3 (10.7%)

* 23 of the 28 respondents had received some training outside of their home country.

Funding source for dialysis, transplantation and immunosuppression

The private funding was the sole source for dialysis (64.3%), transplantation (57.1%) and immunosuppression (75%) access. The state was the sole funding source available to the patients for 10% of respondents. A combination of private or state funding sources were available to a quarter of the patients for haemodialysis and transplantation. (Table 7: Funding source for dialysis, transplantation and immunosuppression)

Table 7: **Funding source for dialysis, transplantation and immunosuppression**

Treatment	State	State and Private	Private
Haemodialysis	3 (10.7%)	7 (25.0%)	18 (64.3%)
Transplantation	4 (14.3%)	8 (28.6%)	16 (57.1%)
Immunosuppression	3 (10.7%)	4 (14.3%)	21 (75.0%)

Laws and Legal Regulations

Only Kenya, Nigeria, Rwanda, Sudan and Tunisia had legislation covering organ donation and transplantation. In Ethiopia and Ghana legislation was under development. Most doctors were unsure of the legal status of brain death in their country. In Rwanda, Sudan and Tunisia there is legislation regarding the declaration of brain death. In practice however brain death was accepted in more countries (Cameroon, Kenya and Zambia) despite there being no legislation in those countries. Laws against giving or receiving payment for organs did exist in all countries except Malawi and Cameroon. On further questioning formal penalties existed for commercialization of transplants in 5 countries: Ethiopia, Ghana, Rwanda, Sudan and Tunisia. Rwanda was the only country with formal arrangements to allow transplants to take place abroad. Malawi allowed travel for transplant on an ad hoc basis. Only Tunisia had laws in place governing the transplantation of foreigners within their borders. (Table 8: Laws and legal regulations)

Table 8: **Laws and legal regulations**

	Cameroon	**Ethiopia**	**Ghana**	**Kenya**	**Malawi**	**Nigeria**	**Rwanda**	**Sudan**	**Tunisia**	**Zambia**
Legislation covering organ donation and transplantation	N	D	D	Y	-	Y	Y	Y	Y	N
Legislation regarding declaration of brain death	-	-	N	-	-	-	Y	Y	Y	-

Acceptable for death to be declared upon irreversible cessation of brain/brain-stem functions	Y	-	N	Y	-	Y	Y	N	Y	Y
Acceptable for death to be declared upon irreversible cessation of cardio-respiratory function	Y	-	Y	-	-	Y	N	Y	N	Y
Laws against giving or receiving payment for organs	-	Y	Y	Y	-	Y	Y	Y	Y	Y
Penalties associated for commerce with organs	-	Y	Y	-	-	N	Y	Y	Y	-
Prohibition of organ trafficking	Y	Y	D	Y	-	N	Y	Y	Y	N
Patient confidentiality	Y	N	Y	Y	-	Y	N	Y	Y	Y
Agreements to allow patients to be transplanted abroad	N	N	N	N	Ad hoc	N	Y	N	N	N
Agreements to allow foreigners to be trasnplanted	N	N	N	N	N	N	N	N	Y	N

“Y” = Yes, “N” = No, “D” = Draft stage, “-“ = Unknown

Dialysis and transplantation activity

There was marked variability in access to dialysis across the countries participating. Tunisia and Sudan had large dialysis programs with 8962 and 6067 patients respectively. All countries had some government / public dialysis service except for Ethiopia where all dialysis occurred in the private sector. Most dialysis was in the form of haemodialysis with no countries other than Tunisia (250 patients) and Sudan (100 patients) having more than 10 patients on peritoneal dialysis.

Four countries Cameroon, Ethiopia, Malawi and Zambia had no transplant centres. Kenya, Nigeria, Sudan and Tunisia had more than 5 transplant centres each. Apart from Kenya where four centres were in the private sector the majority of centres in Nigeria, Sudan and Tunisia were in the public sector. Ghana and Rwanda each had a single transplant centre. Local transplant activity was limited with only Sudan and Tunisia performing over 100 transplants. Rwanda had yet to perform a transplant in their centre. All countries had patients travelling for transplants outside of their country. There was no deceased organ donation taking place in any of the countries and no heart or liver transplantation activity reported. (Table 9: Country Dialysis and Transplant Activity Breakdown 2012)

Table 9: **Country Dialysis and Transplant Activity Breakdown 2012**

	Cameroon	**Ethiopia**	**Ghana**	**Kenya**	**Malawi**	**Nigeria**	**Rwanda**	**Sudan**	**Tunisia**	**Zambia**
Population (millions)	20.5	86.5	24	42	15.5	160	11	31	10.8	13
Patients on dialysis	497	150	300	803	37	1502	64	6067	8962	50
Public	495	0	300	451	19	1000	64	6067	2825	40
Private	2	150	0	352	18	502	0	0	6137	10
Patients on waiting list	0	0	15	39	0	1500	36	156	1153	0
Transplant Centres	0	0	1	5	0	8	1	6	6	0

Public	0	0	1	1	0	6	1	5	6	0
Private	0	0	0	4	0	2	0	1	0	0
Living donor transplant	0	0	3	60	0	14	0	165	122	0
Public	0	0	3	33	0	6	0	134	122	0
Private	0	0	0	27	0	8	0	31	0	0
Patients travelled abroad for transplant	3	26	3	10	0	150	11	90	3	9

Barriers to Living Donor Transplantation

For living donor transplantation, the largest barrier to was assessed to be cost. Infrastructure for appropriate donor and recipient matching and securing a consistent supply of immunosuppressive drugs were the next largest obstacles identified. Institutional support for living donor transplantation did not seem to be lacking with the infrastructure already in place for handling the cases in theatre and supporting patients pre and post operatively. In Nigeria, Zambia and Malawi cultural and religious attitudes towards organ donation and transplantation were a concern for the respondents. (Table 10: Barriers to living donor organ transplantation)

Table 10: **Barriers to living donor organ transplantation** (Participant ranking of barriers to successful graft management, from least important (1) to most important (10).)

	Cameroon	Ethiopia	Ghana	Kenya	Malawi	Nigeria	Rwanda	Sudan	Tunisia	Zambia	Average rank
Ability of patients to meet cost	.	10	6.5	2.3	4	8.3	8	1	1	10	7.7
Resources to perform screening and donor recipient crossmatching	2	9.5	6.5	6.5	6	5.9	6	1	1	9	6.1
Consistent supply of immunosuppressive drugs	.	4	3.5	6.8	8	7.0	1	1	1	7.3	5.9
Cultural or religious attitudes toward organ donation and transplantation	2	2	2	2.8	7	4.3	1	1	2	6	3.6
Availability of suitable living donors	2	2	2.5	2.8	5	3.9	1	9	2	4	3.5
Awareness of medical professionals	.	5	3.5	5.3	4	2.6	3	1	2	4.3	3.4
Appropriate pre- and post-operative care	.	6.5	1.5	4	5	2.2	1	1	2	5.7	3.1
Ability to provide appropriate in theatre care	.	6.5	1.5	3.5	3	2.4	1	1	2	5	3
Support for the practice at your institution	1	5.5	1.5	2.5	3	2.6	1	6	2	3.7	2.9

Barriers to deceased Donor Transplantation

For deceased donation cost was the major obstacle assessed in most countries. Legal issues were also a significant concern for all countries except Rwanda and Tunisia. The logistics of transplantation such as matching and allocation

It was felt that there was less institutional support for deceased donation than living donation. Religious and cultural objections were also felt to be more of an issue with deceased donation. ICU resource constraints and education of medical professionals in identifying potential donors were other impediments highlighted. In Tunisia the lack of ICU physicians willing to identify and refer donors was seen as the major factor limiting deceased donation. (Table 11: Barriers to Deceased Donation and Transplantation)

Table 11: **Barriers to Deceased Donation and Transplantation** (Participant ranking of barriers to successful graft management, from least important (1) to most important (10).)

	Cameroon	Ethiopia	Ghana	Kenya	Malawi	Nigeria	Rwanda	Sudan	Tunisia	Zambia	Average rank
Ability of patients to meet costs	.	9.5	5.5	7.7	3	8.7	1	2	1	9.7	7.5
Legal issues	.	5.5	8.5	7.3	7	8.2	1	2	1	6.7	7
Availability of resources to perform donor screening and donor - recipient crossmatching	.	10	8	7	7	6	6	4	1	9.7	6.8
Ability to co-ordinate deceased donation and organ allocation	.	10	6.5	8.7	9	5.6	10	3	1	7.3	6.6
Level of organization and coordination of services	.	10	4.5	9.7	6	5.5	10	6	8	5	6.5
Cultural or religious attitudes	.	10	6	8	7	6	1	3	7	6.7	6.4

Consistent supply of immunosuppressive drugs	.	5	4	6	8	6.7	1	4	1	7.3	5.9
Identification of deceased donors	.	8.5	5	5	10	4.2	4	6	4	9	5.5
Critical care capabilities	.	10	7.5	4.3	9	4.4	1	4	6	7	5.4
Availability of suitable deceased donors	.	9.5	6.5	2.3	10	3.4	4	2	7	6	4.6
Awareness of medical professionals	.	8.5	6.5	5	8	3.3	3	2	8	3.7	4.5
Support at your institution	.	5.5	4	3.7	3	3.2	10	6	6	3	3.9
Willingness of ICU physicians to participate in organ donation	.	9	6.5	2.7	7	2	5	2	8	5.7	3.9
Ability to provide appropriate in theatre care	.	6.5	2.5	3.3	3	2.4	1	1	2	5.3	3
Ability to provide appropriate pre- and post-operative care	.	6.5	2.5	3.3	4	2	1	1	1	5.7	2.8

Barriers to Successful Transplant Outcomes

Cost was seen as the major barrier to good transplant outcomes. The risk of infectious disease complications while acknowledged was not felt to be as major an issue as laboratory and pathology resources or consistent supply of immunosuppressive drugs. (Table 12: Barriers to Good Transplant Outcomes)

Table 12: **Barriers to Good Transplant Outcomes** (Participant ranking of barriers to successful graft management, from least important (1) to most important (10).)

	Cameroon	Ethiopia	Ghana	Kenya	Malawi	Nigeria	Rwanda	Sudan	Tunisia	Zambia	Average rank
Ability of patients to meet costs associated with transplantation	.	9.5	6.5	8	3	7.9	3	4	1	8.7	7.3
Availability of imaging pathology and histocompatibility labs	.	9.5	3.5	7	7	6.4	3	9	1	5.7	6.2
Consistent supply of immunosuppressive drugs	.	4	4	6	7	7.1	1	2	1	7.3	5.9
Risk of infectious disease post-transplantation	.	7.5	3.5	3.5	6	5.2	2	9	6	6.3	5.2
Ability to provide physician-orientated care, incl. drug levels and long-term follow-up	.	9	2.5	4.3	6	4.8	1	2	1	6.3	4.7
Patient compliance with immunosuppressive drugs	.	3.5	3	4	6	5.3	2	1	3	4	4.3
Burden of comorbid disease in the population	.	2	3	5	6	4.3	1	5	3	4.7	4.1

Barriers to Organ Donation and Transplantation

The major barrier seen by clinicians in the transplant field throughout Africa was the lack of histocompatibility testing facilities this was followed by the cost of immunosuppressive drugs. The need for a donor transplant registry was also identified as a significant barrier. This was highlighted the major need in Tunisia together with institutional support. Overall surgical training was noted to be more of a

barrier than nephrology training. This was the most important concern for Rwanda.

(Table 13: Barriers to Transplantation in General)

Table 13: **Barriers to Transplantation in General** (Participant ranking of barriers to successful graft management, from least important (1) to most important (10).)

	Cameroon	Ethiopia	Ghana	Kenya	Malawi	Nigeria	Rwanda	Sudan	Tunisia	Zambia	Average rank
Histocompatibility testing	.	10	6.5	7.5	8	7.1	7	9	1	9.3	7.5
Cost of immunosuppressive drugs	.	8	8	6	8	8.1	5	4	1	9.3	7.4
Construction of a donor transplant registry	.	10	3.5	6	9	8.4	1	2	9	6.3	7.1
Surgical training	.	10	6	8	7	4.6	10	6	1	7.7	6.2
Legal protection for physicians and surgeons	.	6	4	4.3	5	7.8	1	3	1	7	6
Educational needs	.	9.5	2.5	7.5	7	5.1	5	9	5	7	6
Protocol and guidelines	.	10	2	1.8	5	4.2	1	5	3	5.7	4.1
Nephrology training	.	9.5	2	4.5	7	3.3	1	6	1	2.7	3.9
Institutional support	.	5.5	3.5	2.8	4	2.5	1	3	9	3.3	3.2

DISCUSSION

Africa has a pressing need to develop organ donation and transplantation services to allow effective treatment of patients with irreversible end organ failure. A logical

starting point is renal transplantation as patients can be maintained on dialysis while awaiting transplant and the burden of disease is so great. Living donors and deceased donors (both DBD and DCD) are potential sources for donated kidneys with established international protocols in ethical practices and protections for living donors / work-up and follow-up of living donors. In our study representatives of African countries representing 414.3 million people gave insight into challenges facing the provision of transplantation in their country.

Unfortunately, there are many challenges to overcome before transplantation can be readily available. These challenges vary greatly between countries on a continent of a billion people. Adequate resource allocation to health care systems is essential and has begun to improve as the GDP of various countries gets better. There is however a lack of good data to inform government policies and a lack of governance systems and legislation in place. Only half of the countries (Kenya, Nigeria, Rwanda and Sudan) had legislation covering organ donation and transplantation.

Drives to create renal registries across Africa would greatly help to inform policy and resource allocation.(101) Tunisia was the most advanced country in terms of an effective registry of dialysis patients.(83) and with a central coordinating authority for transplantation activity was the most advanced country in renal transplants per million population.

There are limited academic publications from many African countries. Scholarship should go hand in hand with the development of new medical services and may be

especially needed in areas with limited government oversight. Tunisia had the most scientific publications (n=28) when conducting the literature review for this study.

The need for targeted approaches for each country to improve was apparent with countries' transplant programs being at various stages of development. All countries reported patients travelling abroad in 2012 for transplantation except Malawi. It is essential that all countries have national transplant programs governed by rigorous regulations to ensure equitable access to transplantation services. The inability of countries to meet the transplantation needs of their population is identified as a major driver for organ trafficking. (3) This is paramount for deceased donation where the whole population needs to have the potential to benefit from a donor as the donor pool is considered to be that whole population. In Nigeria a mistrust of the health care system was a major reason for people not to donate.(59) Scientific reports related to organ trafficking have come from Sudan (57 asylum seekers to Egypt had sold organs) and Tunisia (20 patients travelled to Iraq, Egypt and Pakistan for transplantation) (78)

Studies on public opinion towards organ donation were few. Cultural, religious and knowledge deficits were revealed across all countries where such studies have been performed (Ghana, Kenya and Nigeria).(39, 40, 47, 58-62) In Kenya the only such study looked only at attitudes towards xenotransplantation.(47) No published reviews of attitudes towards organ donation were found from the other countries. The lack of knowledge and support was not only in the general public but also shown among health care professionals and first-degree relatives there was a low rate of support of support for organ donation in Ghana (only 41% after brain death).(39) An awareness

of transplantation as a therapeutic modality was relatively unknown amongst healthcare professionals in Nigeria (only 60% were aware of renal transplantation as a treatment option).(62) Even in countries where support for organ donation is high such as the United States (95%) consent rates to donation are lower than the support rate. This must be a concern in Africa where public awareness and healthcare professional awareness is at much lower levels.

Respondents in our study were well qualified with the majority being locally educated and with postgraduate qualifications but having travelled abroad for further training. 92% had teaching positions but salary levels were low with 60.7% earning less that $1500 per month and 42.9% doing private work to subsidize their income. The ability to create an environment to retain medical staff (salary, living and working conditions, access to medical technology, and stable political environment) is important as “brain drain” from developing to developed countries is acknowledged as contributing more harm than good to developing countries.(102)

Surgeons, nephrologists and anaesthetists were present in all institutions. And while nursing specialization in nephrology existed at most centres, nurses trained in ICU specialization and transplant coordination was more lacking.

Hospital resources varied widely but core components to the surgical delivery of transplantation was available in all countries. The most pressing infrastructure resource need to ensure good transplant outcomes was HLA tissue typing facilities. The cost of immunosuppressive drugs considered to be the second most significant barrier to transplantation. Coupled to that immunosuppressive drug availability was

also shown to be limited. Only 75% had access to cyclosporin and 64.5% to tacrolimus. Over 80% of respondents did not have access to T cell therapy (Anti T-cell lymphocytes or thymoglobulin) although 92.3% could access plasmapheresis.

International collaborations are occurring on the African context and assist with skills transfer and development. However the scalability of these projects is limited and dependent on local financing and support to ensure that the effort is build into something more sustainable. On the African continent itself South Africa is in an excellent position to share expertise with the rest of Africa in the field of transplantation.

Limitations

This study is limited by the quality of its data, in that it is from selected individuals from certain institutions in selected African countries. The reproducibility of this study would be challenging as the questionnaires were administered at the 25th Southern African Transplantation Society Congress and Global Alliance for Transplantation Workshop in Durban, a non-recurring meeting, funded by a grant from the Transplantation Society. Analysing the data we have used both individual respondent data and pooled other data for country specific issues. As this is a descriptive study aiming to highlight needs in Africa, rather than an exhaustive analysis of individual needs for specific centres, and the data was so heterogenous, we have performed only this limited analysis. Further, more rigorous research is needed on this pressing health need. Country specific research, in terms of legislation, cultural acceptance of organ donation and transplantation, logistical and

resource considerations, to fuel an academic, public and political discourse on improving transplantation in Africa is needed. While surveys of local experts, as in our study, offer a basic overview or description of what is happening within a specific country, use of other study methodologies, for example, use of registry data would inform improvement efforts and public policy more effectively. The number of participants from Nigeria does bias the interpretation of individual responses however it is a large country (160 million people) and respondents were from a number of different institutions and from different specialities.

Conclusion

The expansion of organ donation and transplantation in Africa faces many challenges. Large numbers of patients in many African countries do not have access to organ transplantation as a therapeutic option. This is reflective of large challenges to the health care systems in general. Legislative gaps and inadequate health care resources (financial constraints) are the main rate limiting steps. International assistance is welcome yet systems for health resource motivation and good governance needs to be created from within each country.

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APPENDIX 1: **Research Protocol Submission**

DEPARTMENT OF SURGERY

MMED RESEARCH

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TITLE: DIALYSIS & TRANSPLANTATION IN AFRICA - Where do we currently stand?

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SUPERVISOR: DR. E. Muller

CONTENTS **PAGE**

TITLE:

Dialysis and transplantation in Africa. Where do we currently stand?

1. INTRODUCTION

Chronic kidney disease (CKD) and end-stage renal failure (ESRD) present a major challenge in Africa, because of a lack of dialysis and organ transplantation. Africa is the second most populous continent with a population of 1 billion people and yet there is very limited treatment of end-stage renal failure and mortality remains high. The lack of registries in most African countries makes it difficult to obtain accurate statistics regarding CKD.(1) In Africa the burden of disease may be three to four times more than in developed countries.(2) and yet fewer patients are being dialysed and transplanted than any other continent. Transplantation is the most cost effective way to treat end-stage kidney disease but requires an extensive infrastructure to be possible.

Renal transplantation is currently being performed in 6 countries in North Africa (Algeria, Egypt, Libya, Morocco, Tunisia and Sudan) and 4 countries in Sub-saharan Africa (Cameroon, Kenya, Mauritius and South Africa)(2) out of a total of 54 African countries.

Personal details regarding training, employment and work load of health care workers looking to start up transplantation have not been assessed. Government legislation, funding and support are also difficult to gauge.

Nursing within a specialized renal unit did not emerge until haemodialysis use became more frequent and the burden of disease had increased causing a need for specialist nurses, including those in ICU. The scope of nursing practice has expanded with the nurse becoming the primary health care professional providing the dialysis. The need for specialized nurses is therefore crucial to the development of a dialysis unit & transplant service.(3)

Resources relating to transplantation are many. But access to dialysis is the first step. Then the source of organs needs to be considered.(4) The two options are deceased donation and living donation. Deceased donation requires cultural acceptance and ICU support for potential donors. It also requires maintenance of a tissue typing laboratory capable of rapidly screening recipients against donors. These difficult logistics have resulted in many countries beginning with a living related program where the donor and recipient can be worked up with less time restrictions and both parties are completely happy with the process of donation having discussed it at length and had time to come to terms with it.

Surgical skills and nephrology support for transplantation

need to be trained and retained.(5) The infrastructure needs to be assessed in order to minimize any risk (primarily anaesthetic) to the donor and risk to the recipient – both surgical and related to infectious diseases and immunosuppression in the post transplant period.

Currently two partnerships exist in Africa. In Cameroon an organization called WORTH (World organization of Renal Therapies) has successfully implemented and is managing to maintain a dialysis unit(6). Transplant links (TLC) was founded in 2006. They have founded a partnership with Accra in Ghana. The teaching hospital already had haemodialysis available but with the help of TLC they were able to do their first organ transplant in Ghana in November 2008.(7)

Financing of health care in Africa remains a real concern with very limited state support of transplant services.

There are many obstacles to transplantation ranging from legislation, experienced health professionals, government support, transplant coordinators, tissue-typing laboratories to cheaper and more accessible immunosuppression post-transplantation. All of the previously mentioned factors are however obstacles that can be overcome with commitment and a dedicated team.

2. Aim

The purpose of the study is to assess the various factors influencing the furthering of organ transplantation within Africa countries by interviewing health professionals looking to establish organ transplantation services within their country.

3. Proposed methodology

Administer a structured interview (30 minutes duration) and questionnaire to African delegates attending the 25th Southern African Transplantation Society Congress and Global Alliance for Transplantation Workshop in Durban in 2013. Topics covered were questions related to skills, incentives to stay and work within their countries, the availability of post-graduate training, resources available (internet connectivity, laboratory capability, radiology services, theatre access, and availability of immunosuppression medication) The questionnaire also covered perceived causes of renal failure, age distribution of disease, the availability of dialysis and transplantation and funding resources. The greatest needs and obstacles to developing a transplantation program within each country were assessed.

3.1 Study design

Observational cross-sectional study

4. Ethics

Voluntary participation in the study with verbal consent for the information provided to be used for further academic study. In accordance with the Declaration of Helsinki Oct 2013.

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APPENDIX 2: **Ethics Approval**

UNIVERSITY OF CAPE TOWN

Department of Surgery

Departmental Research Committee
Professor Anwar Suleman Mall
J-45 Room Old Main Building, Groote Schuur Hospital,
Observatory 7925, South Africa
Tel (021) 406 6168/6232/6227 Fax (021) 448 6461
Email: Anwar.Mall@uct.ac.za

2nd December 2013

Dr F Gool
Department of Surgery
Division of General Surgery
Groote Schuur Hospital
University of Cape Town

Dear Dr Gool,

RE: PROJECT 2013/132

PROJECT TITLE: Dialysis and transplantation in Africa: Where do we currently stand?

The above proposal was reviewed by the Department of Surgery Research Committee and I am pleased to inform you that the committee approved the study.

Please use the above project number in all future correspondence.

Yours sincerely

signature removed to avoid exposure online

PROFESSOR ANWAR S MALL
CHAIRMAN: RESEARCH COMMITTEE

APPENDIX 3: **Questionnaire**

Durban Survey

Personnel Details

Name:_____ E-mail address: _____

Institution: _____

Country: _____ Contact number: _____

Position: _____

How long have you been working there? _____

Who pays your salary? _____

Percentage of income from private work? _____

Where did you do your undergraduate training? _____

Where did you do your post-graduate training? _____

Have you trained overseas at some stage? If so where? _____

_____

Is post-graduate specialization available in your country? Y / N

Do you lecture at university? Y / N

Average doctor salary? _____

No. of surgeons at hospital? _____

No. of surgeons willing to do transplantation? _____

No. of physicians/internists? _____

No. of nephrologists? _____

No. ofanaesthetists/anaesthesiologists? _____

Work distribution:

Nephrologist (%s)		Surgeon (%s)	
Acute dialysis		General surgery	
Chronic dialysis		Vascular surgery	
General Medicine		Urological work	
Teaching		Teaching	
Administration		Administration	

Nursing

Can nurses specialize in nephrology? Y / N
Can nurses specialize in intensive care? Y / N
Do you have transplant co-ordinators? Y / N
Do nurses travel overseas to get further education? Y / N

Work-up of donors

Could you ventilate a brain dead patient for 24 hours?Y / N
48 hours? Y / N
Would it be possible to have a dedicated ICU nurse to manage the potential donor? Y / N
Is the work-up of living donors done by physicians or nurses? _____
Is brain death a concept willingly accepted by the majority of the population? Y / N
If not is education or religious objections the major stumbling block? Or both?
In your opinion is a deceased donor program currently possible in your country Y / N
If not, why not? _____

Historically

Year of first living donor transplant? _____

Year of first deceased donor transplant? _____

Liver or heart performed? _____

First corneal transplant? _____

Criteria for dialysis

Financial means to pay for it? Y / N

Minimum standard / exclusion criteria of care for kidney failure patients:

Age limit _____

Exclusion due to co-morbidities _____Must be transplantable to qualify for dialysis Y / N

Education level of patients receiving dialysis?

% primary school _____

% high school educated _____

% tertiary_____

Who maintains dialysis waiting list? (eg. Physician, treating hospital, Ministry of Health?)

_____

Is there any accreditation system or monitoring system for transplants?

_____

Are there any training programs related to transplantation?

_____

Are there any academic meetings related to dialysis? And transplantation?

_____

Resources

Do you have easy internet access? Y / N

The speed of internet allows effective Skype conversations with video? Y / N

CT scan? Y / N How many slice? _____

Interventional radiology – Can do percutaneous nephrostomy? Y / N

Do you have ultrasound capabilities to diagnose obstructed ureter? Y / N

Urological cystoscopy and stenting possible? Y / N

Renal biopsy performed? Y / N

Nuclear medicine studies available – renogram possible? Y / N

Can you perform GFR estimations? Y / N

Blood bank? Y / N

Laparoscopic surgery?Y / N

Level of complexity - Laparoscopic cholecystectomy? Y / N

Laparoscopic colectomy? Y / N

Laparoscopic nephrectomy? Y / N

Do you have bone marrow transplantation facilities? Y / N

Do you have pathology services capable of diagnosing acute rejection? Y / N

Do you have a pharmacology laboratory offering drug levels – next day results? Y / N

Laboratory capabilities

- Daily creatinine Y / N
- HIV – Elisa testing Y / N
- Hep B surface antigen Y / N
- Syphilis serology Y / N
- CMV viral load Y / N

Can you get infective blood test screening within 24 hours? Y / N

Can perform 24hr BP monitoring? Y / N

Can perform microalbuminuria testing? Y / N

Could diagnose haemolyticuraemic syndrome? Y / N

Do you have erythropoietin (EPO) available? Y / N

Can you vaccinate for

- Hepatitis B Y / N
- Yellow fever Y / N
- Pneumovac Y / N

Do you have infection control committee at your hospital? Y / N

Can you offer post transplant patients their own room away from infectious patients in post-operative period? Y / N

Can you offer epidural anaesthesia? Y / N

How many 24 hour operating rooms are running in your hospital? _____

How many laparotomy sets do you have available? _____

How many microinstrument (AV fistula) sets do you have available? _____

Post operativecare and immunosuppression

Drug	Available Y/N	Cost/month
Cyclosporin		
Azathioprine		
Tacrolimus		
Anti-T lymphocyte		
Myofortic		
Plasmaphoresis		
Solumedrol		
MMF		
Thymoglobulin		
Rituximab		

Do you have immunosuppression protocols? Y / N If so what? _____

_____

What is cost of one year of immunosuppression? US $_____

Do you have access to antivirals

- Acyclovir Y / N
- Valgancyclovir Y / N
- Anti-retrovirals Y / N

Regarding setting up a partnership

Where is your country most deficient in terms of transplantation?(select one)

Nephrologists(and dialysis) or Surgeons or

Infrastructure or Government support

What method of support? (select one)

Would you prefer to be supported by being visited by experts from a sister program for a month?

or

Would you prefer to go to foreign center for training for a year?

or

Would you prefer to obtain a foreign specialization/subspecialization qualification?

What do you see as the most immediate priorities for physician training in your country?

_____

What do you see as the most immediate priorities for surgeon training in your country?

_____

Patient characteristics

What are the causes of end-stage kidney failure in your country %s?

Hypertension	
Diabetes	
Glomerulonephritis	
HIV	
Other	

What are the main causes of end-stage liver failure in your country?

_____

What is the average age of end-stage kidney failure patients?

___ 0-24 ___25-34 ___35-44 ___45-54 ___55-64 ___ 65+

What is the average age of end-stage liver failure patients?

___ 0-24 ___25-34 ___35-44 ___45-54 ___55-64 ___ 65+

Does a professional society for transplantation exist in your country? (e.g. The South African Transplantation Society) If so name?

_____

Does an authority exist in your country that is responsible for the oversight of transplantation activities?

_____

If yes, which of the following activities does this authority have responsibility for?

Guideline development ___
Donor and recipient registry ___
Organ allocation ___
Waiting list management ___

Does a system exist in your country for reporting adverse events in transplant recipients?

_____

_____

Does a system exist in your country for recording the long-term outcomes of transplant recipients and living donors?

_____

_____

Financing

Is private health insurance available in your country? Y / N

What is the most common method of payment for transplantation surgery in your country?

Purely state sponsored ____
Private and state sponsorship combined ____
Purely privately funded – cash payments ____

What is the most common method of payment for immunosuppressive medications in your country?

Purely state sponsored ____
Private payment but with a state subsidy ____
Purely privately funded – cash payments ____

What is the most common method of payment for maintenance hemodialysis in your country?

Purely state sponsored ____
Private and state sponsorship combined ____
Purely privately funded – cash payments ____

Do transplantation centers receive any public funds to meet costs? Y / N

If yes, do these public funds pay for?

Physician salaries____
Nursing salaries____
Infrastructure costs___

How are these public funds administered?

Within the global hospital budget_____
As reimbursements for services_____

Do you have access to charitable organization funds to help patients sponsor/subsidize dialysis and/or transplantation? Y / N

Barriers to provision of organ transplantation

For each of the potential barriers to transplantation listed below, please indicate on a scale from 1 to 10 how important each barrier is to either the initiation or expansion of LIVING donor transplantation in your country.

	Does not affect development of transplantation in my country									A major barrier to the development of transplantation in my country
Support for the practice of transplantation at your institution	1	2	3	4	5	6	7	8	9	10
Cultural or religious attitudes towards organ transplantation	1	2	3	4	5	6	7	8	9	10
Availability of suitable living donors	1	2	3	4	5	6	7	8	9	10
Ability of patients to meet the costs associated with transplantation	1	2	3	4	5	6	7	8	9	10
Consistent supply of immunosuppressive drugs	1	2	3	4	5	6	7	8	9	10
Availability of resources to perform donor screening and donor/recipient cross-matching	1	2	3	4	5	6	7	8	9	10
Awareness of medical professionals	1	2	3	4	5	6	7	8	9	10
Ability to provide appropriate in-theater care	1	2	3	4	5	6	7	8	9	10
Ability to provide appropriate pre- and post-operative care	1	2	3	4	5	6	7	8	9	10

For each of the potential barriers to transplantation listed below, please indicate on a scale from 1 to 10 how important each barrier is to either the initiation or expansion of DECEASED donor transplantation in your country

	Does not affect development of transplantation in my country									A major barrier to the development of transplantation in my country
Support for the practice of transplantation at your institution	1	2	3	4	5	6	7	8	9	10
Level of organization and coordination of services at your institution	1	2	3	4	5	6	7	8	9	10
Cultural or religious attitudes towards organ transplantation	1	2	3	4	5	6	7	8	9	10
Availability of suitable deceased donors	1	2	3	4	5	6	7	8	9	10
Identification of suitable deceased donors	1	2	3	4	5	6	7	8	9	10
Ability of patients to meet the costs associated with transplantation	1	2	3	4	5	6	7	8	9	10
Consistent supply of immunosuppressive drugs	1	2	3	4	5	6	7	8	9	10
Availability of resources to perform donor screening and donor/recipient cross-matching	1	2	3	4	5	6	7	8	9	10
Awareness of medical professionals	1	2	3	4	5	6	7	8	9	10
Willingness of Intensive Care physicians to participate in organ donation	1	2	3	4	5	6	7	8	9	10
Critical care capabilities / coordination of trauma care	1	2	3	4	5	6	7	8	9	10
Ability to provide appropriate in-theater care	1	2	3	4	5	6	7	8	9	10
Ability to provide appropriate pre- and post-operative care	1	2	3	4	5	6	7	8	9	10
Ability to coordinate deceased donation and organ allocation	1	2	3	4	5	6	7	8	9	10
Legal issues	1	2	3	4	5	6	7	8	9	10

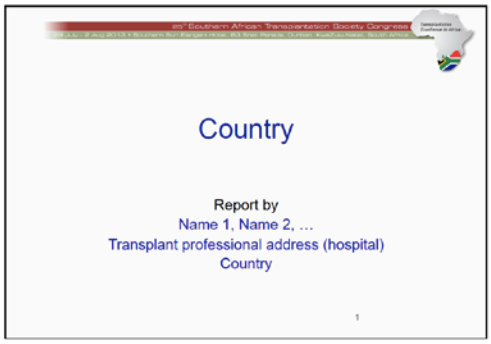
For each of the potential barriers to transplantation listed below, please indicate on a scale from 1 to 10 how important each barrier is to SUCCESSFUL RECIPIENT/GRAFT MANAGEMENT in your country.

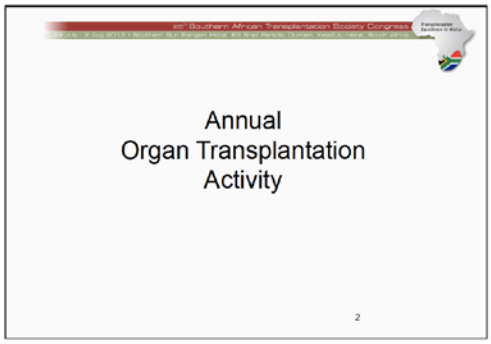
	Does not affect successful graft management in my country									A major barrier to successful graft outcomes in my country
The burden of comorbid disease in the population	1	2	3	4	5	6	7	8	9	10
Risk of infectious disease post-transplantation	1	2	3	4	5	6	7	8	9	10
Ability of patients to meet the costs associated with transplantation	1	2	3	4	5	6	7	8	9	10
Consistent supply of immunosuppressive drugs/drug supply chain	1	2	3	4	5	6	7	8	9	10
Patient compliance with immunosuppression post-transplantation	1	2	3	4	5	6	7	8	9	10
Availability of imaging, pathology and histocompatibility laboratories	1	2	3	4	5	6	7	8	9	10
Ability to provide physician-oriented care, including labs, drug levels and long-term follow-up	1	2	3	4	5	6	7	8	9	10

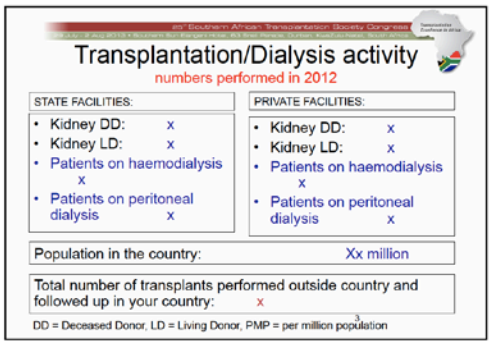
Below is a list of potential unmet needs with respect to organ donation and transplantation. For each of the needs please indicate on a scale from 1 to 10 how large each need is.1 being negligible issue to 10 being a major stumbling block.

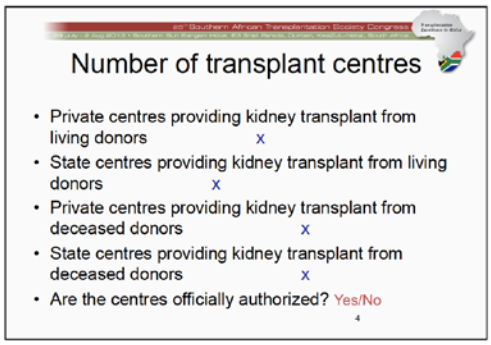
	Already sorted out &not much of a issue									A major stumbling block to a successful transplant program
Construction of a donor and transplant registry	1	2	3	4	5	6	7	8	9	10
Institutional support for organ donation and transplantation	1	2	3	4	5	6	7	8	9	10
Legal protection for surgeons and physicians participating in organ donation and transplantation	1	2	3	4	5	6	7	8	9	10
Cost of immunosuppressive drugs	1	2	3	4	5	6	7	8	9	10
Surgical training	1	2	3	4	5	6	7	8	9	10
Nephrology training	1	2	3	4	5	6	7	8	9	10
Protocol and guidelines	1	2	3	4	5	6	7	8	9	10
Histocompatibilty testing	1	2	3	4	5	6	7	8	9	10
Educational needs	1	2	3	4	5	6	7	8	9	10

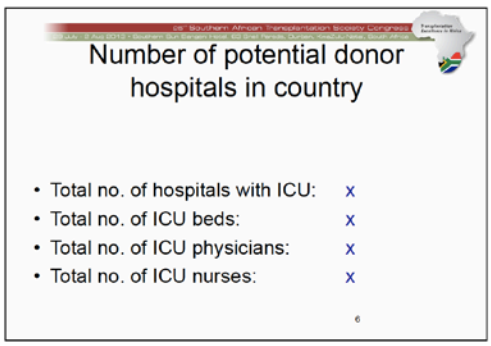
APPENDIX 4: **Country Presentation Template**











Authority and Mandate

7

Is transplantation/deceased donation included in the health-care agenda of the Government?

X

Is organ donation and transplantation a priority in the further development of health care system?

X

Is there a centralized budget allocated to dialysis?

X

What is the government currently doing to support patients with renal failure in your country?

Verbal response

8

Laws or legal regulations:

- Is there any legislation or are regulations in place for donation/transplantation? x
- Determination of death
- What is acceptable to certify a patient dead in your country?
  - Irreversible cessation of brain/brain stem functions X
  - Irreversible cessation of cardio-respiratory functions X

9

Are there laws or legal regulations concerning:

- Prohibition of giving or receiving payment for organs X
  - If yes, are there penalties in the event of commerce with donated organs? x
- Prohibition of organ trafficking? X
- Confidentiality (e.g. data protection law)? X
- Import/export of organs? X
- Are doctors familiar with the Declaration of Istanbul in your country? X

10

Laws or legal regulations:

- Are there cooperation agreements to allow patients to be transplanted abroad? X
- Are there cooperation agreements to perform transplants to foreigners in the country? X
- Are there cooperation agreements to exchange organs with other countries? X

11

National Organization with Coordination Authority

12

Are there facilities for:

- Potential deceased donor identification? X
- Donor management? X
- Procurement? X
- Compatibility testing (HLA, X-match) X
- Storage and transportation? X
- Allocation, selection of recipients? X
- Screening of transmissible disease (cancer, infection)? X
- Comments:

13

Funding

- Are patients' costs covered for
  - Deceased donation X
  - Transplantation X
  - Post-transplant care X
  - Living donation X
  - Living donor follow up X

Response (government, private, insurance?)

14

APPENDIX 5 – **Per country analysis of dialysis and transplant activity in 2012**

See overleaf – 2 countries per page

Cameroon	
Population (millions)	20.5
Patients on dialysis	497
Public	495
Private	2
Patients on waiting list	0
Transplant Centres	0
Public	0
Private	0
Living donor transplants	0
Public	0
Private	0
Patients travelled abroad for transplant	3

Ethiopia	
Population (millions)	86.5
Patients on dialysis	150
Public	0
Private	150
Patients on waiting list	0
Transplant Centres	0
Public	0
Private	0
Living donor transplants	0
Public	0
Private	0
Patients travelled abroad for transplant	26

Ghana	
Population (millions)	24
Patients on dialysis	300
Public	300
Private	0
Patients on waiting list	15
Transplant Centres	1
Public	1
Private	0
Living donor transplants	3
Public	3
Private	0
Patients travelled abroad for transplant	3

Kenya	
Population (millions)	42
Patients on dialysis	803
Public	451
Private	352
Patients on waiting list	39
Transplant Centres	5
Public	1
Private	4
Living donor transplants	60
Public	33
Private	27
Patients travelled abroad for transplant	10

Malawi	
Population (millions)	15.5
Patients on dialysis	37
Public	19
Private	18
Patients on waiting list	0
Transplant Centres	0
Public	0
Private	0
Living donor transplants	0
Public	0
Private	0
Patients travelled abroad for transplant	0

Nigeria	
Population (millions)	160
Patients on dialysis	1502
Public	1000
Private	502
Patients on waiting list	1500
Transplant Centres	8
Public	6
Private	2
Living donor transplants	14
Public	6
Private	8
Patients travelled abroad for transplant	150

Rwanda	
Population (millions)	11
Patients on dialysis	64
Public	64
Private	0
Patients on waiting list	36
Transplant Centres	1
Public	1
Private	0
Living donor transplants	0
Public	0
Private	0
Patients travelled abroad for transplant	11

Sudan	
Population (millions)	31
Patients on dialysis	6067
Public	6067
Private	0
Patients on waiting list	156
Transplant Centres	6
Public	5
Private	1
Living donor transplants	165
Public	134
Private	31
Patients travelled abroad for transplant	90

Tunisia	
Population (millions)	10.8
Patients on dialysis	8962
Public	2825
Private	6137
Patients on waiting list	1153
Transplant Centres	6
Public	6
Private	0
Living donor transplants	122
Public	122
Private	0
Patients travelled abroad for transplant	3

Zambia	
Population (millions)	13
Patients on dialysis	50
Public	40
Private	10
Patients on waiting list	0
Transplant Centres	0
Public	0
Private	0
Living donor transplants	0
Public	0
Private	0
Patients travelled abroad for transplant	9