

**AWARENESS AND ATTITUDE ON KIDNEY ORGAN DONATION AND
TRANSPLANT AMONG HEALTHCARE PROFESSIONALS AND CAREGIVERS
AT KENYATTA NATIONAL HOSPITAL**

DR. DAVIS OMBUI OGETO

H58/81017/2015

MBChB (UoN)

**A DISSERTATION SUBMITTED IN PART FULFILLMENT OF THE
REQUIREMENTS FOR THE AWARD OF THE MASTER OF MEDICINE
DEGREE IN INTERNAL MEDICINE**

DECLARATION OF ORIGINALITY

Name of student : Dr. Davis Ombui Ogeto
Registration number : H58/81017/2015
College : College of health sciences
School : School of medicine
Department : Department of clinical medicine and therapeutics
Course name : Master of medicine in clinical medicine and therapeutics
Title of course work : awareness and attitude on kidney organ donation and transplant among healthcare professionals and caregivers at Kenyatta national hospital

STUDENT'S DECLARATION

I understand the nature of plagiarism and I am aware of the University policy on the same. I declare that this dissertation is my original work and has not be submitted elsewhere for examination, award of a degree or application. Where others peoples work or my own work has been used, this has been properly acknowledged and referenced according to the university of Nairobi referencing requirements.

I have not sort or used any services of any professional agencies to produce this work.

I have not allowed, and shall not allow any person to copy my work with the intention of passing it to off as his/her own work

I understand that any false claim in respect of this work shall result in disciplinary action, in accordance with university plagiarism policy

Dr. Davis Ombui Ogeto MBChB

Signed..... Date.....

SUPERVISORS' APPROVAL

This dissertation has been submitted with our approval as university supervisors.

Prof. E. Amayo M.B.Ch. B, MMED Internal Medicine

Professor, department of clinical medicine and therapeutics, university of Nairobi

Consultant Physician & neurologist

Signed..... Date.....

Prof. J. Kayima, MBChB. M.MED INTERNAL MEDICINE,

Associate Professor, department of clinical medicine and therapeutics, university of Nairobi

Consultant Physician & Nephrologist

Signed..... Date.....

ACKNOWLEDGEMENT

To my heavenly father for the grace and strength to see this endeavor through to the end. I take this opportunity to offer my sincere and humble gratitude to the following people who made this study possible. My supervisors; Prof Amayo and Prof Kayima for your guidance and supervision. To the ward in charges of the medical wards for giving me access to patients register and their caregivers contacts, doctors and nurses in the medical wards for participating in the study, the caregivers to the patients in the medical wards for participating in the study, my statistician Mr. Philip Ayieko for your assistance with the analysis, my family and friends for their support throughout this study.

TABLE OF CONTENTS

DECLARATION OF ORIGINALITY	ii
STUDENT’S DECLARATION	ii
SUPERVISORS’ APPROVAL	iii
ACKNOWLEDGEMENT.....	iv
TABLE OF CONTENTS	v
LIST OF TABLES	vii
LIST OF ABBREVIATIONS	ix
ABSTRACT.....	1
1.0 CHAPTER ONE: INTRODUCTION	3
1.1 Background.....	3
1.2 Literature Review.....	4
1.2.1 Kidney Failure Treatment: Dialysis vs. Kidney Transplant	4
1.2.2 Types of Kidney Donors.....	4
1.3 Donor Selection Criteria.....	5
1.3.1 Living Donor	5
1.3.2 Deceased Donor.....	5
1.4 Graft Survival: Deceased vs. Living Kidney.....	5
1.5 Kidney Organ Donation and Transplant Statistics.....	6
1.5.1 International Statistics	6
1.5.2 Kenyan Statistics.....	6
1.6 Kidney Organ Donation and Transplant Procedure at Kenyatta National Hospital	7
1.7 The Roles of Healthcare Professionals in Kidney Organ Donation Process.....	7
1.8 Awareness and Attitude of Healthcare Professionals on Kidney Organ Donation and Transplant	8
1.9 Awareness and Attitude of Caregivers on Kidney Organ Donation and Transplant	9
1.10 Does Change of Attitude and Improvement on Awareness Result to Increased Kidney Organ Donation Rates and Upsurge in Kidney Transplant?	11
1.11 Study Questionnaire Review	12
1.12 Study Questionnaire Measure of Reliability.....	12
1.13 Study Questionnaire Measure of Validity.....	12
1.14 In-Depth Interview Guide	12

CONCEPTUAL FRAMEWORK	13
2.0 CHAPTER TWO: JUSTIFICATION OF THE STUDY	14
2.1 Research Question	15
2.2 Broad Objective	15
2.3 Primary Objectives	15
2.4 Secondary Objectives	15
3.0 CHAPTER THREE: STUDY DESIGN AND METHODOLOGY	16
3.1 Study Design	16
3.2 Study Setting	16
3.3.1 Targeted Healthcare professionals	16
3.3.2 Targeted caregivers	16
3.4 Inclusion Criteria for the Healthcare Professionals	16
3.5 Inclusion Criteria for Caregivers	17
3.6 Exclusion Criteria for Healthcare Professionals	17
3.7 Exclusion Criteria for Caregivers	17
3.8 Sample Size Estimation	18
3.9 Sampling	19
3.9.1 Sampling and recruitment of caregivers	19
3.9.2 Sampling and recruitment of healthcare professionals	19
3.10 Sampling Procedure for Providers for In-Depth Interviews	19
3.11 Study procedure	19
3.12 Definition of Study Variables	20
3.13 Independent Variables	21
3.14 Dependent Variables	21
3.15 Quality Assurance	21
3.16 Ethical Considerations	21
3.16.1 Independent Ethics Committee Approval	21
3.16.2 Informed Consent	22
3.16.3 Respondents Confidentiality	22
3.16.4 Disclosure of Information	22
3.17 Data Management	22
3.17.1 Data Collection	22
3.17.2 Data Handling	23
3.18 Data Analysis	23
4.0 CHAPTER FOUR: RESULTS	24

4.1 Flowchart of caregivers recruitment into the study.....	24
4.2 Flowchart of healthcare professionals recruitment into the study	24
4.3 Baseline details of healthcare professionals	25
4.4 Baseline details of caregivers.....	27
4.5 Awareness on kidney organ donation and transplant among caregivers	28
4.6 Attitude towards kidney organ donation and transplant among caregivers.....	30
4.7 Attitude towards kidney organ donation and transplant among healthcare professionals.....	32
4.8 Willingness of participants to sign up a will to be deceased donors	34
4.9 Results of key informants’ interview	35
4.9.1 Reasons that may prevent people from being living kidney donors.....	35
4.9.2 Factors that may make it easy to decide to donate a kidney	37
4.9.3 Reasons that will make individuals uncomfortable to write a will to be deceased donors	40
5.0 CHAPTER FIVE: DISCUSSION.....	42
5.1 CONCLUSION.....	46
5.2 RECOMMENDATIONS	46
5.3 LIMITATIONS	46
APPENDIX: QUESTIONNAIRE.....	47
Appendix V: Questionnaire in English.....	47
BIBLIOGRAPHY	50

LIST OF TABLES

Table 1: Transplant trends at KNH.....	6
Table 2: Conceptual Framework.....	13
Table 3: flow chart of caregiver’s recruitment	24
Table 4: caregivers recruitment flowchart	24
Table 5: Doctors characteristics.....	25
Table 6: Nurses characteristics.....	26
Table 7: Caregivers characteristics	27
Table 8: level of awareness among caregivers on kidney organ donation	28
Table 9: level of awareness on kidney transplant among caregivers	29
Table 10: attitude towards kidney organ donation among caregivers	30
Table 11: Attitude towards kidney organ transplant among caregivers	31
Table 12: attitude towards kidney organ donation among healthcare professionals.....	32
Table 13: Attitude towards kidney organ transplant among healthcare professionals ..	33
Table 14: willingness to sign up to be a deceased donor	34
Table 15: reasons that may prevent people from being living donors.....	35

Table 16: factors that may make it easy to decide to donate a kidney.....37
Table 17: reasons that will make individuals uncomfortable to write a will to be deceased
donors.....40

LIST OF ABBREVIATIONS

CKD-	Chronic Kidney Disease
DOCMT-	Department of Clinical Medicine and Therapeutics
ESRD-	End Stage Renal Disease
GFR-	Glomerular Filtration Rate
HCP-	Healthcare Professional
IRB-	Institution Review Board
KDIGO-	Kidney Disease Improving Global Outcomes
KNH-	Kenyatta National Hospital
NOTA-	National Organ Transplant Act
OPO-	Organ Procurement Organization
OPTN-	Organ Procurement and Transplant Network
SPSS-	Statistical Package for The Social Science
TDC-	Transplant Donor Coordinators
UNOS-	United Network for Organ Sharing
UoN-	University of Nairobi
VAS-	Visual Analogue Scale
WHO-	World Health Organization

ABSTRACT

Introduction to the Study

Kidney transplant is now the preferred renal replacement therapy in patients with end-stage renal disease. Most transplant programs worldwide are plagued with organ shortages. Awareness and attitude of healthcare professionals and the general public have been demonstrated severally to influence organ donation and transplant rates.

Objectives

To determine the level of awareness and attitude on kidney organ donation and transplant among caregivers and healthcare professionals at Kenyatta national hospital.

Methods and materials

This was a hospital based cross-sectional study that was conducted at Kenyatta national hospital in Kenya. The tools for the study comprised of a closed ended questionnaire that assessed attitude and awareness on a 5-point likert scale and in-depth interviews of key informants

Results

368 participants comprising of 245 caregivers and 128 healthcare professionals took part in the study. Among caregivers, 86% were aware that a living person can donate a kidney to a patient, 23% were aware that a patient can be transplanted with a kidney harvested from a deceased donor, 72% were willing to donate a kidney to a relative, 27% were willing to donate a kidney to a non-relative and only 21% were aware that a patient could be transplanted with a cadaveric kidney. Among healthcare professionals, 89% were willing to donate a kidney to a relative, 47% were willing to do the same to a non-relative, 95% were willing to accept a kidney from a living donor but only 12% were willing to accept a cadaveric kidney for transplant. 35% of caregivers and 48% of healthcare professionals were willing to sign up will to be deceased donors. The most common reasons against being a live donor and signing up will to be a deceased donor were concerns of health status post donation and definition of death by healthcare professionals respectively. The most favoured factor that can make it easy for people to be living donors was for the enhancement of knowledge publicly on kidney organ donation and transplant

Conclusion

Caregivers are aware on kidney organ donation however there is negative attitude towards altruistic kidney donation, deceased kidney organ transplant and willingness to sign up will to be deceased kidney donors among participants. Strategies should be put in place to change the attitude of healthcare professionals and caregivers towards embracing altruistic kidney donation both living and cadaveric and change their attitude to accept kidneys harvested from deceased donors for treatment of end stage renal disease.

1.0 CHAPTER ONE: INTRODUCTION

1.1 Background

By 2010, Chronic kidney disease was the 18th highest cause of death worldwide (1) WHO data published in May 2014 showed that kidney disease Deaths in Kenya reached 3,080 or 0.92% of total deaths (2)

It is estimated that by 2030, more than 70% of patients with end-stage renal disease will be living in low-income countries where the gross domestic product per person is on average less than 155,000 Kenyan shillings per year (3). This is majorly due to the rising prevalence of risk factors such as hypertension, type 2 diabetes, and the HIV pandemic. The huge cost implication of its treatment, its role in cardiovascular morbidity and mortality and the fact that the disease largely afflicts the economically productive younger age groups is a worrying trend (4) This estimation is unnerving in view of the fact that the global prevalence of maintenance dialysis has doubled since 1990, and that renal replacement therapy was accessed by 1.8 million people worldwide in 2004 with less than 5% of that population coming from sub-Saharan Africa (5) Despite kidney transplant being the best treatment modality for end stage renal disease, organ donation and transplant uptake in Africa has been low mainly due to availability of specialists, cultural and religious attitudes towards organ donation, trust in health systems and costs. (6)

The gateway to any good management of any condition starts with awareness. No studies have been done in Kenya to highlight the level of awareness and attitude on kidney organ donation and transplant. The gap that exists between dialysis and transplant in Kenya has been documented but as to the reasons why that gap exist has never been researched. In Africa, such studies have been carried out in Nigeria (7-9) with the aim of trying to close that gap through well informed targeted awareness and education campaigns. These kind of studies have been proven to be of benefit elsewhere in the world in formulating policy on how to approach transplant as a form of treatment by focusing and addressing the issues surrounding data collected on how people perceive transplant as a mode of treatment (10)

1.2 Literature Review

1.2.1 Kidney Failure Treatment: Dialysis vs. Kidney Transplant

World Health Organization (WHO) and kidney disease improving global outcomes initiative (KDIGO) both recommend kidney transplantation as the commonly recognized by consensus best treatment for end stage renal disease in terms of both quality of life and cost effectiveness. (11-13) Dialysis as an alternative treatment for end stage renal disease is not cost effective and the outcomes have also been documented to be inferior to kidney transplant (14).

It has been shown in various publications that survival rates in kidney transplant both living and deceased are higher than in maintenance dialysis. (15, 16)

1.2.2 Types of Kidney Donors.

All transplanted kidneys come from three sources: ⁽¹⁷⁾

- a) Deceased (or Cadaveric) Donor: This is a kidney which comes from a person who has just died and the family or donor had given permission for the kidneys to be donated for transplant.
- b) Living Related Donor: A kidney which comes from a blood relative such as a parent, brother or sister.
- c) Living Unrelated Donor: A donated kidney from someone not related to the person who needs a transplant such as a spouse or friend.

Donation in Kenya is currently limited to living related donors as no law has been enacted to address deceased and unrelated organ donations

1.3 Donor Selection Criteria

1.3.1 Living Donor

The generally accepted contraindications for living renal donation include reduced renal function, coercion, children below legal adulthood, hypertension, renal disease, malignant or infectious disease transmissible to a recipient, diabetes mellitus, significant cardiopulmonary disease, and significant urolithiasis(18) Upon consent, the donor undergoes laboratory, imaging and psychiatric evaluations to rule out any contraindications listed above.(19, 20) Living relative donor kidney is the option available for patients requiring kidney transplant in Kenya at the moment.

1.3.2 Deceased Donor

This option will be available in Kenya once all the policies have been drafted and the structures set in place as per health bill 2016. Kenya will become the third country in Africa after South Africa and Tunisia that will have laws allowing for deceased organ donation. (21) The criteria for deceased donor selection is always set by the transplant program in a particular country in line with laws governing the same

1.4 Graft Survival: Deceased vs. Living Kidney

Kidney grafts from living donors have shown better short-term related complications and longer graft survival rates than kidneys from deceased donors. (22, 23). This is largely due to effect of brain death on the kidneys before they are harvested i.e. hypoxia, ischemia and electrolyte changes that accompanies brain death. Storage in ice before transplant also interferes with normal physiological parameters of the harvested kidneys.

1.5 Kidney Organ Donation and Transplant Statistics

1.5.1 International Statistics

The first successful kidney organ transplantation is said to be between identical twins performed in Boston on 23 Dec 1954. (24) Data from the united network for organ sharing shows that 410,064 kidney transplants have been done from 1988 to march 2017 worldwide. (25) In Africa, Nigeria, South Africa and Egypt experienced a rise in kidney transplants largely due to establishment of nationwide transplant programs. It is worth noting that the same countries experienced kidney organ shortage due to a rise in the number of patients needing kidney transplant. (26)

1.5.2 Kenyan Statistics

Kidney transplantation in Kenya is limited to living donation. The statistics below are from the renal unit Kenyatta national hospital for the period 2010-2016. All the donors so far documented have been from related donors only.

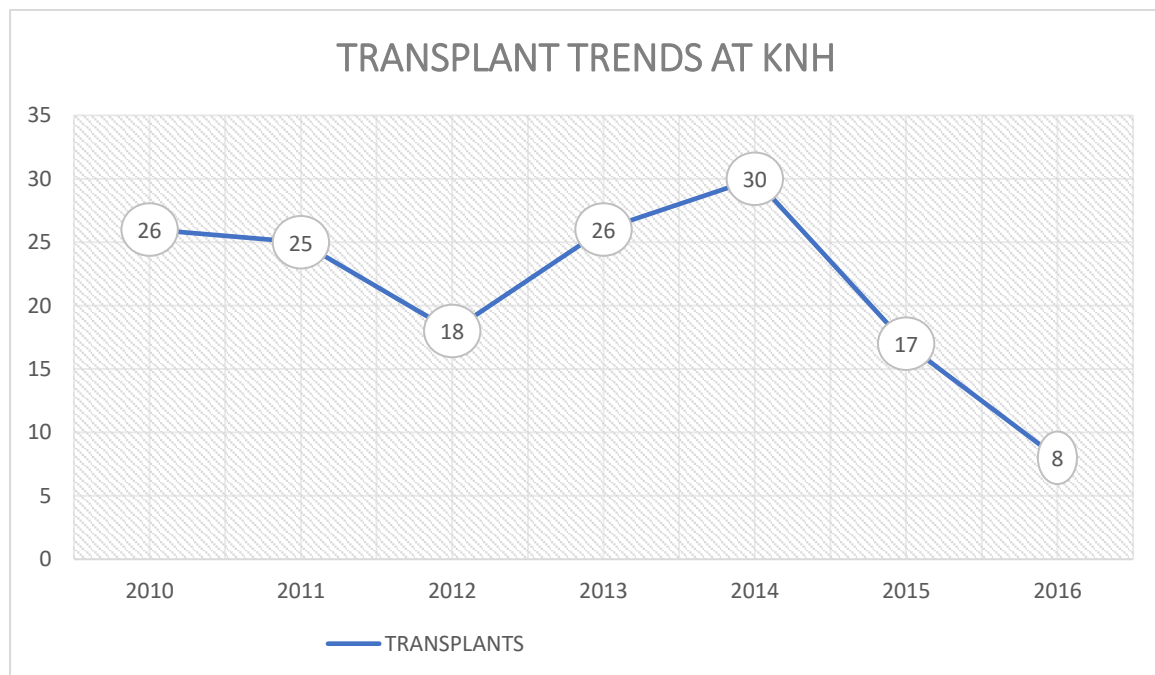


Table 1: Transplant trends at KNH

1.6 Kidney Organ Donation and Transplant Procedure at Kenyatta National Hospital

Donation and transplant of kidneys is under the renal unit at Kenyatta national hospital. The unit has five nephrologists and 23 nurses trained in renal medicine. It has one trained organ and tissue transplant nurse, 2 counsellors, 3 nutritionists, a fully equipped laboratory and its own health records unit. Before dialysis is commenced at Kenyatta national hospital, the relatives of the patients undergo counselling at the renal unit under the renal counsellor to be educated on the procedure, health implications, cost and treatment alternatives before the patient starts on hemodialysis,

If the patient opts for kidney transplant after being stabilized on hemodialysis, the family and the patient visit the transplant coordinators office where they undergo further counselling before volunteers come out to be matched.

The pre-transplant procedure involves six visits i.e. one weekly visit by both the donor and the recipient(s) depending on their finances before a date for transplant is set.

1.7 The Roles of Healthcare Professionals in Kidney Organ Donation Process

- a) Identification of patients who need renal replacement therapy by taking history, undertaking clinical examination and investigating with laboratory parameters and medical imaging
- b) Analyzing the extent of organ failure by use of clinical, laboratory and imaging modalities
- c) Discussing treatment options and giving sound advice on the best treatment plan with the patients and relatives
- d) Answering all questions raised by the concerned parties on the illness, modes of treatment, process of kidney organ donation and transplant, complications and prognosis
- e) Identification of potential donors both living and deceased and assessing their organ viability for donation
- f) Counselling both the donors and recipients on organ donation and transplantation and obtaining consent for both procedures if a match is confirmed
- g) Doing pre-transplant workup for both the donor and recipient and pre-transplant assessment of a deceased organ

1.8 Awareness and Attitude of Healthcare Professionals on Kidney Organ Donation and Transplant

Healthcare professionals are the first in contact with patients who are in end stage kidney disease at the setting of health facilities. They are in a position to diagnose and manage such patients and hence have influence on what kind of treatment modality the patient will chose based on what advice they give to the patient. Perceptions and awareness of the healthcare professionals on kidney organ donation and transplant have been demonstrated severally to influence on what advice they give to the patients. (27, 28).

In a study conducted in Saudi Arabia to assess awareness and attitude on kidney organ donation and transplant by healthcare professionals in 2012 (29), majority of the healthcare professionals supported organ donation; physicians (89.0%), nurses (82.3%). There was however negative attitude among the physicians to donate a kidney to a family member i.e. 24% physicians and 20% nurses respectively. Though majority supported organ donation, majority had negative attitude towards deceased kidney organ donation as more than half of the physicians (51.3%), nurses wanted to be buried with all their organs intact. Religion did not have any impact on willingness to donate kidneys.

In a study conducted among healthcare workers in three tertiary hospitals in south west Nigeria by Adejumo et al (8) A total of 563 CGs and HWs took part in the study. Sixty percent of them were aware of kidney donation (KD) but only 43.7% had a favorable attitude towards it, and these were predominantly HWs (63.4% vs 33.1%, $P < .001$). A quarter of the participants were adequately willing to donate a kidney; HWs were significantly more willing than CGs (45.4% vs 15.8%, $P < .001$). The study showed that very few caregivers were aware of the laws allowing for and governing organ donation and transplant in the country as compared to the healthcare professionals. This study concluded that there is a low level of willingness alongside negative attitudes toward kidney donation among our participants.

Another study to find out the willingness to donate kidneys by healthcare workers in Nigeria by Agaba et al (30) showed that majority (93.3%) of participants had heard of organ donation; 82.5% had desirable knowledge. Only 29.5% and 39.4% would be willing to donate and counsel potential organ donors, respectively; 36.5% would consider signing organ donation cards. Only 19.4% believed that organ transplantation is often effective and 63.4% believed they were permitted by their religion to donate.

Permission by religion (OR 3.5; 95% CI 2.3 to 5.3), good knowledge (OR 2.9; 95% CI 1.4 to 5.7), readiness to sign donation cards (OR 2.6; 95% CI 1.7 to 3.8), discuss organ donation (OR 2.7; 95%CI 8.0 to 63.8), and knowing somebody who had donated (OR 2.9) independently influenced willingness to donate organ. It concluded that there is disparity in knowledge of organ donation and willingness to donate among health care workers. Efforts should be intensified to give comprehensive and appropriate education to health care workers about organ donation to bridge this gap

In a study to evaluate attitude and awareness toward cadaveric kidney organ donation in southern Nigeria by Agwu et al in 2018 (31) on 470 respondents, showed that while almost all the respondents (98.1%) were aware of deceased kidney donation, only about half (51.9%) were willing to accept deceased kidney donation. Furthermore, 43.4% were willing to give consent to donate deceased relative's kidney, and 26.1% were willing to carry an organ donation card. Predictors of willingness to accept deceased kidney donation were male sex, being a medical doctor or laboratory scientist and being a Moslem (Odds ratio >2 , $P < 0.05$). The major disincentives reported were fear that it may not work (42%) and fear of disease transmission (37.0%).

No Kenyan study has been undertaken to assess for the awareness and attitude of healthcare professionals toward kidney organ donation and transplant.

1.9 Awareness and Attitude of Caregivers on Kidney Organ Donation and Transplant

Knowledge, attitude and behavior are the key factors that influence rates of organ donation (32, 33). Culture and religion have also been documented to affect the decision-making process of organ donation among caregivers (34).

In a study done in Iran by Mahboob et al (35) among 79 respondents who were relatives of trauma patients at an emergency centre in Tehran, the results showed that 73.1% of participants agreed with organ donation. 62.0% of the studied people had positive view regarding organ donation and 34.2% of them well informed about. The major causes of disagreements were lacking of consent among relatives and religious beliefs. The most important causative factors for poor knowledge in this context were male gender and self-employed occupation. In addition, poor knowledge and self-employed job were two factors associated with inappropriate attitude toward organ donation.

This study was conducted at the emergency outpatient setting among relatives of patients who were potential cadaveric organ donors. Emotional factors at that setting could have influenced majorly on the responses got from the relatives. This study was conducted in a predominantly Muslim country where “organ-for-pay” is allowed by law.

In a similar study done in western India among the public by Manish et al (36) with 250 respondents. About 86% of participants were aware of the term organ donation but knowledge about its various aspects was low. 48% had heard about organ donation through medical fraternity, whereas only about 21% became aware through mass media. About 59% of the respondents believed there was a potential danger of donated organs being misused, abused or misappropriated. About 47% of the respondents said they would consider donating organs, while only 16% said they would definitely donate irrespective of circumstances. 81% of the respondents were of the opinion that consent for organ donation after death should be given by family members.

In a study to assess Knowledge of Kidney Donation Among Care Givers in Two Tertiary Hospitals in Southwest Nigeria by Adejumo et al (37) among 244 respondents, the proportion of respondents with adequate knowledge of kidney donation was 63.4%. In a similar study done in South Africa Pike at el (38) to assess the attitude the public has toward organ donation, 1299 urban white, 625 rural black and 826 urban black South Africans were examined. Eighty-nine per cent of white, 84% of rural black and 76% of urban black South Africans are prepared to donate their own organs.

All groups were willing to donate the organs of close relatives (76% white, 76% rural black and 67% urban black). Most people felt that this decision should be made by the person before death. Most black people (88%) felt that the race of both donor and recipient were irrelevant. Only 23% of black people were prepared to donate their corneas, compared with the 69% and 70% willing to donate their kidneys and heart respectively

No such study to assess awareness and attitude on kidney organ donation and transplant has been conducted in Kenya.

1.10 Does Change of Attitude and Improvement on Awareness Result to Increased Kidney Organ Donation Rates and Upsurge in Kidney Transplant?

Health care personnel have been considered as a key factor for the success or failure of transplant programs (39). Teresa J et al formulated a system redesign to address organ donation shortage in the united states of America through an initiative run in 95 hospitals. Before the Collaborative was created, responsibility for a hospital's organ donation performance was solely in the hands of the organ procurement organization (OPO) serving that institution.

The views and opinions of healthcare professionals on the donation process have facilitated the identification of potential donors and thus are highly influential in the way people think about the process. Attitudes and lack of knowledge among health care professionals have been identified as barrier and pivotal to successful organ donation. A study conducted in Malaysia in 2013 by Abidin et al (40) to address organ donation shortage found out that of the health care correspondents who participated in the survey those who could not diagnose brainstem death were 38.5%, those with no knowledge on how to contact the Organ Transplant Coordinator were 82.3%, and those who had never approached families of a potential donor were 63.9%. The study concluded that there was a general attitude of passivity in approaching families of potential donors and activating transplant teams among many of the health professionals. A misunderstanding of brainstem death and its definition hinder identification of a potential donor.

Educating health care personnel about organ donation and transplant can alter their attitudes, behavior and knowledge about the process positively that results in increased uptake of organ donation and transplant among patients with end organ failure. Through an article published in the British medical journal, Donald McGlade et al in (41) demonstrated through a pre and posttest model the participants' knowledge improved over the programme of study with regard to the suitability of organs that can be donated after death, methods available to register organ donation intentions, organ donation laws, concept of brain death and the likelihood of recovery after brain death. Changes in attitude post intervention were also observed in relation to participants' willingness to accept an informed system of consent and with regard to participants' behavior.

1.11 Study Questionnaire Review

The study instrument used was a provider administered questionnaire consisting of four parts [Appendix V: Questionnaire in English](#). It was adapted and modified from a validated questionnaire on caregivers and healthcare workers willingness to donate kidneys in Nigeria (7). One questionnaire with the same questions was used to evaluate awareness and attitude in both healthcare professionals and caregivers. The questionnaire was available in English for healthcare professionals and in either English and Kiswahili for caregivers.

Section A captured demographic data of the respondents

Section B Had four statements that assessed awareness of the respondent on kidney organ donation and transplant on a five-point Likert scale.

Section C Had four statements that assessed the respondents' attitude toward kidney organ donation and transplant on a five-point Likert scale.

Section D Had a 100mm visual analogue scale that was used to determine if the respondents were willing to sign up to be deceased donors. A cut off of 50mm and above was regarded as willing

1.12 Study Questionnaire Measure of Reliability

Upon approval to conduct the research, a pilot study consisting of forty two respondents as suggested by Connelly et al (42) which represent 10% of the intended study population was carried out by the principal investigator to test the reliability of the questionnaire to provide consistent results under similar conditions (43). Cronbach's alpha reliability coefficient was used to test for reliability. The reliability ratings of the awareness and attitudinal scales were 0.73 and 0.71 respectively

1.13 Study Questionnaire Measure of Validity

To ensure validity, the questionnaire was presented to the supervisor for review. Recommendations made were incorporated in the final questionnaire.

1.14 In-Depth Interview Guide

The key informant interview guide was generated with the input of my supervisors

CONCEPTUAL FRAMEWORK

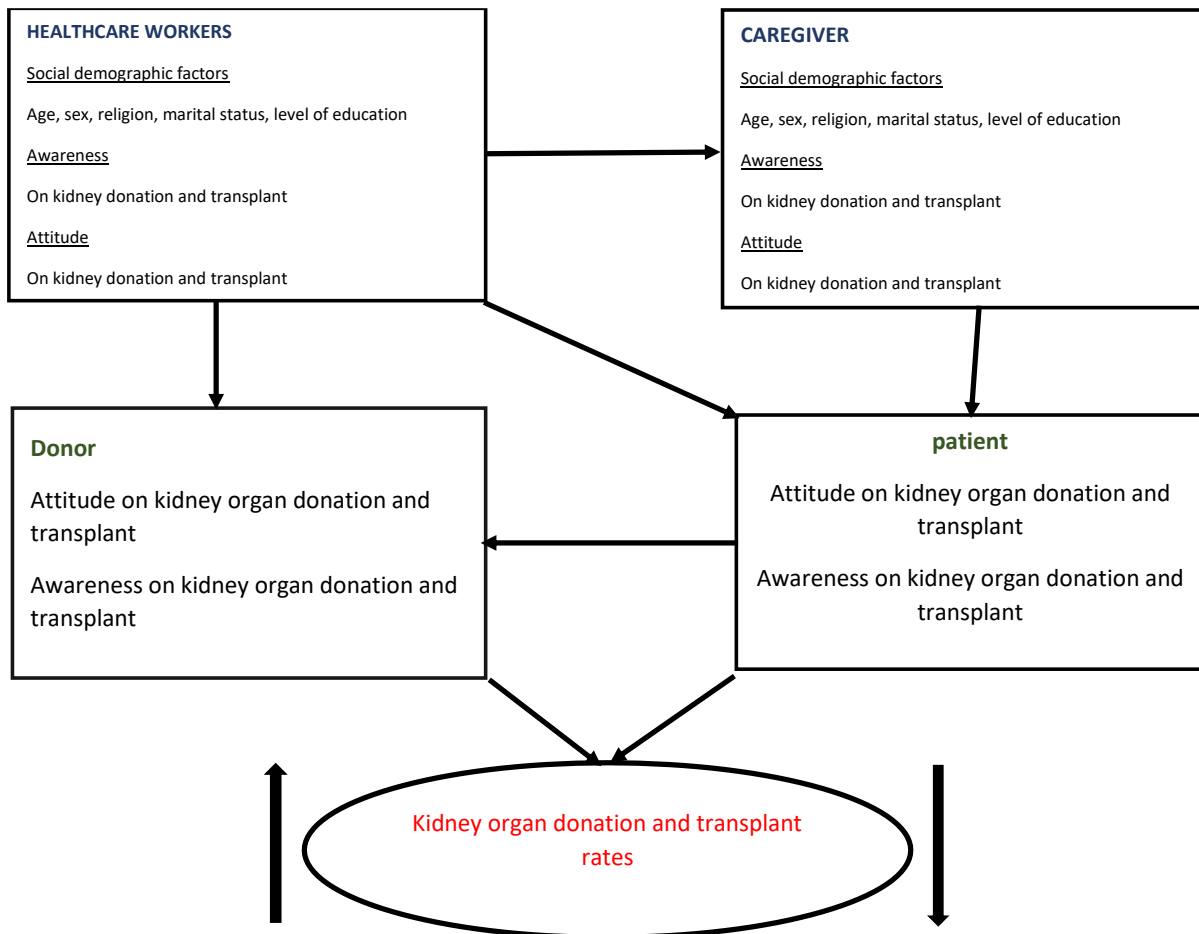


Table 2: Conceptual Framework

2.0 CHAPTER TWO: JUSTIFICATION OF THE STUDY

Awareness and attitude by both the healthcare workers and caregivers have been demonstrated severally to influence the rates of kidney organ donation and transplant (9, 44, 45) both positively and negatively.

Determining what both the healthcare professionals and caregivers know about kidney organ donation and transplant and their attitude on the same will go a long way to help formulate policies and guidelines that will shape future kidney transplant coordination activities

Healthcare professionals are not only strategically positioned as the primary intermediaries between organ donors and transplant recipients, but also professionally situated as the implementers of organ donation and transplantation processes. This favors positive impact as healthcare professionals will be at the centre stage in transplant programs as allowed in the Kenya health act of 2017. It has also been demonstrated that inadequate awareness among healthcare professionals as among the reasons that have underpinned global initiatives to increase organ donation rates among donors. As such, this study will help to determine the scope of understanding of organ donation and transplant by the public and healthcare workers and secondly, the findings generated can be utilized to shape policy on how the government will approach sensitization programs to increase organ donation and transplant rates in the country as we have no such study done in Kenya.

2.1 Research Question

What is the level of awareness and attitude of the healthcare professionals and caregivers towards kidney organ donation and transplant?

2.2 Broad Objective

To determine awareness and attitude on kidney organ donation and transplant among healthcare professionals and caregivers at kenyatta national hospital

2.3 Primary Objectives

- a) To determine the level of awareness and attitude among caregivers toward kidney organ donation and transplant
- b) To determine the attitude among healthcare professionals toward kidney organ donation and transplant

2.4 Secondary Objectives

- a) To determine the willingness of healthcare professionals and caregivers to sign up will to be deceased organ donors

3.0 CHAPTER THREE: STUDY DESIGN AND METHODOLOGY

3.1 Study Design

A hospital based cross-sectional study.

3.2 Study Setting

The study was undertaken at kenyatta national hospital in patient medical wards. The registered medical doctors and nurses working on these floors as per the register of the chief resident, department of clinical medicine and therapeutics for both university of Nairobi and Kenyatta national hospital were one and hundred and forty (**140**) **doctors** and one hundred and twenty (**120**) **nurses** respectively. Each ward has a capacity for **60 medical beds** bringing to a total of four hundred and eight (**480**) **beds** in the medical wards. All kinds of medical conditions are managed in these wards

3.3.1 Targeted Healthcare professionals

Registered medical doctors and nurses working at Kenyatta national hospital adult medical wards. The target group comprised of the consultants, registrars in training and registered nurses working in the medical wards in the 7th and 8th floors. A list of all doctors and nurses working in the medical wards were obtained from the administrative departments of the university and kenyatta national hospital.

3.3.2 Targeted caregivers

Caregivers to patients in the medical wards at kenyatta national hospital. They were identified by the principal investigator obtaining next of kin contacts from the patients files and making contact through telephone for possible recruitment into the study during visiting hours.

3.4 Inclusion Criteria for the Healthcare Professionals

- Registrered medical doctors and nurses working in the in pateint medical wards at kenyatta national hospital

3.5 Inclusion Criteria for Caregivers

- Caregivers who are 18yrs and above who are in the company of patients or with patients at kenyatta national hospital medical wards
- Caregivers who fulfill the above criteria and consent to be respondents

3.6 Exclusion Criteria for Healthcare Professionals

- Medical doctors and nurses permanently working in the renal unit at kenyatta national hospital to avoid bias

3.7 Exclusion Criteria for Caregivers

- Caregivers of patients with kidney conditions undergoing dialysis or awaiting transplant
- Caregivers with cognitive impairment and those who decline to consent to the study

3.8 Sample Size Estimation

Sample size for this study was derived using Cochran's formula for descriptive studies (46).

$$N = \frac{Z^2 pq}{d^2}$$

Z = usually set at 1.96 which corresponds to the 95% confidence interval

P = the proportion in the study population estimated to be aware of kidney donation from previous study on caregivers and healthcare workers willingness to donate kidney in three tertiary institutions in southern Nigeria that had a total of 563 correspondents was 60.8% Abiodun et al (47) was used.

$$q = 1.0 - p$$

d = degree of accuracy desired, usually set at 0.05

$$\frac{Z^2 pq}{d^2} = \frac{(1.96)^2 \times 0.6 \times (1 - 0.6)}{(0.05)^2} = 368$$

$$n = 368$$

The caregiver-to-healthcare professional recruitment ratio was set at **2:1 as applied in a similar study in Nigeria (7)**

As such the number of caregivers targeted was **245** while the targeted healthcare professionals was **123**.

3.9 Sampling

3.9.1 Sampling and recruitment of caregivers

Two hundred and forty five (**245**) **caregivers** were divided proportionally by simple stratified sampling into thirty one (**31**) **caregivers** equally to each of the eight medical wards.

In each ward they were randomly sampled into the study by use of the patient register in the wards till the target sample size was achieved

3.9.2 Sampling and recruitment of healthcare professionals

One hundred and twenty three (**123**) **doctors and nurses** were divided proportionally by stratified sampling into sixteen (**16**) **equally to each of the eight medical wards**

The doctors to nurses ratio was set at **1:1**

List of the doctors and nurses working in each respective wards was obtained from the doctor and nurse in charge of the ward. They were randomly sampled into the study until target sample size was achieved

3.10 Sampling Procedure for Providers for In-Depth Interviews

Two doctors, four nurses and six caregivers were chosen by purposive sampling to participate in the in-depth interviews. Five In-depth interviews were conducted before saturation was detected (48)

3.11 Study procedure

A list of all medical doctors and nurses working in the medical wards on the 7th and 8th floors was obtained from the respective administrative offices from the university of Nairobi and Kenyatta national hospital.

List of the doctors and nurses working in each respective wards was obtained from the doctor and nurse in charge of the ward at the time of study.

Two hundred and forty five (245) caregivers were divided proportionally by simple stratified sampling into thirty one (31) caregivers equally to each of the eight medical wards.

One hundred and twenty three (123) doctors and nurses were divided proportionally by stratified sampling into sixteen (16) equally to each of the eight medical wards

The doctors to nurses ratio was set at 1:1

List of the doctors and nurses working in each respective wards was obtained from the doctor and nurse in charge of the ward. They were randomly sampled into the study until target sample size was achieved

A study proforma was used to collect data on the demographic variables including age, sex, marital status and level of education from the eligible participants.

A structured questionnaire was then interviewer administered to obtain data on awareness towards kidney organ donation and transplant on section B and attitude towards kidney organ donation and transplant on section C. Willingness to be sign up will to be a deceased donor was collected using a visual analogue scale on section D

3.12 Definition of Study Variables

Caregiver

A caregiver is the person who takes responsibility for someone who cannot fully take care of themselves. It may be a family member, a trained professional or another individual who fundamentally is on close contact with the person receiving treatment.

Healthcare Professional

Is an individual who has undergone training in a medical/nursing school and certified by the respective licensing board to provide preventive, curative, promotional or rehabilitative health care services in a systematic way to people, families or communities.

Registrar

Is a licensed doctor who is undertaken a master degree program in a medical university to acquire knowledge and skills in a specialized field in medicine

Relative a person connected by blood or marriage to the patient

Organ Donation

Is the process of surgically removing an organ or tissue from one person (the organ donor) and placing it into another person (the recipient)

3.13 Independent Variables

- Age
- in years
- Sex – will be either male or female
- occupation
- Religion
- Marital status
- Education level

3.14 Dependent Variables

- Level of awareness on kidney organ donation and transplant
- Attitude on kidney organ donation and transplant
- Willingness to donate or accept a kidney

3.15 Quality Assurance

Research assistants were trained about the tool to be used through role play and simulations. They were taught on how to approach the respondents, how to take consent, how to administer the questionnaire and how to store the data collected to maintain confidentiality.

3.16 Ethical Considerations

3.16.1 Independent Ethics Committee Approval

The study protocol was submitted for ethical review upon approval by the Department of Clinical Medicine and Therapeutics. The Kenyatta National Hospital and University of Nairobi ethics and research committee gave approval for the study to be conducted. The informed consent, respondent information sheet and any other written information that was provided to respondents were granted approval

3.16.2 Informed Consent

The investigator took full responsibility to obtain written informed consent from the respondents. All respondents taking part in this study continue with their duties and no coercive methods were used to influence their participation in this study

3.16.3 Respondents Confidentiality

The investigator ensured that the respondent's confidentiality was maintained. No patient identifiers were used on the questionnaire. No confidential information obtained from the respondents was disclosed to any other parties without the respondent's consent. No data obtained from this study was used for any other purpose other than meeting the objectives stated in this dissertation. The questionnaires were stored in a lockable cabinet accessible to the principle investigator alone. At the completion of the study all data collected soft and hard were submitted to the department of clinical Medicine and Therapeutics for follow up studies after which can be destroyed after 5 years.

3.16.4 Disclosure of Information

In order to allow the use of the information derived from this study, the investigator understood that he had the obligation to provide complete results and all data generated from this study to the department of medicine of University of Nairobi and KNH in order to aid in policy change. Verbal or written discussions of the results will be made to the patient or their legal representative.

3.17 Data Management

3.17.1 Data Collection

Data on demographics, awareness and attitude was collected using a predesigned questionnaire that was issued by the researcher to the respondent

Key informant interviews were recorded with an audio recorder for analysis after the interview

3.17.2 Data Handling

Confidentiality of participants was maintained throughout the study. Potential identifiers such as names were replaced by serial numbers. Questionnaires were kept in lockable cabinets only accessible to the principal investigator, the study supervisors, the DOCMT and the IRB upon request. Data was entered into a password protected database

3.18 Data Analysis

The data was analyzed using SPSS version 20.0 statistical software for Windows (IBM, Armonk, N.Y., United States). Doctors and nurses were analyzed together as healthcare professionals

Demographic characteristics of the study population was analysed and presented as numbers and percentages.

For objective one, the data on awareness and attitude among caregivers toward kidney organ donation and transplant was analyzed by use of proportions and percentages.

Responses of “strongly agree” and “agree” were cumulatively considered to be aware while responses of “disagree” and “strongly disagree” were cumulatively considered not aware. Responses of “very willing” and “willing” were cumulatively considered as positive attitude while responses of “unwilling” and “totally unwilling” were considered cumulatively as negative attitude.

For objective two, the data on attitudes towards kidney organ donation and transplant among healthcare professionals was analyzed by use of proportions and percentages. Responses of “very willing” and “willing” were cumulatively considered as positive attitude while responses of “unwilling” and “totally unwilling” were considered cumulatively as negative attitude.

On objective three, willingness to sign up to be deceased donors was analyzed into proportions and percentages

Key informant interviews were recorded. audio scripts and notes taken were transcribed by the principal investigator and the qualitative data was analysed according to the emerging themes

4.0 CHAPTER FOUR: RESULTS

4.1 Flowchart of caregivers recruitment into the study

Table 3: flow chart of caregiver’s recruitment

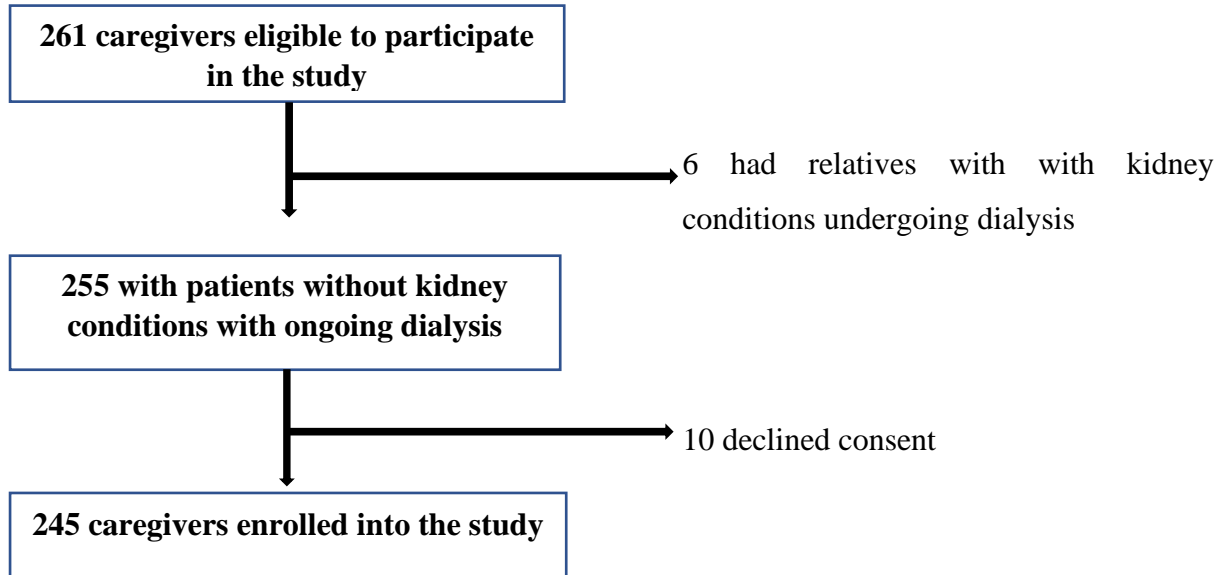
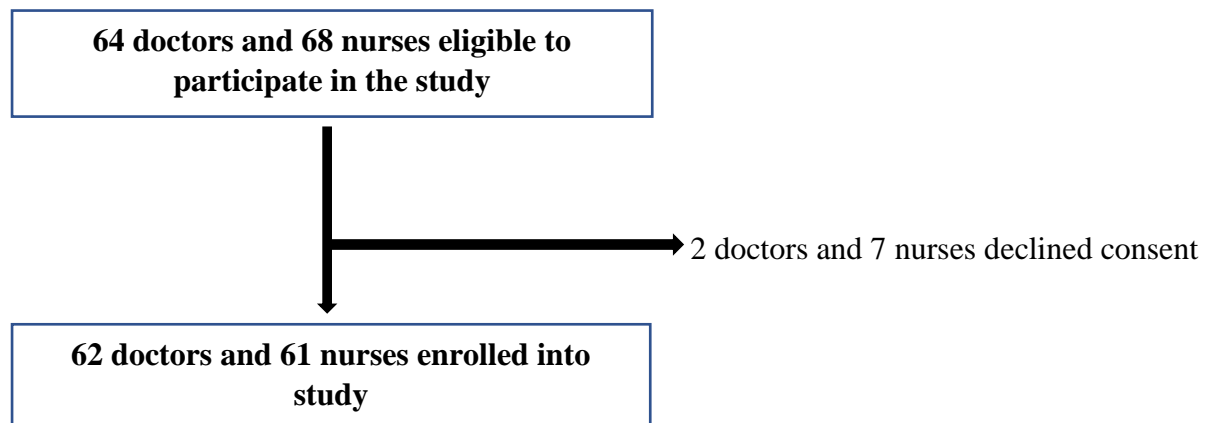


Table 4: caregivers recruitment flowchart

4.2 Flowchart of healthcare professionals recruitment into the study



4.3 Baseline details of healthcare professionals

Table 5: Doctors characteristics

Variable	Category	Number	Proportions in %
Titles	Consultants	2	3.22
	registrars	56	90.32
	Medical officers	4	6.45
Age group	21-30	7	11.3
	31-40	53	85.5
	41-50	2	3.2
Sex	Male	26	41.9
	Female	36	57.1
Religion	Christianity	56	90.3
	Islam	4	6.5
	Hindu	2	4.2
Marital Status	Married	27	43.5
	Single	35	56.5

Baseline details for doctors

62 doctors were recruited in the study. The mean age for doctors was 34.5 ± 5.2 . The male to female ratio was 1:1.93. They were predominantly Christians (90.3%), single (56.5%)

Table 6: Nurses characteristics

Variable	Category	numbers	Proportions in %
Age group	21-30	34	42
	31-40	12	30.2
	41-50	13	13.5
	51-60	2	7
Sex	Male	14	49
	Female	47	51
Religion	Christianity	60	94.7
	Islam	1	5.3
	Hindu	0	0
Marital Status	Married	47	64.5
	Single	11	30.2
	Divorced	2	2
	Widowed	1	3.3

Baseline details for nurses

61 nurses were recruited in the study. The mean age for nurses was 33.5 ± 4.7 . The female to male ratio was 3.35:1. They were predominantly Christians (89.4%), married (63.4%).

4.4 Baseline details of caregivers

Table 7: Caregivers characteristics

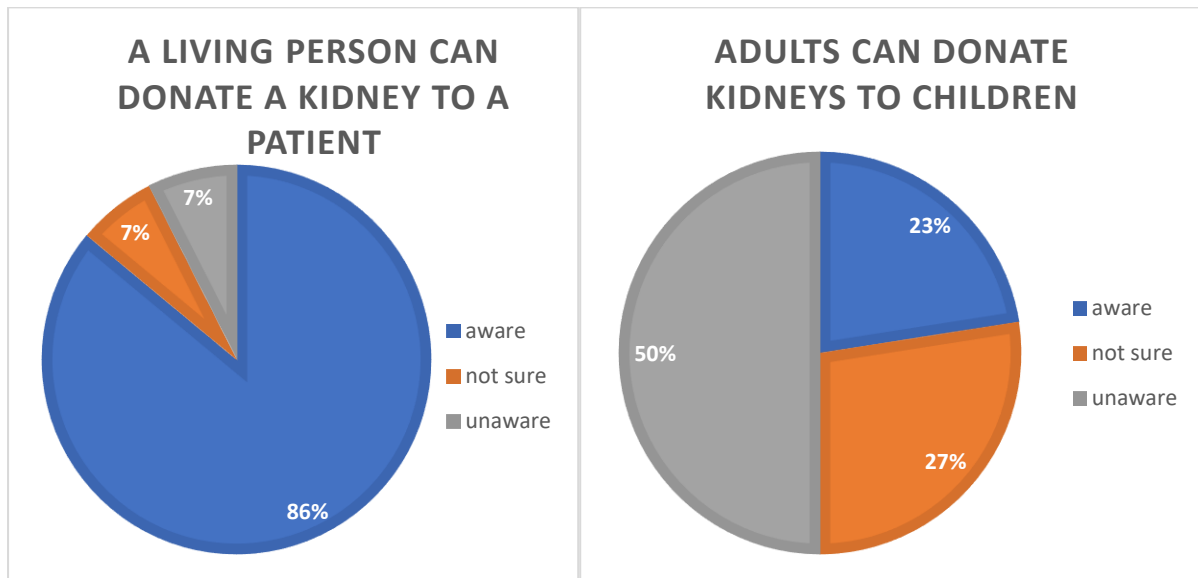
Variable	Category	numbers	Proportions in %
Age group	<=20	12	4.9
	21-30	103	42
	31-40	74	30.2
	41-50	33	13.5
	51-60	17	7
	61-70	6	2.5
Sex	Male	120	49
	Female	125	51
Religion	Christianity	232	94.7
	Islam	13	5.3
	Hindu	0	0
Marital Status	Married	158	64.5
	Single	74	30.2
	Divorced	5	2
	Widowed	8	3.3
Education level	Primary	41	16.7
	Secondary	96	39.2
	Tertiary	108	44.1
Employment status	Employed	91	37.1
	Unemployed	154	62.9

Baseline details of caregivers

A total of 245 participants comprising of 66.6% of the study population took part in the study. The mean age for caregivers was 34.07 ± 10.6 . The male to female ratio was 1:1. They were predominantly Christians (94.7%), married (64.5%), with a tertiary level of education (44.1%) and unemployed (62.9%).

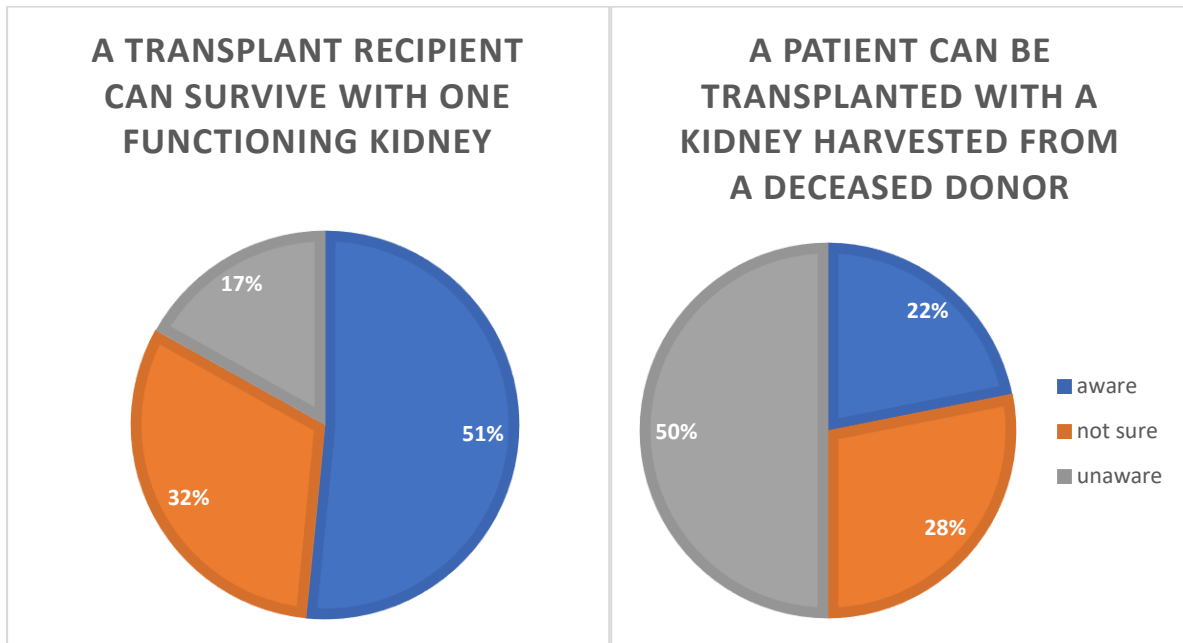
4.5 Awareness on kidney organ donation and transplant among caregivers

Table 8: level of awareness among caregivers on kidney organ donation



While 86% of the caregivers reported that they were aware that a living person can donate a kidney to a patient. 7.4% were not aware and 6.6% did not know that a living person can donate a kidney to a patient. 50% did not know that adults could donate kidney to children, only 22.5% knew that and 27.5% were not sure.

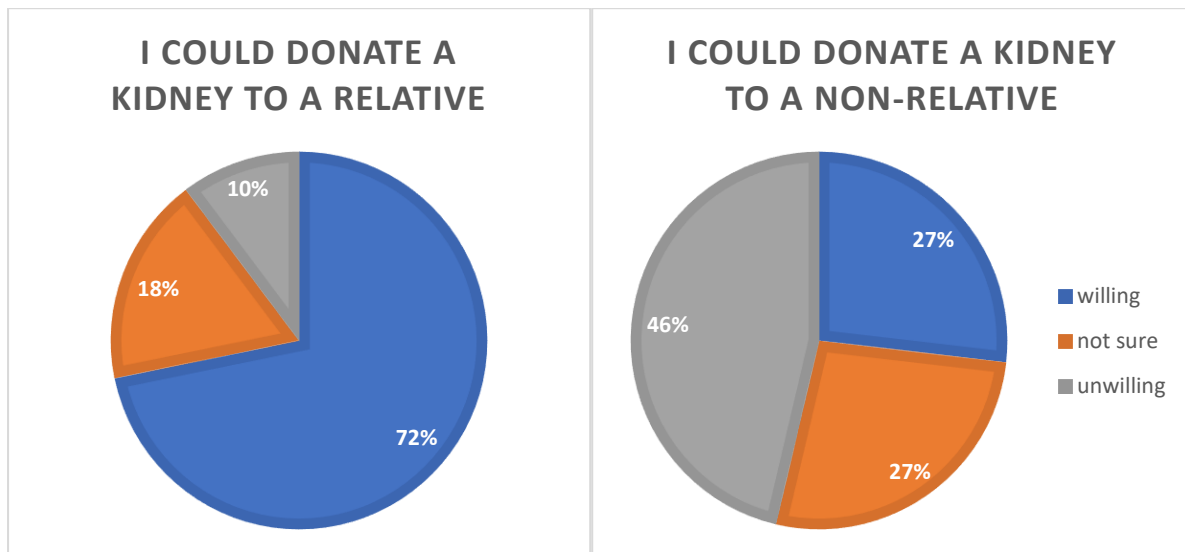
Table 9: level of awareness on kidney transplant among caregivers



52% of the caregivers reported that they knew that transplant recipients could survive with one functioning kidney, 17% did not know and 32% were not sure. On the contrary, 52% reported that they did not know that patients could be transplanted with kidneys harvested from deceased donors. Only 21% knew that while 27% were unsure about it.

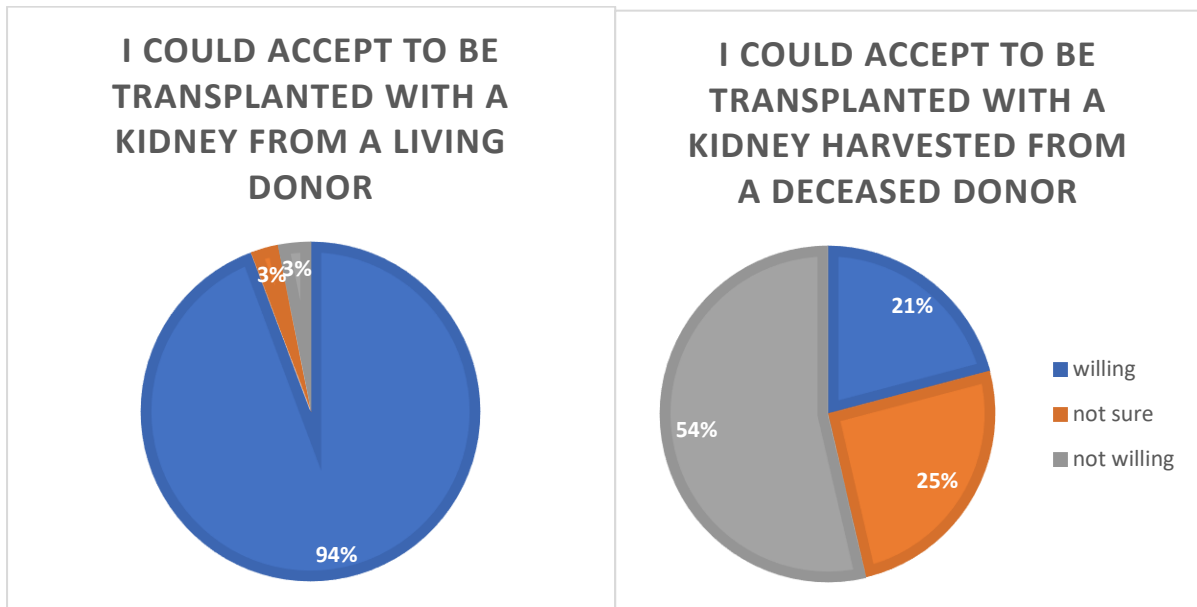
4.6 Attitude towards kidney organ donation and transplant among caregivers

Table 10: attitude towards kidney organ donation among caregivers



71.8% of the caregivers were willing to donate a kidney to a relative, only 10.3% were not willing and 18% not sure if they could donate to a relative. Only 26.8% reported their willingness to donate a kidney to a stranger while the majority at 46.3% were not willing to do the same.

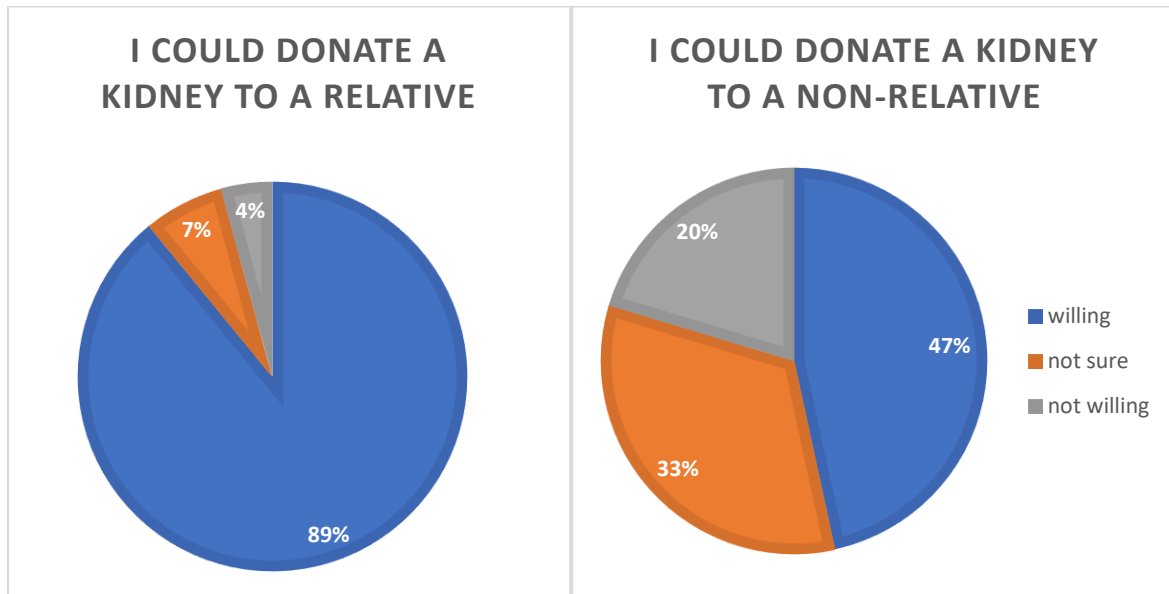
Table 11: Attitude towards kidney organ transplant among caregivers



94.3% of the caregivers reported of their willingness to be transplanted with a kidney from a live donor. Only 3.3% were not willing to accept a kidney from a live donor and 2.6% were unsure if they could accept that. Most of the caregivers (53.6%) were not willing to be transplanted with a kidney harvested from a deceased donor. Only 21% were willing to accept a kidney harvested from a deceased donor.

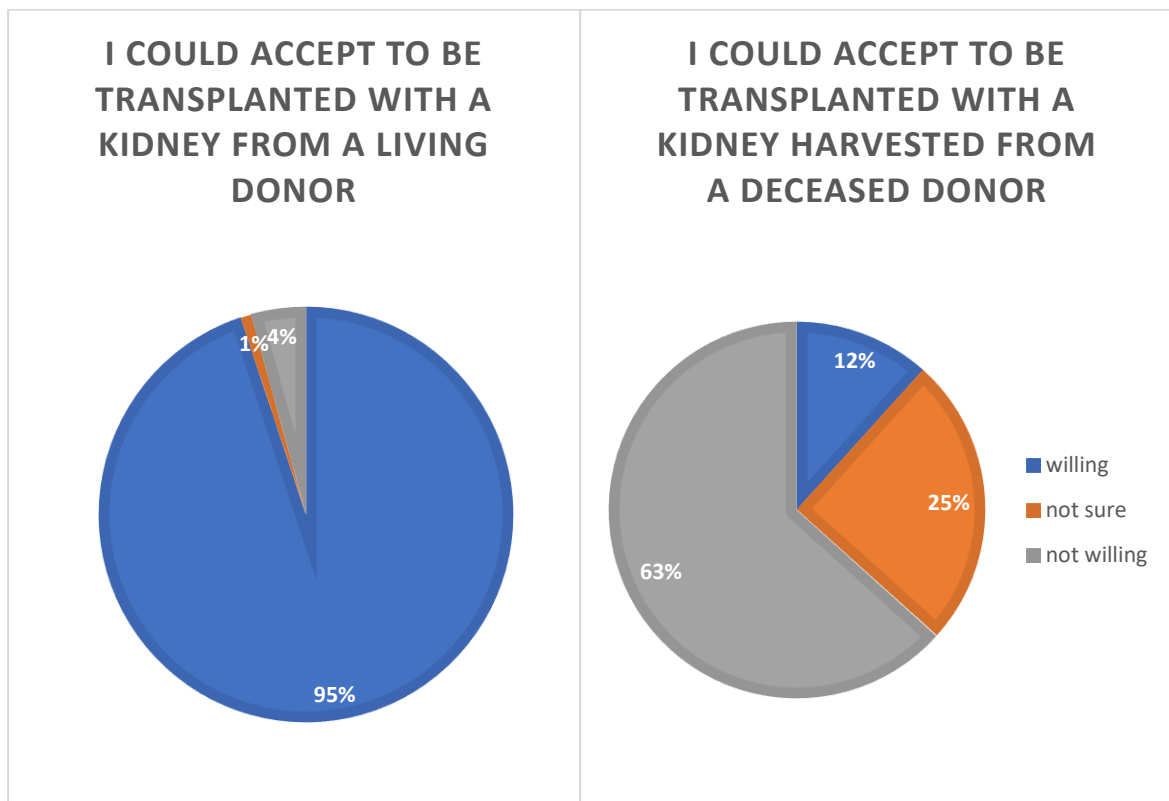
4.7 Attitude towards kidney organ donation and transplant among healthcare professionals

Table 12: attitude towards kidney organ donation among healthcare professionals



Among the healthcare professionals, 89.1% were willing to donate a kidney to a relative. Only 4.2% of the respondents were not willing to donate a kidney to a relative and 6.7% were not sure. Majority of the healthcare professionals at 46.6% were not willing to donate a kidney to a non-relative. Only 20.3% were willing to donate to a non-relative while 33.1% were not sure if they could make that decision.

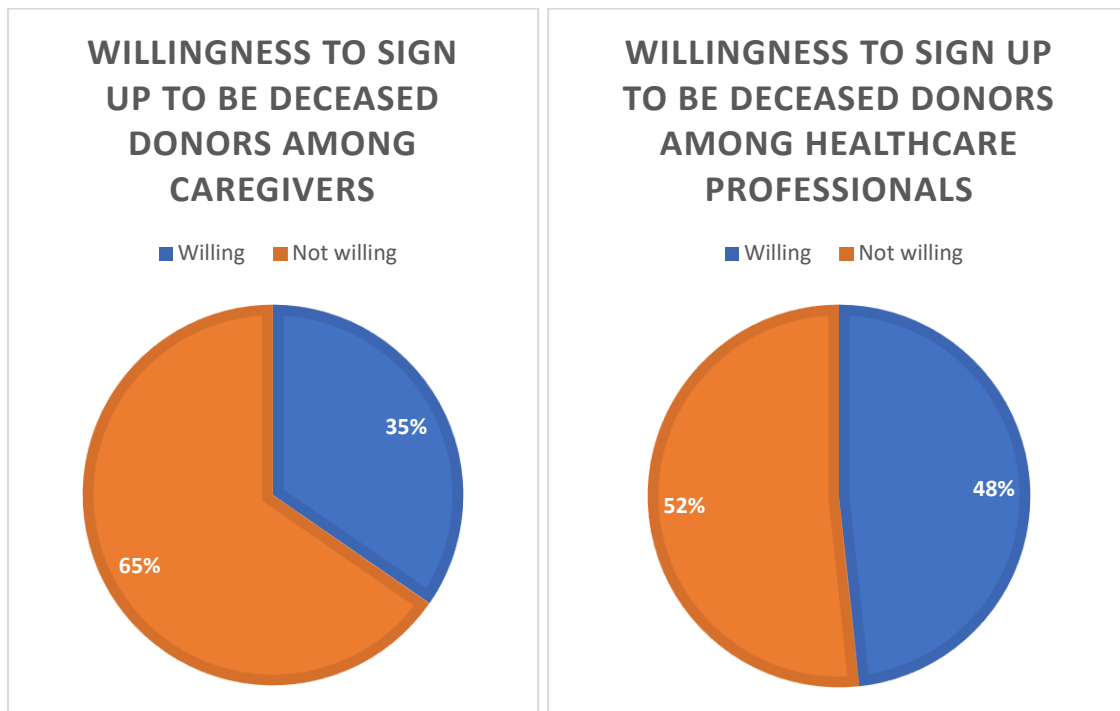
Table 13: Attitude towards kidney organ transplant among healthcare professionals



Majority of the healthcare professionals at 94.9% were willing to accept a kidney from a live donor and only 4.2% were not willing to accept that, only one respondent was undecided on that decision. Majority comprising 63.3% were not willing to accept a kidney harvested from a deceased donor for transplant. Only 11.9% were willing to accept kidney from a deceased donor while 25% were not sure if they would accept a kidney from a deceased donor.

4.8 Willingness of participants to sign up a will to be deceased donors

Table 14: willingness to sign up to be a deceased donor



From the above data, 39.5% of the respondents in overall were willing to sign up to be deceased donors. Among healthcare professionals, only 48. % of participants were willing to be deceased donors while 35% among caregivers were willing to do the same. Overall, the attitude towards signing up to be deceased donors was unfavorable.

4.9 Results of key informants' interview

Twelve participants were recruited to participate in these interviews and comprised of two medical doctors, four nursing officers and six caregivers. A total of six in-depth interviews were carried out before saturation was detected. The section was divided into 3 parts

-Reasons that may prevent people from donating kidneys

-Factors that may make it easy for people to make decision to donate kidneys

-Reasons that will make individuals uncomfortable to write a will to be deceased donors

Themes that arose from the interviews were coded and thematic analyses was conducted under each sub section

Table 15: reasons that may prevent people from being living donors

4.9.1 Reasons that may prevent people from being living kidney donors

Themes have been arranged in order of most concerning to least concerning

number	Main themes
1	Concerns on health status post donation
2	Fear and uncertainty regarding the donation process
3	Lack of adequate public knowledge and information regarding kidney organ donation and transplant
4	Acceptance by family to donate
5	Cultural restrictions
6	Religious restrictions

The extracted themes in order of concern that could prevent people from being kidneys donors were health status post donation, fear of donation process, inadequate public knowledge on donation and transplant, acceptance of will by family. Religion and culture were not of concern as impediments to kidney organ donation by the respondents

Concerns on health status post donation

It came out clearly that most respondents were not comfortable of the health status of their bodies post donation.

Excerpt 1

Caregiver by the name Mr. D.L whose brother was a patient admitted in one of the medical wards

“What if my one remaining kidney fails? Sasa ata mimi nitaanza kutafuta mtu anipee figo (so you mean i will also start to look for a person to give me a kidney if mine fails?)?”

Fear and uncertainty regarding the donation process

Concerns were raised regarding the donation process. They questioned how safe the procedure was

Excerpt 2

Caregiver by the name Miss. A.C whose daughter was a patient admitted in one of the medical wards

“What if I die on the table while they are removing one of my kidneys? What if they interfere with the other organs? Things go wrong during surgery, right?”

Lack of adequate public knowledge on kidney organ donation and transplant

It was clear that many respondents decried of the little information that is out there concerning chronic kidney disease and its treatment

Excerpt 3

Caregiver by name Mr. T.O who was a workmate to a patient admitted in one of the medical wards

“Mimi ata sikujua mtu anaweza kuishi na figo moja pekee. Shida yenu madaktari ni kutuambia hizi maneno mtu akiwa na mgonjwa hospitali. Hizi maneno tunatakikana kujua tukiwa huko nje” (personally i didn’t know someone can survive with only one functioning kidney. The problem with medics is you only get to inform us of such information when we have a sick person in hospital. We are supposed to be informed of such while we are out there)

Acceptance by family to donate

Some respondents alluded to the fact that the decision to donate a kidney might be a selfish venture that will have negative impact to the people dependent on the donor

Excerpt 4

A healthcare professional who has been working for 11 years

“I would not allow my daughter or son to donate a kidney to me. They are young and i am old. I cannot compromise their future because of my health”

4.9.2 Factors that may make it easy to decide to donate a kidney

Table 16: factors that may make it easy to decide to donate a kidney

Themes have been arranged in order of most concerning to least concerning

number	Main themes
1	Adequate public information on donation and transplant
2	Assured free post donation follow up and treatment
3	Proper counselling and assurance
4	Some form of financial incentive
4	Enacting laws that govern donation
6	Breaking cultural restrictions
7	Support of organ donation by politicians

The extracted themes in order of concern that could make it easier for an individual to a donate a kidney include, access to adequate information on kidney organ donation and transplant, guarantee of free healthcare post donation, proper counselling and inclusion of some form of financial incentives. Among the factors that could make it easy for individuals to donate kidneys, breaking cultural restrictions and having politicians support organ donation would have the least impact to rally people towards donating kidneys.

Adequate public information on donation and transplant

This point was highlighted over and over again as the single most important undertaking that should be addressed to increase rates of donation and transplant. It was decried that little information is out there regarding this kind of treatment

Excerpt 1

Mr. N.A who was a cousin to a patient admitted in one of the medical wards

“We see health campaigns for safe sex and polio vaccination on TV. I have never seen health education on chronic kidney conditions and its treatment modalities. You can imagine the amount of information relatives have to digest when they are told that their kin need a kidney. Where do they even start?”

Proper counselling and assurance

It came out that the medical professionals are the custodians of knowledge on how to treat various conditions. Interestingly most respondents believe that the medical professionals have the last say on treatment options. They felt that if well counselled and assured of their health post donation that could make many people to be comfortable to donate

Excerpt 2

Mrs. G.L whose wife was a patient admitted in one of the medical wards

“Bwana yangu ako na cancer ya damu. Tiluambiwa anahitaji kitu inaitwa bone marrow transplant. Vile huyo daktari msichana alituongolesha juu ya hiyo transplant ata mzee alipona kwa moyo. Matibabu si dawa pekee, vile mgonjwa na watu wake wanaongelehwa inasaidia sana. Ndugu yake ata alikubali kumtolea hiyo bone marrow”

(My husband has cancer of the blood. We were told that he needs bone marrow transplant. The way that female doctor talked to us about that treatment my husband even felt healed already. Treatment is not just medicine to swallow. The way a sick person is talked to helps a lot. His brother even agreed to be the donor)

Guaranteed donation and post donation care and treatment

Most respondents alluded that if those who are willing to be donors could get all their costs covered including a health cover for life after donation, that will really help to increase donation rates.

Excerpt 3

A healthcare professional in one of the medical wards

“I strongly feel that if the burden of healthcare cost is removed from those who are willing to donate to be covered by the government fully it will go a long way to make people comfortable to donate. That will be a vote of confidence to the public that now that you have one kidney the government can put you in a program to ensure your well-being to prevent any circumstances to befall you as the donee”

Some form of financial incentives

Ideas like some form of incentives either in cash or tax breaks would encourage people to donate they said

Excerpt 4

Mr. J.E whose brother was a patient admitted in one of the medical wards

“Let the government say that donors will be given some cash or tax break of some sort and see how hospitals will flock with donors. We are Kenyans, we love money”

4.9.3 Reasons that will make individuals uncomfortable to write a will to be deceased donors

Table 17: reasons that will make individuals uncomfortable to write a will to be deceased donors

Themes have been arranged in order of most concerning to least concerning

Number	Main themes
1	Mistrust of medical staff regarding confirmation of death
2	Acceptance of will by family and community
3	Mistrust of medical staff regarding right use of the organs
4	Doubts if the organs will work
5	Spread of diseases
6	Mischief by powerful people to kill those signed up to get organs

The extracted themes in order of concern that could make it difficult for individuals to feel uncomfortable to sign wills to be deceased donors include the definition of death, acceptance of will by family , concerns of right use of the organs and doubt about the viability of those organs. What ere not so concerning were spread of diseases and mischief by powerful people to kill those signed up to get organs

Mistrust of medical staff regarding confirmation of death

This issue became a recurring issue from most respondents. The sticking question of when is it really that someone is pronounced dead.

Excerpt 1

Mr. O.M who was a father to a patient in one of the medical wards

“we have heard of people waking up in the morgues and they had already been pronounced dead by the doctors. This is a very scary issue to imagine that i am being cut out alive just so that my organs can be used to save someones elses life ”

Acceptance of will by family and community

Most respondents said that it can be every easy for them to write a will to have organs harvested off them when they die but most were sure that their families and communities where they come from will not agree to their wishes

Excerpt 2

A healthcare professional working in one of the medical wards

“I cant even imagine how my dad will react to find out that I have written a will to have organs extracted off me when i die. He will tear that paper into pieces and say that i had gone mad when signing it. Most of our cultures wish to bury us intact if possible”

Mistrust of medical stuff regarding right use of organs

Mosr respondents were not comfortable with the fact that those in control of how the organs will be used will not be their relatives. Some decried that corruption could creep into the donation program

Excerpt 3

Mr. W.O who was a brother to a patient in one of the medical wards

“Uoga yangu ni kuwa corruption itaingia kwa hii program. “ (my fear is that corruption will creep into this donation program”

Cultural restrictions

Most respondents raised concerns that our cultures do not allow our bodies to be mutilated for any other purpose before they are buried.

Excerpt 4

Mrs. W.L who was a mother to a patient in one of the medical wards

“Ni jamii gani itakubali kuzika mwili yenye viungo zake zimetolewa? Huyo mtu atapumzika kweli?”

(which community will agree to bury a body with some organs missing? Will that person really rest?)

5.0 CHAPTER FIVE: DISCUSSION

In this study, 86% of the caregivers were aware that a living person can donate a kidney to a patient. This is similar to findings from a study done in Nigeria (7) in whose mean of 4.75 out of 5 on the likert scale were aware of the same. Both studies used similar questions to assess for the same. This is a positive pointer towards efforts to sensitize the public towards live kidney organ donation as a treatment modality for end stage renal disease,

On the question of if adults could donate kidneys to children, both studies and our findings showed that majority of the caregivers were not aware. This could be as result of inadequate knowledge in the public about the criteria of who can donate and receive kidneys in terms of age limits. Kenya and Nigeria do not have well coordinated interagency transplant programs that could centrally package the message of organ donation and transplant to the public. In a study on public knowledge and attitudes regarding organ and tissue donation: an analysis of the northwest Ohio community (49) among 1000 participants showed that 96% of the correspondents were aware on matters concerning tissue organ donation and transplant. The Ohio program shows well legislated programs can improve the level of awareness among its people.

Majority of the respondents were unwilling to accept a kidney from a deceased donor. This is in keeping with similar findings from a study on Awareness and attitude towards deceased kidney donation among health-care workers in Nigeria (31) That study used close ended questionnaires and was applied to all cadres of healthcare workers unlike in our study that was limited to doctor and nurses. The findings showed that barely half of the respondents (51.6%) were willing to accept a kidney from a deceased donor. Reasons as to why healthcare workers are unwilling to accept kidney from a deceased donors can only be speculative as they were beyond the scope of this study

Our results on the level of awareness towards kidney organ transplant among caregivers were similar with a study conducted in Nigeria (7). In our study, 51% were aware that a transplant recipient can survive well with one good functioning kidney while on the contrast , half the respondents were also unaware that a patient can be transplanted with a kidney harvested from a deceased donor. In that study, majority of the caregivers ie mean of 4.65 out of 5 on the likert scale were aware that a person could survive well with one good functioning kidney.

In a related study in Saudi Arabia on Knowledge and attitudes of health care professionals toward organ donation and transplantation, majority of the healthcare professionals supported organ donation; physicians (89.0%), nurses (82.3%). It was a cross sectional study that included emergency medical services professionals in that study. In our study, majority of the caregivers had positive attitudes towards live kidney donation and negative attitude towards deceased kidney donation. Our results paint a grim picture towards acceptance of deceased kidneys for the treatment of end stage renal diseases.

On attitude towards kidney transplant, our findings showed that both groups had positive attitude towards receiving a kidney from a living donor and negative attitude towards accepting a kidney harvested from a deceased donor. In contrast to a study done in Nigeria (31) on awareness and attitude to deceased kidney donation among health-care workers, 51.6% of the respondents were willing to accept to be transplanted with a kidney from a deceased donor, a percentage higher than the majority from our cohort who are willing to do the same. We may not have plausible explanation as to the lower rates of acceptance of deceased kidneys for transplant among our respondents as we can only speculate on the reasons behind that.

From our study, both the healthcare professionals and caregivers were willing to donate a kidney to a relative but not a non-relative. Both healthcare professionals and caregivers were willing to accept kidneys from living donors but both groups were not as willing to accept cadaveric kidneys for transplant. A study in Nigeria also confirmed our findings that show healthcare professionals have a better attitude towards kidney organ donation than the caregivers. In that study on caregivers and healthcare willingness to donate a kidney in three tertiary institutions (7), only 43.7% of participants had a favorable attitude towards kidney donation, and these were predominantly healthcare workers. Both studies used similar questions to evaluate attitude among its participants but the study in Nigeria treated the data collected using likert scales as ordinal data. The differences in attitude between the two groups could be as a result of knowledge bias that the healthcare professionals have on matters on kidney organ donation and transplant

In our study, 12% were willing to accept kidney from deceased donors in contrast to a study by Agwu et al (31) in which 52% were willing to accept them. Reasons for the stark difference in attitude could not be ascertained from this study. Among the caregivers,

Most respondents were not willing to sign up donation cards to be deceased donors. In our study, only 39.5% were willing to sign up to be deceased donors. Healthcare professionals were more willing than the caregivers to be deceased donors at 48.7% vs 34.8% . These findings are related to similar studies done to assess respondents willingness to sign up donor cards. In a study by Aboidun et al on caregivers and healthcare workers' willingness to donate Kidney in Three Tertiary Institutions in Southern Nigeria, only 25.6% were willing to be donors. These low rates of willingness to be deceased donors could be attributed to many factors among them fear, cultural restrictions and taboo.

These results were similar to the findings obtained from studies done in Greece and Baltimore to assess willingness of caregivers and medical students to be deceased donors. Symvoulakis et al (50) in the greek study to assess Kidney organ donation knowledge and attitudes among health care professionals showed that half of the respondents 52% of nurses and 51.2% of physicians were not willing to sign up as kidney donors nor donate their kidneys after death. In the baltimore study to assess willingness to donate among medical and nursing students, 55.6% were willing to donate organs upon death, while the remaining 44.4% were unwilling to donate. Interestingly, only 8.8%) had donor cards.

All the findings from our study and the other studies from other regions as shown above point to a low rate of acceptance to be deceased donors by the respondents.

Globally this could be attributed to many factors among them controversies on definition and accurate diagnosis of brain death, fear of organs being misused and rejection of donors will to be a deceased donor by the family.

Among the many reasons sighted by respondents as possible factors that may prevent people from being living donors included concerns of health status post donation, fear and uncertainty regarding donation process and generally lack of adequate information and knowledge regarding organ donation transplant in the general public. There is paucity of data regarding reasons that may hinder people from being living donors in literature. Part of the reason behind that may be much of research and literature has focused on awareness, attitude and willingness toward deceased donation

From the in-depth interviews with key informants, most respondents alluded that information and free healthcare post donation would be among the factors that could motivate people be living donors. These findings were in tandem with results from a study done by Lin et al (51) on factors associated with the willingness of clinical health care professionals for living organ Donation. From that study, the predictors of willingness to engage in living organ donation were the desire to help others , positive attitude toward living organ donation , financial support from the government, and fewer physical concerns. The willingness to donate a living organ was not associated with age, sex, religious belief, education level, participation in voluntary work, years of clinical work, type of profession, or knowledge about living organ donation. Controversies surrounding brain death has been a sticking issue regarding possible barriers to people signing up to be deceased donors. In thid study, majority of the respondents aired their concern on the same as a possible barriers to people signing donation cards. The other factors raised as concerns were acceptance of will by family and doubt of right use of organs for the intendeded purpose and recipients by healthcare professionals. These are the same concerns from other studies. In a study titled Awareness and attitude to deceased kidney donation among health-care workers in Nigeria (31), among the reasons sighted for respondents to refuse to be deceased donors included fear that it may not work and fear of disease transmission , same reasons that our study obtained from the key informant interviews. In a study titled Factors Influencing the Willingness of Allied Health Students to Donate Organs or Tissues by Elsafi et al (52) showed that the most frequent cause of refusal to donate organs among students with negative attitudes was the mistrust of medical staff regarding brain death diagnosis , followed by bodily concerns and religion

5.1 CONCLUSION

Healthcare professionals had positive attitude towards kidney organ donation but negative attitude towards cadaveric kidney organ donation and transplant. Caregivers are aware on kidney organ donation. However, there is negative attitude towards altruistic kidney donation, deceased kidney organ transplant and willingness to sign up will to be deceased kidney donors among participants.

Strategies should be put in place to change the attitude of healthcare professionals and caregivers towards embracing altruistic kidney donation both living and cadaveric and change their attitude to accept kidneys harvested from deceased donors for treatment of end stage renal disease.

5.2 RECOMMENDATIONS

1. Sensitize communities on donating organs at death for treatment of various medical conditions
2. Construct strategies that will change the attitude of the community towards acceptance of cadaveric kidneys for treatment of end stage renal disease
3. Focus on strategies that will increase the rates of altruistic donations from living donors to strangers for paired transplant programs

5.3 LIMITATIONS

1. Some healthcare professionals may have answered the questions with information bias
- 2 .Some caregivers had difficulties understanding some concepts of organ donation and transplant eg braindeath

APPENDIX: QUESTIONNAIRE

Appendix V: Questionnaire in English

SECTION A: GENERAL INFORMATION

1. RESPONDENT

HEALTHCARE PROFESSIONAL

- DOCTOR
- NURSE

CAREGIVER

- SPOUSE
- PARENT
- SIBLING
- EXTENDED FAMILY
- NEIGHBOUR
- GUARDIAN
- FRIEND
- CHILD

2. AGE YEARS

3. GENDER

- MALE
- FEMALE

4. RELIGION

- CHRISTIANITY
- ISLAM
- HINDU
- TRADITIONAL
- ARELIGIOUS

5. MARITAL STATUS

- MARRIED
- SINGLE
- DIVORCED
- WIDOWED

6. EDUCATION LEVEL

- PRIMARY
- SECONDARY
- TERTIARY

7. EMPLOYMENT STATUS

- EMPLOYED
- UNEMPLOYED

SECTION B: AWARENESS

5=fully aware 4=aware 3=unsure 2=unaware 1=fully unaware

	5	4	3	2	1
1. A living person can donate a kidney to a patient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Adults could donate kidneys to children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. A living person can survive well with one functioning kidney	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. A patient can be transplanted with Kidney from a deceased donor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION C: ATTITUDE

5=very willing 4=willing 3=unsure 2=unwilling 1=totally unwilling

	5	4	3	2	1
1. I could donate one of my kidney to a relative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I could donate one of my kidneys to a non-relative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I could accept to be transplanted with a kidney From a live donor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I could accept to be transplanted with a kidney From a deceased donor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

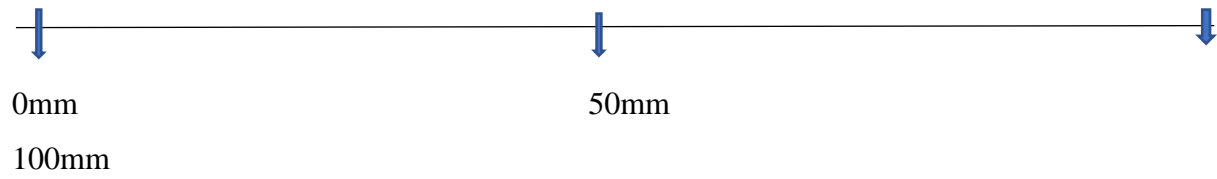
SECTION D: WILLINGNESS TO BE A DECEASED DONOR

I will accept to sign up to be a deceased organ donor

With a pen mark along this visual analogue scale your level of acceptance with the above statement

Totally unwilling
willing

very



BIBLIOGRAPHY

1. Lozano R, Naghavi M, Foreman K, Lim S, Shibuya K, Aboyans V, et al. Global and regional mortality from 235 causes of death for 20 age groups in 1990 and 2010: a systematic analysis for the Global Burden of Disease Study 2010. *Lancet*. 2012;380(9859):2095-128.
2. rankings wh. Kidney Disease in Kenya 2017 [Available from: <http://www.worldlifeexpectancy.com/kenya-kidney-disease>].
3. Naicker S. Burden of end-stage renal disease in sub-Saharan Africa. *Clin Nephrol*. 2010;74 Suppl 1:S13-6.
4. Barsoum RS. Chronic kidney disease in the developing world. *The New England journal of medicine*. 2006;354(10):997.
5. Grassmann A, Gioberge S, Moeller S, Brown G. ESRD patients in 2004: global overview of patient numbers, treatment modalities and associated trends. *Nephrol Dial Transplant*. 2005;20(12):2587-93.
6. Muller E. Transplantation in Africa - an overview. *Clin Nephrol*. 2016;86 (2016)(13):90-5.
7. Abiodun MT, Solarin AU, Adejumo OA, Akinbodewa AA. Caregivers and Healthcare Workers' Willingness to Donate Kidney in Three Tertiary Institutions in Southern Nigeria. *Transplant Proc*. 2015;47(10):2810-5.
8. Adejumo OA, Solarin AU, Abiodun MT, Akinbodewa AA. Knowledge of Kidney Donation Among Care Givers in Two Tertiary Hospitals in Southwest Nigeria. *Artif Organs*. 2016.
9. Alsaied O, Bener A, Al-Mosalamani Y, Nour B. Knowledge and attitudes of health care professionals toward organ donation and transplantation. *Saudi J Kidney Dis Transpl*. 2012;23(6):1304-10.
10. Woodle ES, Boardman R, Bohnengel A, Downing K. Influence of educational programs on perceived barriers toward living donor kidney exchange programs. *Transplant Proc*. 2005;37(2):602-4.

11. Kdigo. CKD EVALUATION & MANAGEMENT | KDIGO 2017 [Available from: <http://kdigo.org/home/guidelines/ckd-evaluation-management/>].
12. Tonelli M, Wiebe N, Knoll G, Bello A, Browne S, Jadhav D, et al. Systematic review: kidney transplantation compared with dialysis in clinically relevant outcomes. *Am J Transplant*. 2011;11(10):2093-109.
13. WHO | Outcomes of organ transplantation. WHO. 2013.
14. Voelker R. Cost of transplant vs dialysis. *JAMA*. 1999;281(24):2277-.
15. O'Seaghdha CM, Canney M, O'Kelly P, Conlon PJ, Williams Y, Kaballo MA. A comparative analysis of survival of patients on dialysis and after kidney transplantation. *Clinical Kidney Journal*. 2017;11(3):389-93.
16. Carbonell E, González-Martínez F, Fernández-Cean J, Curi L, Mazzuchi N, Orihuela S. Comparison of survival for haemodialysis patients vs renal transplant recipients treated in Uruguay. *Nephrology Dialysis Transplantation*. 1999;14(12):2849-54.
17. KidneyLink. Types of Donors. 2017.
18. Delmonico F. A Report of the Amsterdam Forum On the Care of the Live Kidney Donor: Data and Medical Guidelines. *Transplantation*. 2005;79(6 Suppl):S53-66.
19. Pisarski P. [Living kidney donation--selection criteria for the donor]. *MMW Fortschr Med*. 2007;149(31-32):24-6.
20. Fauchald P. Living donor kidney transplantation: evaluation and selection of the donor. *Transplant Proc*. 2003;35(3):931-2.
21. Ghods AJ. Current status of organ transplant in Islamic countries. *Exp Clin Transplant*. 2015;13 Suppl 1:13-7.
22. Lee S, Kim J, Shin M, Kim E, Moon J, Jung G, et al. Comparison of outcomes of living and deceased donor kidney grafts surviving longer than 5 years in Korea. *Transplant Proc*. 2010;42(3):775-7.

23. Nemati E, Einollahi B, Lesan Pezeshki M, Porfarziani V, Fattahi MR. Does Kidney Transplantation With Deceased or Living Donor Affect Graft Survival? *Nephro-urology Monthly*. 2014;6(4):e12182.
24. Murray JE. Ronald Lee Herrick Memorial: June 15, 1931-December 27, 2010. *Am J Transplant*. 2011;11(3):419.
25. sharing unfo. *Transplant trends | UNOS*. 2017.
26. White SL, Hirth R, Mahillo B, Dominguez-Gil B, Delmonico FL, Noel L, et al. The global diffusion of organ transplantation: trends, drivers and policy implications. *Bull World Health Organ*. 2014;92(11):826-35.
27. Spital A. Attitudes of health professionals toward living kidney donation. *Am J Kidney Dis*. 1998;31(3):555.
28. Alsaied O, Bener A, Al-Mosalamani Y, Nour B. Knowledge and attitudes of health care professionals toward organ donation and transplantation. *Saudi Journal of Kidney Diseases and Transplantation*. 2012;23(6):1304-10.
29. Alsaied O, Bener A, Al-Mosalamani Y, Nour B. Knowledge and attitudes of health care professionals toward organ donation and transplantation. 2012;23(6):1304-10.
30. Agaba EI, Ocheke IE, Agaba PA, Idoko OT, Ugoya SO, Yerima Y, et al. Willingness of Nigerian healthcare workers to donate kidneys. *Int J Artif Organs*. 2008;31(4):329-32.
31. Agwu NP, Awosan KJ, Ukwuani SI, Oyibo EU, Makusidi MA, Ajala RA. Awareness and Attitude to Deceased Kidney Donation among Health-care Workers in Sokoto, Nigeria. *Annals of African Medicine*. 2018;17(2):75-81.
32. Rithalia A, McDaid C, Suekarran S, Myers L, Sowden A. Impact of presumed consent for organ donation on donation rates: a systematic review. *BMJ*. 2009;338.
33. Rithalia A, McDaid C, Suekarran S, Norman G, Myers L, Sowden A. A systematic review of presumed consent systems for deceased organ donation. *Health Technol Assess*. 2009;13(26):iii, ix-xi, 1-95.

34. Chung CK, Ng CW, Li JY, Sum KC, Man AH, Chan SP, et al. Attitudes, knowledge, and actions with regard to organ donation among Hong Kong medical students. *Hong Kong Med J.* 2008;14(4):278-85.
35. Pouraghaei M, Tagizadieh M, Tagizadieh A, Moharamzadeh P, Esfahanian S, Shahsavari Nia K. Knowledge and Attitude Regarding Organ Donation among Relatives of Patients Referred to the Emergency Department. *Emerg (Tehran).* 2015;3(1):33-9.
36. Balwani MR, Gumber MR, Shah PR, Kute VB, Patel HV, Engineer DP, et al. Attitude and awareness towards organ donation in western India. *Renal Failure.* 2015;37(4):582-8.
37. Adejumo OA, Solarin AU, Abiodun MT, Akinbodewa AA. Knowledge of Kidney Donation Among Care Givers in Two Tertiary Hospitals in Southwest Nigeria. *Artif Organs.* 2017;41(5):446-51.
38. Pike RE, Odell J, Kahn DJSAMJ. Public attitudes to organ donation in South Africa. 1993;83(2):91-4.
39. Shafer TJ, Wagner D, Chessare J, Zampiello FA, McBride V, Perdue J. Organ donation breakthrough collaborative: increasing organ donation through system redesign. *Critical care nurse.* 2006;26(2):33-42, 4-8; quiz 9.
40. Abidin ZL, Ming WT, Loch A, Hilmi I, Hautmann O. Are health professionals responsible for the shortage of organs from deceased donors in Malaysia? *Transpl Int.* 2013;26(2):187-94.
41. McGlade D, Pierscionek B. Can education alter attitudes, behaviour and knowledge about organ donation? A pretest–post-test study. *BMJ Open.* 2013;3(12).
42. Connelly LM. Pilot studies. *Medsurg Nurs.* 2008;17(6):411-2.
43. Mugenda OM, Mugenda AG. *Research methods: Quantitative and qualitative approaches:* Acts press; 1999.
44. Akgun HS, Bilgin N, Tokalak I, Kut A, Haberal M. Organ donation: a cross-sectional survey of the knowledge and personal views of Turkish health care professionals. *Transplant Proc.* 2003;35(4):1273-5.

45. Barnieh L, Klarenbach S, Gill JS, Caulfield T, Manns B. Attitudes toward strategies to increase organ donation: views of the general public and health professionals. *Clin J Am Soc Nephrol*. 2012;7(12):1956-63.
46. ZELLEN M. William G. Cochran. New York: Wiley; London: Chapman & Hall, 1953. 330 pp. *Science*. 1953;118(3070):523-4.
47. Abiodun MT, Solarin AU, Adejumo OA, Akinbodewa AA. Caregivers and Healthcare Workers' Willingness to Donate Kidney in Three Tertiary Institutions in Southern Nigeria. *Transplantation Proceedings*.47(10):2810-5.
48. Malterud K, Siersma VD, Guassora AD. Sample Size in Qualitative Interview Studies. *Qualitative Health Research*. 2016;26(13):1753-60.
49. Sander SL, Miller BK. Public knowledge and attitudes regarding organ and tissue donation: an analysis of the northwest Ohio community. *Patient Education and Counseling*. 2005;58(2):154-63.
50. Symvoulakis EK, Tsimtsiou Z, Papaharitou S, Palitzika D, Markaki A, Stavroulaki E, et al. Kidney organ donation knowledge and attitudes among health care professionals: findings from a Greek general hospital. *Appl Nurs Res*. 2012;25(4):283-90.
51. Lin MM, Hsu YN, Wang YW, Weng LC, Chin YF. Factors Associated With the Willingness of Clinical Health Care Professionals for Living Organ Donation. *Transplantation Proceedings*. 2018;50(8):2320-2.
52. Elsafi SH, Al-Adwani MM, Al-Jubran KM, Abu Hassan MM, Al Zahrani EM. Factors Influencing the Willingness of Allied Health Students to Donate Organs or Tissues. *Transplantation Proceedings*. 2017;49(6):1215-20.