THE PERCEPTION TOWARDS LIVING RELATED KIDNEY DONATION AMONG POTENTIAL DONORS AT MUHIMBILI NATIONAL HOSPITAL

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A Dissertation Submitted in Partial Fulfillment of the Requirements for the Degree of Master of Bioethics of the Muhimbili University of Health and Allied Sciences.

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CERTIFICATION

The undersigned certifies that he has read and hereby recommends for examination by Muhimbili University of Health and Allied Sciences, a dissertation entitled ***" The perception towards Living related kidney donation among potential donors at Muhimbili National Hospital*** " in partial fulfillment of the requirement for the degree master of Bioethics of Muhimbili University of Health and Allied sciences

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(Co-supervisor)

Date_____

DECLARATION AND COPYRIGHT

I, Emmachius Emmanuel declare that, this dissertation is my own original work and that it has not been presented and will not be presented to any other university for a similar or any other degree award.

Signature_____ Date_____

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DEDICATION

I dedicate this work to all CKDs in Tanzania, may the almighty God give them relief in their suffering.

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This Dissertation could not be successful without the contribution of the following, first I would like to thank the almighty God who gave me strength and spiritual balance for all days while at Muhimbili University of Health and Allied sciences. Second from the inner part of my heart I would like to thank my sponsors from the united states of America in pursuing Master of Bioethics within a project titled "**Dartmouth MUHAS Research Ethics Training Project**" ((DMRET) with grant number **5R25TW007693-08**. I am very grateful for dedication, patience and professional guidance of my supervisors Dr. Paschal Ruggajo and Mr. Baraka Morris who gave me tremendous supportive supervision, from the initial development of research proposal to the stage of completing my dissertation. Moreover I would like to thank the Head of department Dr Renatha Josseph, Godwin Pancras who did final correction of this Dissertation and all Staffs at Muhimbili University of Health and Allied Sciences who taught me to swim in this ethical academic ocean, likewise I would like to thank Prof. Muhsin Aboud the Principle investigator (PI) of Muhas Research ethics training project (DMRET), for his good leadership. I would like also to thank Muhimbili National Hospital management lead by Prof Lawrence Mselu; much appreciation goes to the Head of Teaching, Research and consultancy Coordinating unit at Muhimbili National Hospital (MNH) Dr Faraja S. Chiwanga for his help in processing permission letter for collecting data at MNH. Then I would like to thank the head of internal medicine department Dr John Rwegasha at MNH for allowing doing this study in his department. Fifth I would like to thank the Head of Renal unit at MNH Dr Jacqueline Shoo who welcomed me and made contribution in this study, and all staffs in the renal unit. I also appreciate the assistance from Sr Pilly Kidunda (MNH transplant coordinator) during Data collection. I do sincerely appreciate the work done by Dr. Rehema Chande-Mallya on my study, from the time of preparing proposal to the time of completing my dissertation. Much thanks goes to all my classmates for their cooperation during our studies. Finally my sincere gratitude goes to my parents and relatives for their prayers, material support and encouragement during my studies. To you all who have contributed for the successful accomplishment of my studies I have four words "**May God bless you**".

ABSTRACT

Background

Organ Transplantation is a surgical operation in which a damaged or failed organ is replaced with a new one. Organs for transplantation can come from living donor or deceased donor (cadaveric donor) and from other sources. Renal failure transplantation gives a patient good clinical outcome than other treatments options such as kidney dialysis. The demand of organ donors in the world is high while the supply is low. The number of live donors is not fulfilling the live donors' pools, there large number of people in the world who needs kidney transplants but their need is not fulfilled because of shortage of organ (kidney). Some people are not donating because of having inappropriate knowledge about organ donation, this knowledge put them into a dilemma of either donating or not. Moreover others are not donating because of their perceptions towards the act of donating which is caused by cultural aspect, religious aspects and various misconceptions.

Objectives

This study intended to explore the perception and factors influencing ethical dilemma of donating or not facing the potential kidney donors towards living related kidney donation.

Methods

This is an exploratory qualitative study in which the data was collected by using in-depth interview. The study population was the potential donors/relatives (distance or closed related) of a Chronic Kidney Disease patient. The data were analyzed by using content analysis through Nvivo software whereby recording of data was done, verbatim transcription, coding process, developing categories and identification of thematic pattern.

Results: The study shows revealed that the potential donors have positive perception towards organ donation because it saves life of human being, the barrier of organ donation this study shows lack of information about kidney donation, misconception, fear, lack of power to make decision together with ethical dilemmas contributes to shortage of organ donation.

Conclusion: The people have positive perception towards Living related kidney donation because it helps in saving life but what contributes to shortage of kidney donors are misconceptions, power to make decision, lack of knowledge about organ donation and

fear in short all these factors can be summarized in one sentence that people have no correct information about kidney donation (LRKD).

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LIST OF ABBREVIATION

CKD	Chronic Kidney Disease
CMS	Centre for Medicare and Medical Services
ESRD	End Stage Renal Disease
IC	Informed Consent
LD	Living Donation
LKD	Living Kidney Donation
LOD	Living Organ Donation
LRKD	Living Related Kidney Donation
MNH	Muhimbili National Hospital
MUHAS	Muhimbili University of Health and Allied Sciences
OD	Organ Donation
PLD	Potential Living Donor
R	Respondent
UK	United Kingdom
UNOS	United Network for Organ Sharing
WHO	World Health Organization

DEFINITION OF TERMS

Potential donor is an individual who can give an organ to another person (kidney recipient), in this research PD means those who are related to the recipient (CKD Patient)

Organ transplantation is a surgical operation in which an organ is removed from the body of one person (the donor) and put it into the body of another person (the recipient)(1).

Organ donation is an act of giving organ to someone who needs a transplant.

Living related kidney donation Living related kidney donation (LRKD) is the kind of donation done by a parent, brother, sister, grand parent, daughter or son of the recipient(2)

Living kidney Donation is the act of giving a kidney done by a living human being(3)

Living donors (LD) refers to healthy individuals who voluntarily accept to aid a family member, friend or stranger without any physiological benefit to the donor(4)

Kidney Recipient is a human being or a person into whom an organ (kidney) were transplanted(3)

Ischemic Time is the period between when the kidney is removed from the donor and put into the transplant recipient(1).

End Stage Kidney (Renal) Disease refers to a stage of kidney disease when a person's kidneys have stopped working and treatment, such as dialysis or a transplant, is needed to sustain life. This stage is also referred as End Stage Kidney (Renal) Failure (ESKF), kidney failure or stage 5 CKD(1)

Dialysis–is a process done to a person suffering from kidney failure that removes waste products and excess fluid from the blood by filtering the blood through a special membrane

CHAPTER ONE

1.1BACKGROUND

Organ Transplantation is a surgical operation in which a damaged or failed organ is replaced with a new one(5). Organs for transplantation can come from living donor or deceased donor (cadaveric donor) and from other sources. In USA, the first living related kidney transplanting was done among identical twins in 1954 by a transplant team led by Dr Josseph Murray in Boston Hospital and the first kidney transplant from a deceased donor was conducted in 1962.

South Africa had the first kidney transplant in 1966 which happened in Johannesburg. Hence in the year 2016 South Africa celebrated 50 years of Organ transplanting. Tanzania had the first kidney transplant in 2017 at Muhimbili National hospital. Moreover, the second kidney transplant in Tanzania was done at Benjamin Mkapa hospital, March 2018 **(http://allafrica.com/stories/html)**

Living related kidney donation (LRKD) is the kind of donation done by a parent, brother, sister, grand parent, daughter or son of the recipient. Moreover living kidney donation can involve donors who are distantly related like cousin, uncle or aunt(2).Generally living related donors are health blood relatives of the person (recipient) in need of a kidney. LRKD is justified when the relative is sincerely motivated and well informed before donation.

The potential donor has to be left free to exercise his/her autonomy so as to donate or not and has the right to know the risk and benefits associated with donation(6). Living donors can be related to a recipient whereby a relative (parent, grandparent, brother, sister) is related by blood to the recipient. Unrelated donors are those who are not related by blood to the recipient. Non-directed kidney donation (altruistic) occurs when someone donates a kidney to a transplant waiting list, in this case the living donor has no say who should receive the kidney.

Living donation presents ethical dilemma because the physician must risk the life of a healthy person to save the life of a patient(7). The ethical principle of beneficence insists on not doing harm to an individual and maximizing benefits and minimizing harm. Since living donation involves risking a healthy person to save an unhealthy person, one can be in a dilemma of whether if are doing harm or not. The donation process involves a critical

evaluation of benefits and risk to both the donor and recipient; this is to ensure that the principle of beneficence is adhered. If the benefits exceed the risks to the potential donor, they will have a chance of donating but if the risks exceed the benefits, allowing potential donor to donate is to go against the ethical principle of beneficence. Moreover, one can be in a dilemma if living donation respects Kantian categorical imperative rule specifically the second formulation which insist on respecting the human dignity that is not treating someone as a means to an end. The act of risking a health person in order to save another sounds like to use him/her instrumentally.

Living donation can be categorized into three sections and each section has its ethical dilemma. The first is direct donation to a loved one or friend. The ethical concerns that arise from this donation is the worries about the intense pressure that can be put on people to donate, this makes those who are reluctant to do so to feel coerced, in this case the transplantation program has to identify the plausible medical excuse so that the person can bow out gracefully(7). The necessary information must be given to the donor so as not to feel coerced(8).

Sibling donor are vulnerable to strong family pressure, coercion is common in cultures which emphasize family solidarity and build obligations towards it, some with strong religious sanction, Christian or Islamic(8). The second category of living donation is non-directed donation in which the donor is not directing an organ to a specific person rather the donor gives the organ to the general pool to be transplanted to the recipient at the top of the waiting list(7).

This type of living donation causes a dilemma since it is not common in our community for one to make a potentially life threatening sacrifice, hence the radical sacrifice that motivates a person to make this decision has to be carefully analyzed. Robert gives an example in which a man who seemed clinically fanatical with giving away everything starting from his money up to his organs, at the back of his mind he was convinced that doing so was as much as necessity as food, water and air(7).After donating a kidney, the man speculated how he might give the remaining organs in a dramatic suicide.

The dilemma that comes in, is under the ethical principle of respect for person that insist on treating human being as autonomous being, to exercise their autonomy so as to decide on their self-deliberation. Suicide of a Human being so as to offer his/ her organs is under faculty of autonomy but it goes against Kantian categorical imperative second formulation

which insists on respecting the Human dignity. It states that "Act so that you treat humanity whether in your person or in that of another person always as an end and never as a means"(9) therefore, committing suicide so as the organs to be taken for transplantation purpose is not morally right according to Immanuel Kant. Moreover, one can decide to donate an organ not because of helping the patients but to compensate the depression which someone is undergoing, or donation can be done because someone wants to seek media attention (to be known openly because of the act of donating). Donation which is done under the mentioned reasons goes against the intrinsic value of a human being since the donor is using the recipient as a means to an end. Therefore the transplantation team has to assess the potential donors in all these dimensions and prohibit donations that arise serious concern. The third category of living donation is called directed donation to a stranger, this type occurs when the person shows an intention of donating an organ by advertising publicly through mass media like television, magazines or over the internet, this practice is discouraged because it threatens the view that an organ is a gift of life not a commodity to be bought and sold(7). The commodification of human organs have become a serious human right problem(10), due to the magnitude of the problem, the intergovernmental organization has developed the frame work to prevent and fight organ trafficking.

The Declaration of Istanbul (2008) principle number Six prohibits organ trafficking " Organ trafficking and transplant tourism violate the principles of equity, justice and respect for human dignity and should be prohibited"(11). Moreover, UNESCO universal declaration of Bioethics and Human rights article 21 directs the government to take appropriate measures to prevent organ trafficking(12).

The principle of non-commercialization of human' body parts reflects the ethical and legal maxim according to which human organs should not be treated as commodities that can be bought and sold(10).Organ donation from living donors should be based on ethical concern related to selection criteria and procedures, voluntariness, informed consent and disclosure of risks and benefits to both donor and recipient(13). There are various factors that cause donors to be in a dilemma of donating or not donation, one of those factors is risk therefore donor and recipient have right to full disclosure of risk and benefit associated with living donation. If there is no legal regulation on how much risk is ethically and clinically acceptable the program center in the country must set their own standard(13).

Informed consent in living organ donation must constitute the comprehensive information about the process and the donor should be competent individual to grasp and digest the information given. Information about risk and benefit should be disclosed to both donor and recipient. The potential donor should be briefed about the alternative treatment options for the recipient, also the possible impact of donation on the donor's lifestyle, family relationship, finances and future employment.

The consent process has to be appropriate to the potential donor's language skills and educational level(13).In Canada, the guidelines for evaluating living organ donation which was approved by UHN medical advisory committee insist on the protecting of donor's information (Confidentiality of donor information is essential for establishing that donors are acting voluntarily), also in the guideline requires consultative options to assist consensus-building when there is a lack of agreement or serious reservation about the suitability of a donor(14). All these are done in order to ensure ethical adherence in living organ donation.

1.2 PROBLEM STATEMENT

Renal transplantation has become a widely accepted and desirable therapeutic modality for the treatment of end-stage renal disease (ESRD). Chronic Kidney Disease has a high global prevalence with a consistent estimated global CKD prevalence of between 11 to 13% with the majority stage 3(15)

Kidney disease has a greater contribution to morbidity and mortality in Sub-Saharan Africa (16), it is estimated that by 2030, 70% of patients with ESRD will be residing in low income countries such as those in Sub-Saharan Africa(17).

The study which was conducted in 2015 indicated that the prevalence of CKD in Tanzania is estimated to be 7%(18).The shortage of organs is practically a Global problem, this is caused by Lack of appropriate information about kidney donations, moreover perception and ethical dilemma contributes to the shortage of kidney in the living pool donor (19).

Perception and ethical dilemma of people towards organ donation affect much the willingness of donating organs for transplantation(20) People can be reluctant to donate organs to those in need due to lack of information about kidney donation and fear of organs being misused, also people have the perception that organ for donations comes from addicts and poor people (21). In Tanzania, organ transplantation specifically living related kidney donation is a newly introduced service in the country which started in 2017 at MNH, so less is

known about potential donor's perception towards Living related kidney donation. Therefore, this study aims at exploring the perception towards living related kidney donation among potential donors at Muhimbili National hospital Renal Unit.

1.3 RATIONALE OF THE STUDY

Organ transplantation in Tanzania is a new issue and we are still depending on only one source of getting organs for transplantation which is living related kidney donation. Since the issue, is new it is foreseen the perception of people is not known, therefore, the study is aimed at exploring the perception of potential donors, the study tells us why there is shortage of kidney donors. Moreover the study is a cornerstone for increasing the numbers of kidney donors to reduce the shortage of kidneys for transplantation. The study will help the government to know where to start if they want to establish awareness about organ donation specifically living related kidney donation.

1.3 MAIN QUESTION

What are the perception and factors influencing ethical dilemma of donating or not facing the potential donors towards Living related kidney donation

1.4 RESEARCH QUESTIONS

I. What are the perceptions of potential donors towards living related kidney donation?
II. What are the factors for ethical dilemma of donating or not, facing the potential donors towards living related kidney donation?

1.5 STUDY OBJECTIVE

1.5.1General Objective

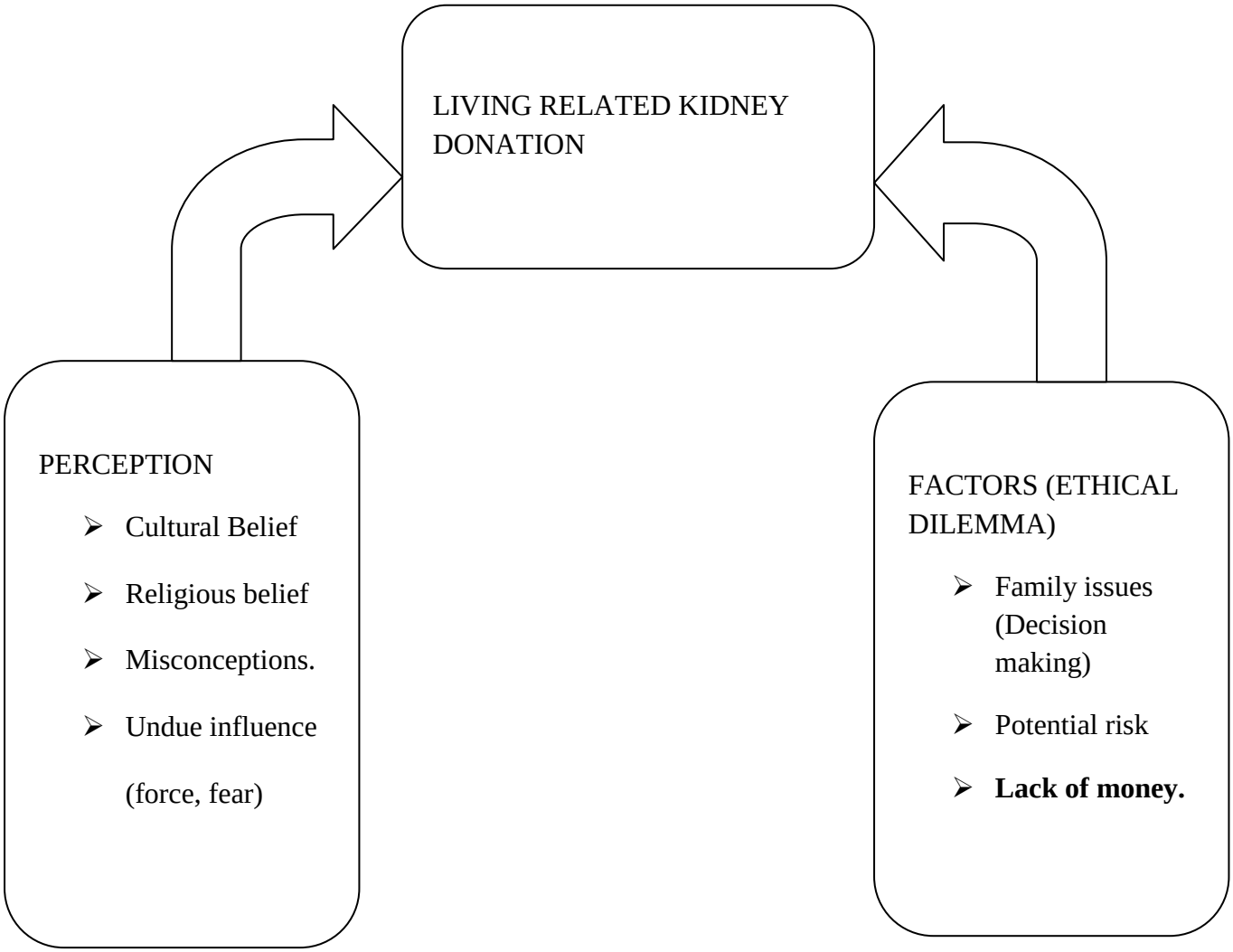
The main purpose of this study is to explore the perception and factors influencing ethical dilemma of donating or not facing the potential kidney donors towards living related kidney donation.

1.5.2 Specific Objectives

I. To explore the perception of potential kidney donors towards of living related kidney donation

II. To explore the factors influencing ethical dilemma of donating or not donating, facing the potential living donors towards living related kidney donation.

1.6 CONCEPTUAL FRAME WORK.



Source: Researcher's own Design.

Conceptual frame work showing the factors that influence potential donors ethical dilemma, moreover the frame work shows the factors that affect the perception of potential donors towards living related kidney donation.

1.6.1 Factors that affect perception of potential donors towards Living related kidney donation.

The perception of potential donors towards living related kidney donation can be affected by different factors, this factors makes them as to have positive perception meaning they support the act of donating kidney. Moreover these factors can make them to have negative perception, meaning that their views, feelings and opinions are against kidney donation this leads to have few numbers of donors hence the shortage of kidney donors.

1.6.1.1 Cultural beliefs

Cultural beliefs are one of the factors that affect the perception of people towards kidney donation especially in the multicultural societies. Some of the culture might be supporting kidney donation something which leads to the increase of organ donors but also some cultures might be against kidney donation this leads to the shortage of kidney donors. Cultural beliefs have caused some of the countries to have low rate of organ donation, for example Greece and Italy have strong cultural beliefs that discourage organ donation(22), hence in order to have higher percent of organ donors, cultural misconceptions have to cleared.

1.6.1.2 Religious beliefs.

Religious beliefs have a great impact in organ donation; this leads a person/community to have positive perception or negative perception. In China Confucian concept of Filial piety directs the individuals, out of respect for their ancestors, are required to return their bodies in the same form that they received them from their parents. For that reason, it is also erroneous for others to hinder a person's hard work to return his or her body undamaged by removing organs from it(23). So according to filial piety principle removing organs for any reason is considered as a violation of this important code. The belief like this automatically will lead to have few numbers of organ donors. The Catholic Church allows organ donation but this has to be done under the respect of human dignity. Pope John Paul II said that "The criteria for assigning donated organs should in no way be discriminatory (i.e. based on age, sex, race, religion, social standing, etc.) or utilitarian (i.e. based on work

capacity, social usefulness, etc.)(24).” The Islamic religion also allows organ donation Grand Mufti of the Republic of Tunisia said “according to Islam a human being is not the owner of a part or the whole of his body. In any case, organs should not be traded, but donated”(24) he made this remark when was addressing the Third International Congress of the Middle East Society for Organ Transplantation in 1992.

1.6.1.3 Misconceptions.

Misconceptions contributes to have views, opinions and feelings about kidney donation hence negative perception, the study which was done in Spain indicated various misconceptions about kidney donation, the following misconceptions were indentified, shorter life expectancy after donating, unable to have children, susceptible to kidney disease after donating and fear to die after surgery(25), all this contributes to have negative perception towards kidney donation hence fewer numbers of kidney donors.

1.6.1.3 Undue influence.

The choice to become a donor has to be done under free will, meaning that a person has to give consent in order to be a donor, if a person is induced to donate because of pressure or coercion this can create a negative perception towards kidney donation. Respect for autonomy signifies that the LDs must be willing to donate and be free from undue pressure to consent to the procedure, if potential donors are forced to donate this can cause to have negative feelings and opinions about living related kidney donation.

1.6.2 Factors influencing the ethical dilemma of donating or not donating facing the potential donors towards Living related kidney donation

In the cause of donation process the potential donor can be in a dilemma of whether to donate or not to donate, this can be influenced by various factors as explained below:-

1.6.2.1 Family issues (decision making)

Family issues can be a factor that can cause a person to be in a dilemma, this can be elaborated in two aspects, first a person can be in a dilemma if the decision to donate has been made by the family members, because of this a potential donor can be in a dilemma to donate or not to donate since the decision was made against his/her will, moreover family conflict is one of the cause of ethical dilemma to donate or not to donate, if the family is in conflict with the prospect recipient, family members can be in dilemma if they are in the

position to help him/her. Sometimes a person may feel coercion to donate especially by family members fearing that relations among family members would disturbed if they denied donation(26)

1.6.2.2 Potential risk.

The minor risk of becoming a donor can be a cause for potential donors to be in a dilemma to donate or not to donate; as a result this leads to the shortage of kidney donors. The study done by Rizwan indicated psychological risk, problem with body image, possibility of post-surgery adjustment and possibility of recipient rejection and needs for re-transplantations as a barrier to organ donation(27), all these foreseeable risk can cause a person to be in a dilemma of donating or not.

1.6.2.3 Lack of money

Lack of money is one of the factors that cause potential donor to be in a dilemma. This happens especially if the prospect recipient was helping a family/ the person who is expected to be a donor. Despite of being in a dilemma of donating or not donating person who has been getting assistance may decide to donate not because of love or affection but because of paying back what was received in the past.

CHAPTER TWO

LITERATURE REVIEW.

2.1 Perception of potential donors towards Living related kidney donation

Human organs are the most precious gifts of a human life. Thousands of lives have been saved and many more blessed with hope and happiness through a better quality of living because of organ transplantation. Organ transplantation specifically Living donation (Living related kidney donation) is a new service in Tanzania. Because of the service to be new most of people in the society are not aware about it or are not used to it, therefore telling someone to donate one of the kidneys it might be difficult to take step because of seeing it as impossible. Therefore in order to increase the number of donors it is crucial to know the perception of the society towards organ donation.

The need for transplant is high and the gap between organs available for transplantation and the number of patients waiting for a transplant is widening globally. Perception towards organ donation prays an important role as it can promote it if people have positive views and feelings about organ donation but also perception can be a hindrance factor to organ donation if people have negative views or feelings about it. Rumors, myth and misunderstanding about organ donation and transplantation are many(28), Some people have perception that by donating organs their organs can be completely removed from the body(26) this is negative thinking towards organ donation. Moreover other think that becoming a donor there is direct benefits to the donor(26). The study which was done by Michelle et al indicated how culture shapes the perception of people towards organ donation, this study indicated that some culture believed that the spirit transferred from the donor to the recipient after donating an organ, moreover other indicated the ancestral permission before donation this enables the remaining family not to lose ancestral protection in the future(29), so in the society like this which ahead the cultural beliefs the number of organ donors will be low. Therefore in order to increase the number of organ donors specifically kidney donors there is the need find out the perception of the particular community or society.

2.2 Living organ donation.

Living organ donation is the donation from living individuals(5) or donors, the shortage of suitable for transplantation has led to the acceptance of living donor transplantation(7). Living organ donation offers the quality of life and survival benefits to the recipient and also the donor gets the psychosocial advantage in a sense of reward(30). Jaboulary was the first person to have a desire to treat organ failure by transplantation(31). He attempted this in the year 1906 by treating two patients with renal failure by transplanting a goat kidney into one and a pig kidney into the other in both cases he joined the renal vessel to the bronchial vessel(31)though both transplants cases failed and the patients passed away. During that era when one developed renal failure there was no alternative to death since the hemodialysis machine was not invented(31). Human kidney was used for the first time in transplantation in 1936 when the Ukraine Surgeon called Yu Yu Voronoy performed the first in a series of six transplants to treat patients dying from acute renal failure. In this attempt by the Ukrainian citizen, all the transplants failed(31). One of the problems which the first pioneer faced is the lack of suitable donor organs which also is still a case up to now. The first surgeon who attempted organ transplants used animal or organs from deceased human(31).

In the year 1950 there came a realization of the need to avoid excessive Ischaemic injury and kidney from live donors began to be used, donors were relative, others unrelated patients having a good kidney removed for other reasons(31). The surgical techniques also needed refinement while a kidney based on the thigh/arm vessel might be technically straight forward, and possibly adequate for the short term treatment of acute renal failure, it was not a realistic solution for long term. That solution came from France in 1951 and involved placing the kidney extraperitoneadly in an iliac Fossa, where the external the external iliac vessel are easy to access and the bladder is close by for anastomosis to the donor ureter, this technique still used today(31)

After solving the technical issue of vascular anastomosis and placement of the kidney, the issue that remained after the latter is the immune response. The work of Medawar's during and after the Second World War which was aiming at studying the rejection of skin grafts had demonstrated the potency of the immune system(32)

2.2 Types of living organ donation.

There are three common types of living organ donation. This donations are, directed donation, non- directed donation and finally paired donation.

2.2.1 Directed Donation

Directed organ donation is when the donor names the specific person to receive a transplant /an organ (33) the donors in this type can be a biological relative(parent, brother, sister, or adult child), biologically unrelated person who has personal or social connection with the receiver here we find people like spouse, friend or co-worker. The last person who can donate in this category is the biologically unrelated person who has heard about the transplant candidate's need(33)

2.2.2 Non-Directed donation

This is the type of donation where the donor does not name a specific person to receive the organ. In this type the match is done basing on medical compatibility with the patient in need. Some donors in this type opt not to meet their recipient, some time they can meet if both consent to do so, but also if the transplant Centre policy allows(33)**.**

2.2.3 Paired Donation

This type involves two pairs of living kidney donor and a transplant candidate who do not have compatible donor (matching blood type). The two candidates exchange donors so that each candidate receives a kidney from a donor with a compatible blood type(33). The following example illustrates well paired donation:- suppose Innocent wants to donate to her sister Inocencia but their blood is not compatible, and Eutropia wants to donate to her husband Felix but they also do not have compatible blood types. Through exchanges of donors' means that Innocent matches Flavian and Eutropia match Inocencia, the transplants are made possible.

2.3 Benefits of living kidney donation (LKD)

Living kidney donation has more benefits compared to deceased kidney donation (DKD). In LKD the transplant success is higher, the study which was done in Australia showed that five years after transplant 90% of kidney transplanted from living donor and 81% of kidney transplanted from deceased donor are still working(1). Another benefit for LKD is timing, it can take a year to get kidney from a deceased donor. LKD facilitates transplant to take place without needing to start **dialysis, hence rescue** a CKD patient from dialysis

cost. Transplant logistics is well organized and planned meaning that the cold Ischaemic time (CIT) when kidney is removed from the donor to the recipient is shorter(1). LKD allows hospital admission and surgery to be planned ahead of time; this gives chance for the donor and a recipient to get prepared psychologically.

2.4 Ethical consideration associated with living organ donation

2.4.1 Respect for person

This is one of the principles illustrated in the Belmont report for protecting human subjects participating in research or in any intervention(34). This principle stresses that individuals should be treated as autonomous agents in decision making, any kind of force, coercion should not be applied in an intervention. In LKD potentials donors' decision on whether to donate or not to donate should be respected. The principle of respect for person also entails informed consent (IC) that the potential donors are to be given appropriate information about the donation **p**rocess. IC consent is a critical aspect of LKD that safeguard clinical practice and protect donor's autonomy(4). UNOS considers IC to be a process that occurs throughout the donation course and remain focused on the donor rather than the transplant recipient(4). The evaluation of a candidate for LKD balances three bioethical values which includes beneficence, non-maleficence, voluntarism and confidentiality(35). Both donors and recipient must be knowledgeable about the expected outcome of the intervention. A complete informed consent requires that potential LKD to have capacity to be informed (competent person) about the surgical procedure and its accompanied risk to their health.

The Belmont report requires that the prospective LKD to have an understanding about the expected outcome, risk, benefits and alternative treatment options available to the recipient(36), all these enables the potential kidney donor to make an informed decision. In USA the Centre for Medicare and Medicaid services (CMS) directly intervened to regulate how transplant hospitals obtain consent for living Donation (LD). CMS requires the transplant hospitals to disclose all aspects of, and potential outcomes from LD(37) Moreover, CMS mandated the hospital providing living donor transplantation to form an independent Living donor advocate(ILDA or ILDA Team(4).

The main task of this team (ILDA) is to assess the potential donor candidate's readiness, independent of recipient care so as to minimize the specious risk. The principle of respect for person requires the potential donor to be competent and comprehend the information given by the transplant team in an understandable language**,** that is a language that has medical jargon; the information given should include benefits and risks of donating(38). Moreover, the respect for autonomy signifies that the LDs must be willing to donate and be free from undue pressure to consent to the procedure. Sometimes pressure from the family can force the potential donor to donate, this kind of donation is unethical since an individual must be treated as an autonomous being and has the right to withdraw from the donation process. The study which was done in Malaysia showed that 4% of LD cited family member as the reason for them to donate(39). Hence the principle of respect for person must be put into consideration in order to make the donation process ethical.

2.4.2 Disclosure of benefit and risk of organ donation.

Disclosure of risk and benefits in organ donation specifically in LKD in this case, is very important since it is one of the components of informed consent. The potential LKD should be informed about the risks and benefits so as to make a voluntary decision (informed decision). Determining the acceptability of an individual candidate for LKD possible risks and anticipated benefits for the prospective donor must be considered(4). To ensure ethical atmosphere in the LKD, the transplant team must disclose all information about benefit and risk of being a donor(13). The process of determining the potential donor acceptability for LKD needs the consideration of possible risk and anticipated benefit for the potential donor(4). When the potential candidate donor for LKD understands, the risk and benefits, this enhances the capacity to make an informed decision. In the place where there is no legal guideline on how much risk is clinically and medically acceptable for the donor, each transplant Centre must set their own standard. In Tanzania currently there is no legal regulation on organ transplant, hence the two transplant centers that are existing now which are Muhimbili National hospital Transplant Center and Benjamin Mkapa Hospital transplant center have their own regulation. MNH transplant center has adopted the declaration of Istanbul regulation on transplantation; hence the regulations which are used at MNH cannot be used elsewhere in the country. The guidelines save as assessment process of all potential donors; this is to ensure that all donors are protected. In Canada,

there is a separate health care team that asses the suitability of the potential donor (PD) and recipient, also there is two physician who act as advocate for donor and recipient(13).Moreover the transplant team has multidisciplinary professionals like social workers, physician and psychiatry staff, all these is to avoid conflict of interest and permit advocacy for the potential donor while suitability is being determined(13). Disclosure of risks and benefits to potential donor and recipient is one of the essential components of informed consent process.

The potential donor must have the capacity to be informed about surgical procedure as well as long term risk to their health status(4). The Belmont report requires the potential donor to be told the expected outcomes, risks and benefits(36). Henderson in his article specifies three categories of risk to be considered when discussing LOD. The first category of risk is short term risk which includes surgical and post-surgical risk, the second categories of risk is long-term risk which results from living with one kidney, the last category of risk is the psychological risk which comes when the potential donor is denied an opportunity to donate(40),Some in the process of evaluating the donors acceptability she/he might not qualify to be a donor because of various factors such as disease.

Hence, because of this, the PD can have psychological harm due to denying him/her the chance to donate. This fact of denying a chance to someone to donate raises the ethical challenge of confidentiality, individual clinical information should not be shared to a third part. The ethical challenge which comes out in this case is on how to tell the CKD patient who is prepared to get a kidney from the donor who is now unsuitable to donate.

2.4.3 Voluntariness.

Voluntariness is one of the criteria in organ donation; a potential donor must be left free to exercise his/her autonomy, without any threat or coercion. The membership statement of the transplantation society of Swaziland states that willingness to donate and freedom from coercion in the following words “the decision to donate is voluntary, free of exploitation and coercion(41),” moreover, the consensus statement of the Amsterdam forum on the care of the live kidney donors states that “the decision to donate should be voluntary accompanied by the freedom to withdraw from the donation process at any time(42)Hence

because of the necessity of voluntariness in organ donation the transplant team has an obligation to make sure that the decision to donate is voluntary and has not been manipulated.

Voluntary decision to donate an organ is not simply the absence of coercion. When voluntary is defined as the absence of coercion, this excludes other essential elements such as persuasion and manipulation(43). These two elements persuasion and manipulation can lead to perceptions of undue pressure incompatible with voluntary decision making. To understand voluntary decision as just the absence of coercion does not capture the fully range of non-voluntary decision especially in Living related donation(41). One might ask if donation in the family is completely free, because in families the donor and recipient are often related to each other, this signifies that the related donor are in a very different, emotional relation to the recipient that unrelated or altruistic donors, due to the blood relationship between the donor and recipient, people might think that the donor can be forced to donate under the influence of blood relationship. Organ removal is ethically justified by self-determination and voluntariness of both the donor and the recipient, which should serve the best interest of the recipient. Voluntariness and self-determination (autonomy) are two elements that form the legal and ethical framework for living donation(44). The decision to become a living donor has to be informed in the sense that the potential donor has to be given appropriate information about donation this will enable him/her to make freely decision without any coercion. The self-determination faculty of the donor has to play part in the donation process(45).

The consent to be an organ donor is only valid if it is truly voluntary, if the consent is taken under coercion or undue influence then it is not valid and there is no valid voluntariness in the process of organ donation.

The pressure to donate can come from various sources, for example, family members, close friends and health care professional(46). When the recipient is a family member, the donor may feel morally obliged to donate but in a real sense does not want to. The donation like this does not meet the criteria of voluntariness in Living kidney donation. Hence voluntariness in organ donation specifically in LKD dealt with in this research should be ensured so as to give room for potential donor to exercise their autonomy.

2.5 Impacts of cultural and religious beliefs in living kidney donation.

Cultural beliefs has a great impact in organ donation, it can promote people to donate or not to donate. Cultural beliefs have led to some countries in the world to have low rate of organ donation. Ann named Eastern Europe, Greece and parts of Italy to have strong cultural beliefs, traditions and religious beliefs that discourage organ donation even though there is legal and religious frame work(47). The study which was done in Canada showed low donation rate among immigrants ethnic minorities, who tend to stick into their traditional and cultural beliefs. Furthermore, low donation rate is visible in the multicultural environment of the United Kingdom and United States societies among native Asian, Black and Chines in the UK but also African-American, American Indians, Hispanic and Asian groups in the US(22). Cultural factors play an important role in organ donation even in the advanced society. In the UK in order to increase organ donation, the Government decided to plan a campaign which aimed at increasing awareness about organ donation. The campaign included renovation of the coordination infrastructure together with a media campaign and comprehensive public education(22). Societies might object to be potential organ donor due to cultural beliefs because of less knowledge about organ donation, hence forth a comprehensive education should be provided in these societies so as to make them aware that organ donation (OD) does not go against their belief system, through such campaign OD will be high.

Promoting OD and transplantation in a multicultural environment is one of the great challenges facing the transplant community. Countries with transplant services cannot overcome the organ shortage if attitudes, cultural and moral concepts are not cleared(22) The team of health care and social workers who are sensitive to the values and traditions of each group have a task to clear any misconception about OD by improving public education through using mass media, conferences, posters and any other acceptable means that can promote awareness and communication. Oniscu said “respect for cultural diversity and a better understanding of the cultural influences are means of building a stronger support for transplantation and ensuring the success of organ donation campaign”(22)Respecting the cultural diversity means that organ donation promoting team should not force community members to be donors rather the appropriate information

which clears any organ donation misconceptions has to be provided so as to give room for the community member to make an informed decision.

2.6 Factors influencing ethical dilemma to potential donors.

The ethical dilemma which arises because of the use of living donors is that they may be subjected to pressure and coercion from the family members(48)**.**The decision to be a donor must be informed and voluntary, all components of informed consent process which are appropriate information, comprehension and voluntariness has to be taken into consideration when evaluating the potential donors. Potential benefits and risk of becoming a donor has to be well explained to the PD. The vulnerable people in the family (incompetent persons- children and mentally retarded) has to be excluded because of their inability to give informed consent.

Moreover potential risks of becoming a donor can cause someone to be in a dilemma of donating or not donating, hence this becomes one of the factors for the shortage of kidney donors. The study done by Rizwan indicated psychological risk, problem with body image, possibility of post-surgery adjustment and possibility of recipient rejection and needs for re-transplantations as a barrier to organ donation(27).

Family conflicts are one of the factors for the shortage of donors because it makes people to be in a dilemma of donating or not donating. The study done by Martin indicated that consent to donation is less likely when there is family conflict(49)

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Study design

An exploratory study was done, .to explore the perception and factors influencing the ethical dilemmas of potential donors towards living related kidney donation. It is exploratory study because it focuses on studying unstudied area. Organ transplantation specifically LRKD is unstudied area in our country since is a new service. Exploratory approach is supported by Nieswiadomy (2008) as a method to use when there is a limited knowledge in the topic(50) hence I explored the perception and factors influencing ethical dilemma faced by potential donors towards LRKD. This study followed the phenomenological approach which seeks to describe in depth something that exists as part of the World in which we live**.** Phenomenologist are concerned with understanding the social phenomena from the perspectives of people involved, moreover phenomenological approach is concerned with lived experiences of the people involved or who are involved with the issue that is being researched(51). This approach is suitable in this study because the potential donors have experiences of caring a CKD patient who might need kidney transplant in the future.

3.1.1 Study area

The study was conducted at Muhimbili national hospital, specifically in the Renal Unit. The history of Muhimbili National Hospital (MNH) can be traced back in 1910 to 1920s known as Sewahaji Hospital. In 1956 the name changed to Princess Margareth Hospital (PMH). The name PMH changed after independence in 1961, this time it was named Muhimbili Hospital up to 1976 when it changed to Muhimbili Medical Centre. Muhimbili National Hospital (MNH) was established by the MNH ACT of Parliament No. 5 of 2000 by separation of the then Muhimbili Medical Centre (MMC) into Muhimbili National Hospital and Muhimbili University College of Health Sciences (MUCHS), now Muhimbili University of Health and Allied Sciences (MUHAS). This Separation was done in November 2004. MNH is a National Referral Hospital with 1,500 bed facility, attending 1,000 to 1,200 outpatients' week, admitting 1,000 to 1,200 inpatients per week, it has a social responsibility to improve the health of future generations. This study site has been

selected purposely because MNH is the first hospital in Tanzania to conduct organ Transplant (kidney) specifically living related kidney donation.The first Living related kidney transplant was done in November 2017, before introducing this service at MNH patients were referred to India.

3.1.2 Study population

The participant for this study was the members of the family where there is a CKD patient(s). In this study, these family members were labeled as potential donor to their relative who is suffering from kidney diseases. From each family member I took one family member this was according to their availability.

3.1.2.1 Inclusion criteria

A family member (potential related donor) aged 18 and above were included in the study

3.1.2.2 Exclusion Criteria

Those Family members (potential related donors) aged 18and above who did not consent to participate were excluded from the study.

3.1.3 Sample size

The sample size for this study was 16 people this sample size was reached after saturation point. Saturation point was reached during the data analysis after seeing the repetition of information in the interviews. During the data analysis it reached a point when there were no new data, no new coding and no new themes were emerging this indicated data saturation. Saturation is the point at which no new information is being found whereby the researcher can develop properties of the categories. As well at this point the researcher sees similar instances over and over again; she/he does not see any new information from the participants even when the question is asked in another form. Therefore at this point the researcher becomes empirically confident that a category is saturated(52). Therefore in research a topic becomes saturated when the participants or interviewee presents no new viewpoints on the topic(51). Cresswell defines saturation in qualitative research data collection as the point when the researcher stops collecting data because fresh data no longer sparks new insights or reveals new properties (Cres Well, 2014).

3.1.4 Sampling procedure

The participants for this study were enrolled using purposive sampling technique (Also called deliberate or non-probability sampling).This method of sampling involves purposive or deliberate selection of participants; moreover purposive sampling involves selection of key people who are knowledgeable, involved and affected(53). The potential donors are affected in the sense that in their family has a CKD patient who needs a therapeutic which involves a kidney transplant(53). The respondents of this study were the family members of the CKD patients who were accompanying their relatives at the renal clinic, the participants were approached and asked to participate in the study, signing the consent forms, then lastly was interviewed. The study participants were found at the renal clinic. These participants were accompanying their relatives who attend the CKD clinic every Wednesday**.**

3.1.5 Data collection tool

Data collection was done through a semi structured interview guide prepared in English and translated in Swahili language. Semi structured interview allows flexibility and probing questions, it is a very useful technique for exploring the views of a person towards something(54)Semi structured interview guide was translated into Swahili because is the language which was understood by the targeted population.

3.1.6 Data collection procedure

In this study data were collected by using In-depth interview, whereby an interview was conducted in the quite places this allowed participant to be flexible and gave rich information. The in-depth interview is suitable in exploring new issues in depth so as to get detailed information from the individual(53). The interview was recorded after getting consent from the participants. In the data the following procedure were followed**.** First the ethical clearance was requested from the director of research and publication at Muhimbili University of health and allied sciences. After getting ethical clearance from Muhas, this clearance together with the copy of the proposal were submitted to the head of teaching, Research and consultancy coordinating unit at MNH in order to get permission letter to collect the data in this institution. The permission letter was given and forwarded to the head of internal medicine department. The head of internal medicine department approved it and forwarded it to the head of renal unit who also approved it and allowed me to collect

data in the unit after being introduced in the department. The data were collected every Wednesday because is the day of CKD patient to attend clinic. After getting the desired information from the participants I thanked the head of department and all staffs in the renal unit, this marked the last day and so I started writing the report.

3.1.7 Ethical consideration.

An ethical clearance was obtained from the Research and Publication Committee at Muhimbili University of Health and Allied Sciences. Permission to conduct the study in Renal units were obtained from the director of Research unit and from the head of internal medicine of Muhimbili National Hospital. Furthermore, written informed consent outlining the purpose of the study, benefits and burdens, voluntariness to or not to participate in a study were obtained directly from each participant. The participant had the opportunity to withdraw from the study at any time. Confidential information shared between the researcher and the participant was anonymously recorded and then stored in a safe place. To ensure privacy the interview were carried out in a place where the conversation between interviewer and interviewee cannot be heard by third parties. In order to acquire the desired information were treated autonomously in concurrent with the ethical principle of respect for person which emphasize on treating individual as autonomous agent.

3.1.8 Data analysis plan

In this study content analysis were used to guide analysis of data by using Nvivo version 11.

Data obtained from in-depth interviews were daily read to gain the sense of the data. The data were transcribed into verbatim using Microsoft Word computer software and then translated in English to be identified by Nvivo software. The transcripts were read several times in order to familiarize and make sense of the data and compared with the audio recorded data.

The information were coded using in the text (in vivo) codes. Coding is a process of breaking data up through analytical ways and in order to produce answers about relationships within and among the data (55). It was an open coding in which a code word or phrase that accurately describes the meaning of the text segment were identified.

Categories and Sub categories were developed through examination and interpretation of codes. It involved noticing similarities, differences, and patterns among codes. Categories were further grouped to form main categories basing on study objectives. Broader meanings of the data were obtained by examining relationships among the identified categories.

3.1.9. Trustworthiness of the study

The trustworthiness of the study based on the ***credibility***, ***transferability***, ***dependability*** *and* ***conformability*** of the study findings.

Credibility this was ensured by selecting suitable participants, introducing them to the aim of the study and asking them permission to participate in the study. The principle investigator and research assistant were meeting regularly to discuss the progress of the research, also more probes were used ensuring that the perception and factors for ethical dilemma facing the potential donors regarding living kidney donation were clearly understood, moreover the interviews were recorded and notes taken to ensure that information provided is not missed, in additional the study was approved by the Institutional Review board (IRB) of Muhas and permission Letter to collect data was obtained from Muhimbili National Hospital.

Transferability refers to the degree to which the results of qualitative research can be transferred to other contexts with other participants; it is the interpretive equivalent of generalizability (56). In ensuring transferability the researcher provided a 'thick description' of the study setting and the way purposeful sampling was done.

Dependability refers to the "stability of findings over time"; getting the same findings if the research is repeated in the same context with the same subjects (56)**.** To meet this criterion, the researcher used an audit trail technique to record all activities of the study, including memos, field notes and made the raw data available.

Conformability establish that data and interpretations of the findings are not fabrications of the researcher's imagination, but are clearly derived from the data (57). This means that the research findings should conform to the data collected. This were achieved by use of direct quotes and ensure that findings are abstracted from experiences and ideas of the

participants and not the characteristics and preferences of the researcher, moreover interviews were recorded by using digital recorder to make sure that all information was captured.

CHAPTER FOUR

FINDINGS

Description of study participants

A total of 16 participants were interviewed, among them 8 were male and 8 were females. The participants were the family members of the CKD patient who are attending renal clinics at Muhimbili National Hospital. The study participants in this study are labeled as Potential donors. The number of sample size was reached after saturation point at which there was no new information or insights coming out from the respondents. Most of respondents aged 18-45, whereas the education level of the respondents 3 had primary education, 7 secondary educations and 6 tertiary educations.

Presentation of findings

Two major themes emerged: (a) perception of potential donors towards LRKD, this Theme has six sub-themes which are: misconception about LRKD, Fear of donating, and Education about organ donation (LRKD), decision making capacity, cultural beliefs and Religious beliefs. (b) Factors influencing ethical dilemma of PD, also this theme has three sub-themes which are family issues in decision making, potential risks and lack of money

Perception of potential donors towards living related kidney donation.

In order to have a great numbers of kidney donors their perception towards the issue has to be positive, in this study all sixteen respondents who were interviewed had positive perception towards Living related kidney donation, nobody who showed negative perception towards LRKD their major concern was “saving life”.

“*I have a positive thinking since is the act of saving life of my relative”* (R.11)

Another respondents when was asked her perception towards LRKD Pointed out that it is a good thing since is the act of saving life, moreover she said that kidney donation is something that needs understanding and sacrifice, a potential donor has to understand the

benefits and risks associated with kidney donation this will make him or her to make an informed decision making in order to value the dignity of the human person.

> "……*it needs understanding and sacrifice, if someone will understanding clearly the benefits and risk of it, then the person will value the dignity of the recipient, more importantly is to understand the health risk which will accompany the donor after donating" (R 10)*

From the answer given above it reveals that this person has a positive perception towards LRKD, but because of not having understanding on kidney donation this creates fear among people about donating. Moreover the study revealed that the following factors create negative perception to peoples hence this leads to the shortage of donors.

Misconception of organ donation (LRKD)

This study revealed that there different misconception in the society about Kidney donation (LRKD), hence this contributes to have negative perception of donating kidney. For example one of the respondents said that there some people who believe that when kidney is taken out is not taken directly to be transplant to the recipient.

> "…….*when someone donates kidney is not taken directly to be transplanted, there is the issues of witches that accompany this" (*R.11).

Another respondent commented that since people are not having right information about kidney donation peoples in the society think that a person is safer if she/he has two kidneys, hence this contributes to have negative perception towards kidney donation

.

> "*People are not donating because of having wrong information; others think that a person is safer if she/he has two kidneys"* R.09)

Moreover there those who believe that kidney donation can lead to death of a person who is donating something which is not correct.

> "…….*because of not having right information about kidney donation people are not donating, For example there people who says donation can lead to death of a donor"* (R.14).

Mostly these misconceptions are found in the streets where there are people who are not informed about LRKD and so they give improper information to people, one of the respondents commented;

> "*Misconceptions we get them from the streets from people who are not aware about kidney donation but if someone goes to the hospital and meets with experts the right information will be given*" (R.14)

Fear of volunteering to donate a kidney

The study also revealed that fear is among the causes of negative perception in the society hence this leads to the shortage of kidney donors. Fear is caused by not having correct information about LRKD.

> "……*what is contributing to the shortage of donors is fear, people are fearing what will happen if they donate*" (R.02)

The understanding of people in the society is that a human being is made up of two kidneys; therefore if one of the kidneys will be removed people think that might not function properly.

> " *The ordinary education which is in the society is that a human being is made of two kidneys, therefore the issue of donating might be difficult for them to take step since they fear what will happen when one of the two kidney is removed. Therefore a massive education has to be provided in the society*" R.16).

Education about Kidney donation (LRKD)

The study has revealed that most of the interviewed people showed there is a necessity of giving education to the society this will increase the number of donors but also will make them to have a positive perception towards LRKD.

> "*I will donate but after getting satisfactory education about it. I have to know when I donate what will be the side effects or if there is no side effect I have to know. I have to understand my safety since in the body there is two kidneys when one will be taken will I function as normal?, therefore if I will be given enough education on this I will donate*" (R.15)

Another respondent supported this by saying that there is a need of conducting seminars on kidney donation so as to equip people with knowledge about organ donation.

> "……..*there is a need of conducting seminars on kidney donation, to tell people that it is possible to live with one kidney, and there are people with good heart who can sacrifice themselves for the benefits of others"* (R.16).

The main reason of having few kidney donors is that people has not understanding about it as one of the respondent said.

> "……..*hence there is no other reason of having few donors, the main cause is understanding, is where there is a problem (R.10)*

Decision making capacity.

This study revealed that there people who cannot make independent decision so even this contributes to have few number of kidney donors. One of the respondents when asked if education might help to increase the number of donors replied as follows.

> "…….*Education is not the only thing that will make donors to increase, people has no independent decision making capacity making. Myself I can decide to donate and nobody who will ask me why I have taken that steps but another person might fear to donate because of somebody, someone might ask himself if I donate and in the future falls into sick how will my aunt comment……"(R.10)*

Religious beliefs

Religion has a great contribution to perception of people towards organ donation specifically living related kidney donation, the study revealed that among sixteen respondents nobody who said that religion and culture goes against organ donation

(LRKD). Most of the respondents said that their religion does not go against organ donation because it saves the life of people; it is a sign of valuing the dignity of a human person. One of the respondents said the following after asking if her religion prohibits kidney donation.

"*….It allows because we are saving life of a human being and all human being we are equal*" (R.03)

Another respondent replied the following,

"In the religion I have never made a follow up to see if it allows or not but I do not think if it prohibits because we are saving life of someone" (R.09)

One of the respondents commented that his region allows organ donation from the aspect of love.

"……..in our religion we are taught to love our neighbor as we love ourselves, if I am the one who has a kidney failure, would like to be helped, why should I not help the one who is in need, as I would like to be helped?....." (R.10)

Hence almost all the participants said that their religion (Christian and Islam) does not go against organ donation the main reason was that of saving life and valuing the human dignity.

Cultural beliefs

In the aspect of culture if it allows organ donation, nobody who mentioned that his/her culture goes against organ donation. One of the participant said that in their culture are allowed to do anything provided that it has a social value, this was her statement

"*……. Freeness of someone to choose what he/she likes provided that it has a social value, we are not restricted by traditions and customs*" (R.10)

One of the respondents from Kilwa said that before education his culture was against organ donation but after being educated all that culture was talking about has no meaning.

"*Before getting education our culture was against organ donation, but after getting education now I know that all that culture was talking about has no meaning"(11)*

When he was asked why the culture was against that this was his response.

"It *is because of customs that when you donate there is a possibility of problems, there is the issues of ancestors that can punish after donating, there is a misconception that when you donate that kidney is not taken directly to be transplanted, it passes through various stages hence because of the process where it passes the donor can get problems (bad fortune)"* (R.11)

Factors influencing ethical dilemma facing the potential donors towards living related kidney donation.

An ethical dilemma is a situation that has an ethical implication, where a person is in a doubt which of the two or more options available is the best to choose (is a situation that has an ethical implication in decision making). The study has revealed that the following factors can contribute to put people in a dilemma to donate (decision to donate or not to donate)

Family issues in decision making

The conflicts that arise in the family between the patients and the family member can cause these relative to be in a dilemma to donate because of the bad relationships among the family members. One of the respondents said the following concerning family conflicts.

"*Family conflicts is an hindrance to kidney donation, if the family is in conflict with the patient this can cause family to be in a dilemma to donate or not hence not to get a donor……..*" (R.11)

One of the respondents added that family conflicts can be a hindrance to kidney donation especially when someone has no independent decision making capacity, meaning that a

person personally in the family can have that will of donating to his or her relative, but at the same time she/he is thinking about the conflict that is existing in the family.

"In the family there can be someone who wants to donate but since the family is in conflict with the patient, the family can decide not to allow the family member to donate, this leads to this person to be in a dilemma " (R.13).

This was supported by another respondent but concluded that despite of conflicts in the family the patient has to be helped

> "*….sometimes the family members are not showing cooperation to the patient because of bad relations which led them to ask themselves whether to donate or not, but if someone is sick has to be helped despite of the existing conflicts*" (R.15).

One of the respondents gave a scenario (Family members are not showing cooperation to the patients who is a CKD, because this patient done a mistake in the past) that happened in her family where some of the family members neglected to show cooperation to the patient because of conflicts

> "*This one can happen but not all who will hesitate to donate because of family conflicts, there will be one who will feel mercy towards the patient. For example my patient, there people who are saying 'that is his disease' are saying so because of the fault which he did in the past, despite of those who are showing no cooperation there are those who are showing cooperation so as to help the patient. Therefore there two sides, not all who will neglect to donate"*. (R.16)

Another respondent said that, family conflicts can put him in a dilemma but because of the blood relationship which is there it is hard to let him/her die

> "*Family conflict can place me in a dilemma, if am not in a good relationship with the patient then to some extent it will be hard to donate, but at the same time that is my relative to let him die while there is a possibility to save him also is hard to conceive*" (R.02).

Moreover the study revealed that also family decision can make a potential donor to be in a dilemma, if the person is selected by the family member to be in the procedure of donating without consulting him/her this can put a person in a dilemma since the person has not exercised his/her autonomy in decision making.

> "*I can be in a mood of donating but the family does not like, or the family can appoint me to donate without my consent so this can put me in a dilemma, should I donate or should I follow the decision made by my family"* (R.13).

This was supported by another respondent who said that someone has to donate under his /her conscience and not of the influence of the family.

> "…….*It is better to donate under my control and not because of the influence of the family, when someone donates while in the conscience there is doubt I do not think if it is good*" (R.15)

Moreover another respondent said that

> "The *family decision can make me to be in a dilemma to donate or not to donate, I have to decide on my own not the family to decide on behalf of me, the family can decide for me to donate but I have the power to refuse*" (R.03).

Also the closeness of the family to the patient, the study revealed that can put someone to donate, this was put forward by one participant who said

> "…..*I have said a person himself has to decide not the family, when the family decides I will check who is suffering because there is mother, father and my children these are people whom I cannot hastate to help*" (R.09)

Potential risk of becoming a donor

The study also revealed that the minimal risk of donating, for example pains after surgery is among the causes of dilemma to potential donors.

> "*I have already seen people who have undergone surgery and now they are in a good condition. So for someone who has no education on potential risk this can put him/her in a dilemma to donate"* (R.12).

Most of the respondents said risk can put in the dilemma though some were not aware what kind of risk they can incur, one of them said

> "*am not aware what kind of risk I will incur because of donating, but if there is risk this can give me a question mark what will happen if I donate*" (R.15).

This was supported by another respondent who said

> "If *there is risk because of donating this can make someone to hastate, myself I do not know if there is risk after donating, so if someone will be told that donating a kidney has risk then because of the nature of human being the person will be in a dilemma*". (R.04).

Another respondent pointed out psychological torture as a risk that can make some to be in a dilemma to donate

> "*Psychological torture is there, how I will live with one kidney...., so this can make a person to be in a dilemma*" (R.O6)

Another respondent said that he will overlook these risks and concentrate on the health of the patient, but he agreed that for someone who has no education on kidney donation this cause a dilemma. He said:

> "I *will overlook these risks and concentrate on the health of my relative, but we differ in accepting things, for another person this can cause a dilemma especially for those who have no right information about kidney donation" (R.O7)*

Lack of money.

Some of the participant said that lack of money can make them to be in a dilemma to donate or not to donate. If a person like this will decide to donate, that will be done not because of love or affection but because of not having money to support him/her in life, especially if the patient was helping the family or the particular person who is suffering from renal Failure.

> "*This one can make me to be in a dilemma, I may decide to donate not because of love but because of money which I have been receiving from my relative who is suffering*" (R.07).

This was supported by another respondent who said

"You *can be tempted to donate not because of love but Lack of money is a push factor*" (R.04).

The study found that there some people whose poverty cannot be a pushing factor to donate.

> "*This one cannot push me to donate, I will decide out of love but to others this can be a pushing factor, they will donate not because of affection but because the patient was or is helping the family"(R.014).*

This was supported by another respondent who said

> *"For me this one cannot push me to donate, I will donate because of love not because of paying what she/he did to me, but to others this can motivate them to donate"* (R.016).

Moreover another respondent said that life is more than money.

> "I *repeat life is more than money, though for someone who was getting assistance from the patient who is rich, money can be an attracting factor to donate" (R.012).*

CHAPTER FIVE

DISCUSSION

Introduction

The main objective of this study was to explore the perception and factors influencing ethical dilemma of potential donors (PD) towards Living related kidney donation (LRKD). Therefore this discussion part of the study will focus on the following specific objectives which are to explore the perception of PD, to find out the factors influencing ethical dilemma of PD towards Living related kidney donation.

Perception of potential donors towards Living related kidney donation

All respondents had positive perception towards living related kidney donation. The reason of having positive perception towards LRKD is because of saving life, or acting for the benefit of their relatives as per beneficence ethical principle which emphasize on maximizing benefits and minimizing harms(36). Most of the participants are ready to donate but they fear because of not having right information about the all process of kidney donation.

Despite of seeing kidney donation as something that has to be promoted through giving education in the society some of the respondents agreed that there are factors that cause the number of donors to be few.

Lack of information about kidney donation

Almost all respondents **mentioned lack of information** as the main factor; this is same as the study done by Eusebio et al, 2009 which reported lack of education as the main factor in support of LOD(58). Many people in the society are not aware about kidney donation something that makes them to hesitate to donate which leads to the shortage of organ donors. Moreover the results of this study is in concurrent with a study done by Michelle et al in Australia which indicated that education has a stronger willingness to be an organ donor(59). Therefore in order to increase the number of organ donors education about kidney transplantation has to be provided in the society, this will clear any misconception about kidney donation in the mind of people, this will lead to have positive perception towards kidney donation.

Misconception

Misconception is one of the factor that affect perception of people towards kidney donation this leads to the shortage of live kidney donors, this is caused by lack of appropriate information about kidney donations. The study done by Ehsan S, et al, 2011 showed that misconception contributes to organ donation, this study showed that people believes that organs for donation comes from addicts and poor people(21). the poor people are in the group of vulnerable people (people who cannot protect their own interest) so to use them for organ donation is not ethical since they will be used as an object something which goes against the human dignity as per Kantian categorical imperative which insist on treating humanity as an end in itself and not as a means towards an end.

Fear of becoming a donor

also contributes to shortage of live donors; this is because of not having correct information about kidney donation, this is the same as the study which was done by Eusebio et al,2009 which showed that the main causes of shortage of donors were lack of knowledge and fear of donation process(58). One of the respondents said that the aspect of surgery makes people fear to donate, but also they fear of what might happen in the future because of having one kidney. The results of this study also is similar to the study which was conducted in Iran by Hosseinrezaei et al which indicated fear of donation as one of the factor for the refusal to be an organ donor(60)

The study also shows that there are some people who might neglect to donate because of the influence of the family something which is not ethical as per respect of person principle, this principle insist on respecting the autonomy of the person, a person has to exercise his autonomy to make a free decision making. For example one of the respondents shared to me that a person was stopped by his mother to donate a kidney to his father because of the family conflict which existed a number of years.

Religious beliefs

Religious beliefs is one of the factor that affect the perception of people towards kidney donation, hence it can make people to have positive views or feelings or opinions about kidney donation this prompts to have positive perception towards Living kidney donation, Moreover religious beliefs can make people to have negative perception towards Living related kidney donation hence this makes a donor to have feelings, opinions which are against kidney donation because of having negative perception or feelings and opinions. The participants of this study were Muslim and Christian all admitted that their religious beliefs do not go against kidney donation because is the act of saving life. The study done by Rithalia et al indicated that catholic denomination favors organ donation as its beliefs recognize organ transplantation as a service of life(61) This is different from the study done by Aaron et al which found that in Confucian concept of 'filial piety' which dictates that "individuals out of respect of their ancestor, are required to return their bodies in the same condition as they received from their parents" because of this it is wrong to interfere person's efforts to return his/her body intact by removing from it(23). Hence in Confucian religious beliefs, the concept of filial piety creates in mind negative perception towards kidney donation. Therefore in order to increase the number of kidney donors it is vital to scrutinize the religious beliefs of various religion and denominations if their beliefs are supporting organ transplantation specifically kidney donation.

Cultural beliefs

Cultural beliefs have a great impact in organ donation, it can cause people to have positive views/feelings/opinions about it or it can cause people to have negative views or opinions about organ donation (kidney donation) in turn this leads to have fewer numbers of organ donors (kidney donors) hence shortage of kidney donors. The study found that cultural beliefs of respondents did not have objections towards kidney donation with exception of one respondent from Kilwa who narrated that before being given education on organ donation his culture was against kidney donation.

The results of this study is different from a study done Rachael et al which found that people have cultural beliefs that object organ donation because of believing that there is a transfer of the spirit from the donor to recipient(29). Also this study found that there is a

society in kilwa which object organ donation because of ancestral issues, that the ancestors can punish a person who has donated his/her kidney, this is concurrent with the study done by Michelle et al Australia which indicated that the community needs ancestral consent before donation this enables the remaining family not to lose ancestral protection in the future(59).

Factors influencing ethical dilemma facing the potential donors towards Living related kidney donation.

The study also shows that the ethical dilemma (to donate or not to donate) that faces the potential donors towards LRKD can be because of family decision, a family can decide for a family member to donate this means that the decision to donate has not come from the person himself but because of the family influence, this is the same as the study done by Grenvik A, 1988 which indicated that the potential donors can be in an ethical dilemma because of being subjected to pressure and coercion from the family members (48)This is against the respect for person principle which insists on respecting the autonomy of the person. The decision to be a donor must be informed and voluntary, all components of informed consent process which are appropriate information, comprehension and voluntariness has to be taken into consideration when evaluating the potential donors.

Moreover the family conflicts puts the potential donors in the dilemma whether to donate or not to donate, if the family member will not show cooperation to the patient because of the conflicts hence this is the act of doing harm and it is against non-maleficence principle but also is an act of maximizing harm to the patient. The study done by Martin A, et al,2001 indicated that consent to donation is less likely when there is family conflict(49).

Moreover the study shows that the respondent pointed out that organ donation has potential risk which makes them to be in a dilemma to donate. To take out an organ from the body is a process, an organ is not taken simply but a donor has to pass into various medical evaluations in order to make sure donation does not pose any unusual risk to the donor and recipient, despite of this information still people are fearing to donate because of potential risk for example risk of surgery. The study done by Rizwan M et al 2018 indicated psychological risk, problem with body image, possibility of post-surgery adjustment and

possibility of recipient rejection and needs for re-transplantations as a barrier to organ donation(27)

Lack of money also were indicated by the respondents as one of the causes of ethical dilemma, this happens when someone who is/was financially dependent to a patient who needs a transplant. This person can be in a dilemma to donate not to donate and if she/he decides to donate this will be not because of affection but because of paying back what she/he received. If a person gets a kidney from a vulnerable person this means that she/he is using that person as a means towards an end, something which goes against Kantian categorical imperative which insist on respecting human dignity by treating it always as an end in itself and not as a means towards an end something which is unethical.

Limitation of the study

There are two major limitations that could be addressed in this study First this is a qualitative study; hence the findings cannot be used to generalize to other potential donors in this country or elsewhere but still the study brings a valuable knowledge on how to increase the number of kidney donors, second limitation is about the inability of the research to include other potential donors who were not accompanying their relatives at the clinic. This is due to the fact that the participants of this research were found at the clinic whereby they were accompanying their relatives.

CHAPTER SIX

CONCLUSION AND RECOMMENDATION

Conclusion

Most of people have positive perception towards the issue because it helps in saving life of people. but what contributes to shortage of kidney donors as a study revealed are misconceptions, power to make decision, lack of knowledge and fear in short all these factors can be summarized in one sentence that people have no correct information/lack of information about kidney donation (LRKD) these contributes to have misconceptions about it which leads to fear.

The issue of religion has a great impact in organ donation, as the study revealed that all respondents who participated in this study said that religion (Christian and Muslim) does not go against organ donation; it is taken as the kind of generosity or affection. Some of the participants said that life is a precious gift so has to be protected. Hence religion promotes organ donation but has to be done ethically, that people has first to be educated about it so as to enable them to make an informed decision making as per respect of person principle, but also has to be done in a manner that it benefits all subjects that is donor and recipient as per beneficence principles.

The issue of culture also respondents said that it does not object organ donation (Living related kidney donation) with the exception of one participant from Kilwa- Lindi (Wangindo tribe) who said that before being given education their culture was against organ donation, in the sense that when someone donates ancestors can punish him/her but after being given education now they know that what was said by culture has no reality it was the matter of education that is what was missing in that particular family (Society).

Therefore as the study revealed that people have positive perception (they support it) towards organ donation because it saves life but what is missing is lack of information about it something that creates various misconceptions in the society and ethical dilemma, hence enormous education has to be provided in the society.

Recommendation

i) The main factor for the shortage of kidney donors is lack of education; hence there should be national campaign in educating the society about kidney donation. Means like mass media, social media has to be used to spread this information. The responsible bodies like ministry of Health should play their role in educating the society about kidney disease and how to abstain it but also the issues pertaining to donation.

ii) The number of CKDs is increasing each day; therefore there is a need of educating the society about the causes of renal failure so to make them abstain risk factors for kidney failure.

iii) Another study which will include a big community has to be done to explore the perception of the community about kidney donation. This is due to the fact that participants of this study are just a part (Representative sample) of a bigger community which might have different perception about living related kidney donation.

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Appendix 1: INTERVIEW GUIDE (English version)

- PERSONAL INFORMATION a) Gender….. ….Age……., Level of education…….

1. What is your perception towards living related kidney donation (LRKD)?
    a. Probe: As a family member of a CKD Patient are you ready to donate?/ why
    b. Probe: Does your culture allow you to be a kidney donor?
        - .insights from your culture which allow/not allow
    c. Probe: Does your religion allow you to be a kidney donor?
        - Insights from your religion which allow/ not allow
    d. Probe: Do you think Living donations can be a way to overcome the organ shortage?
    e. Probe: do you think there is a need of obtaining your consent in order to be a donor?
    f. Probe: Do you think misconceptions about LRKD can accelerate to have negative/positive perception towards LRKD?
    g. Probe: Do you think having adequate knowledge (correct) on LRKD can increase the number of live donors?

2. What are the factors for ethical dilemma facing the potential donors towards living related kidney donation?
    a. Probe: Do you think family decision can lead you to be in a dilemma to donate (if forced/ not under your will)
    b. Probe: Do you think poverty can make you to be in a dilemma to donate?
    c. Probe: Do you think potential risk can lead you to be in a dilemma to donate (physical injury etc.)
    d. Probe: Do you think the family conflicts can cause you to be in an ethical dilemma to donate?

Appendix 2: INTERVIEW GUIDE (SWAHILI VERSION)

(I) Taarifa za muojiwa a) Jinsia……., B) Elimu Yako……., C) umri……

1. Nini mtazamo wakojuu ya utoaji hai wa figo kwa mwanafamilia

a. Dodoso: Kama mwanafamilia wa mgonjwa wa figo, je uko tayari kujitolea figo kwa ndugu yako?

b. Dodoso: Je, utamaduni/ milazinaruhusukujitolea figo?
   - ❖ Ni vitu gani kutoka katika utamaduni wako vinaonyesha kukubalianana dhanahii (kujitolea figo)
   - ❖ Ni vitu gani kutoka katika utamaduni wako vinapingana nadhanahii

c. Dodoso: Je, diniyakoinaruhusu kuchangia figo?
   - ❖ Ni vitu gani vinavyooshesha kuwa dini yako inakubaliana na dhanahii.
   - ❖ Ni vituganivinavyooshesha kuwa dini yako inapinganana dhanahii?

d. Dodoso: Je, unafikiri kuwa na taarifa zisizosahihi zinaweza kupelekea mtu kuwa na mtazamo chanya au hasi juu ya kujitolea wa figo kwa ndugu?

e. Dodoso: Je, unafikiri kuwa na maharifa sahihi kuhusu utoaji hai wa figo kwa ndugu unaweza kuongeza kujitolea figo kwa ndugu?

1. Ni sababu gani (njia panda) zinazoweza kukuweka katika Mkanganyo wa kimaadili katika katika kutoa figo.
   a) Dodoso: Je, unafikiri maamuzi ya kifamilia yanaweza kukuweka katika mkanganyo (njia panda) wa kimaadili katika kuchangia figo (kama umelazimishwa/ sio maamuzi yako)
   b) Dodoso: Je, unafikiri umaskini wakipato unaweza kukuweka katika mkanganyo wa kimaadili katika kuchangia figo.
   c) Dodoso: Je, unafikiri madhara ya kuchangia figo yanaweza kukuweka katika mkanganyo (njia panda) ya kuchangia figo?
   d) Dodoso, Je unafikiri migogoro katika familia inaweza kukuweka katika mkanganyo wa kimaadili katika uchangiaji figo?

Appendix 3: Informed Consent – English Version

Identification Number _____

Title: "The Perception towards living related kidney donation among potential donors at Muhimbili National Hospital"

Consent to Participate In the Study

Greeting! My name is **Emmachius Emmanuel** a student from Muhimbili University of Health and Allied Sciences (MUHAS). I am currently conducting a study titled **"The Perception towards living related kidney donation among potential donors at Muhimbili National Hospital"** at Muhimbili National Hospital

Purpose of the Study

The study is conducted in partial fulfilment of the requirement for the Degree of MSc. Bioethics with the aim of exploring the perception of potential donors towards living kidney at Muhimbili National Hospital renal unit. Please be honest and open because the result of this study may help to plan intervention so as to increase the number of kidney donors since worldwide there is the shortage of kidney donors (organs).

What participation involves

We ask you to participate in the study because you are a relative to a CKD patient who needs a kidney transplant. If you agree to participate in the study you will be asked questions on your knowledge and perception of living related kidney donation

Confidentiality

All information obtained from you will be treated as confidential and will be used only for the intended purposes of this research. Names or any other identifying features will not be documented during the interview with a researcher.

Benefits of participating in the study.

Information obtained from this study might help in the planning of intervention/ programs of educating the society on organ donation specifically related kidney donation in order to increase the number of kidney donors so as to save the lives of CKD patients and removing the burden of dialysis which cost them a lot of money.

Potential Risks

We do not expect any harm to you as a result of your participation in the study.

Right to withdraw

You have the right to participate or not to participate in the study without giving any reason for your decision. When you have decided to participate you are also free to terminate your participation at any time in the course of the study.

Contacts

If you have any questions about this study you are free to contact, the principal investigator, Emmachius Emmanuel (0764491480) or kemmachius@yahoo.com

If you have any questions/concerns about your rights as a participant you may contact Chairman of MUHAS Research and Publications Committee Dr Bruno Sunguya P.O.BOX 65001 Dar es Salaam. Telephone number: 2150302-6, Supervisors Dr Paschal Ruggajo 0688362635 and Mr. Baraka Morris 0658340094.

If you agree to participate in this interview, please sign this consent form.

I …… have read and understood the contents of the consent form and my questions have been answered adequately. I, therefore, consent to participate in the interview regarding the study.

Signature of the interviewee ……..... Date ……

in of the interviewer ……....……. Date ……

Appendix 4: Informed Consent – Swahili Version
FOMU YA RIDHAA

Namba ya Utambulisho _____

Utafiti: "**Mtazamo kuhusu kujitolea figo ya kupandikiza baina ya wanandugu."**

Ridhaa ya kushiriki kwenyeutafiti

Habari! Jina langu ni Emmachius Emmanuel, mtafiti kutoka chuo cha afya na sayansi shirikishi Muhimbili. Kwa sasa nafanya utafiti kuhusu "**Mtazamo kuhusu kujitolea figo ya kupandikiza baina ya wanandugu."**

Lengo la utafiti

Utafiti huu unafanyika kama sehemu ya kukamilisha Shahada ya Uzamili katika Maadili ya Ki afya katika Chuo Kikuu cha afya na Sayansi shirikishi Muhimbili. Utafiti huu una lengo la kuchunguza mtazamo nauelewa wa wanandugu wa mgonjwa anayeumwa figo kuhusu uchangiaji wa figo. Matokeo ya utafiti huu utasaidia kuanzisha program za utoaji elimu kuhusu uchangiaji figo ili kuongeza idadi ya watuwanaoweza kuchangia figo ili kukabiliana na upungufu wa wachangiaji figo.

Nini kinahitajika ili kushiriki

Tunaomba ushiriki wako katika utafitihuu kwasababu wewe ni ni mwanafamilia wa mgonjwa mwenye tatizo la figo, kwa hiyo kwa namna moja au nyingine unaweza ukawa mmoja wapo wa ndugu unayeweza kumchangia figo ndugu yako.Ukikubali kushiriki utaulizwa maswali kuhusu mtazamo nauelewa wako kuhusu uchangiaji hai wa figo kwa ndugu.

Usiri

Taarifa zote utakazotoa zitakuwa siri na hazitatumika kwa matumizi mengine mbali na utafiti huu. Majina au makala nyingine yoyote yautambuzi haitachukuliwa kama kumbukumbu wakati wa mahojiano na mtafiti.

Faida za kushiriki katika utafiti

Taarifa zitakazopatikana kutokana na utafiti huu, zitasaidia katika uandaaji programu zitakazosaidia kutoa elimu katika jamiijuu ya utoaji hai wa figo ili kuwasaidia wagonjwa walio natatizo la figo kufanyakazi, hiini kwa sababu kutakuwepo naongezeko la watu wanaotaka kuchangia figo ilizipandikizwe kwa wagonjwa.

Athari

Katika utafiti huu hatutegemei madhara yoyote kwa mhojiwa kwa kipindi chote cha utafiti au hata baada ya utafiti huu.

Haki ya kujitoa katika utafiti.

Unao uhuru wa kushiriki katika utafiti huu au kutokushiriki pasipo kutoa sababu yoyote juu ya hatua utakayokuwa umechukua.Ukishakubali kushiriki katika utafiti huu na ukaona kwamba huwezi kuendelea unao uhuru wa kusitisha ushiriki wako muda wowote wa utafiti.

Mawasiliano

Kama utakuwa na swali lolote kuhusu utafiti huu unaweza kuwasiliana na kiongozi wa utafiti huu ambaye ni Emmachius Emmanuel - 0764491480 au barua pepe-kemmachius@yahoo.com

Kama utakuwanaswalijuu ya hakiyakokamamshiriki unaweza kuwasiliana na Mwenyekiti wa kamati ya utafiti na machapisho ya chuokikuu cha afya na sayansi shirikishi Muhimbili, Dr Buruno Sunguya kwa anuani S.L.P 65001 Dar es Salaam. Simu ya mezani: 2150302-6, pamoja na wasimamizi wa utafiti huu Dr Paschal Ruggajo 0688362635 na Mr. Baraka Morris 0658340094.

Kama umekubali kuhojiwa, tafadhali saini hapa:

Mimi…….nimesoma nakuelewa kilichoelezwa kwenye fomu hii na maswali yangu yamejibiwa kiufasaha. Hivyo ninakubali kuhojiwa kwaajili ya utafiti huu.

Sahihi ya mhojiwa …….. Tarehe ……..

Sahihi ya mhoji……..…… Tarehe……

Appendix 5: Ethical Clearance

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES

OFFICE OF THE DIRECTOR OF POSTGRADUATE STUDIES

P.O. Box 65001
DAR ES SALAAM
TANZANIA
Web: www.muhas.ac.tz

Tel G/Line: +255-22-2150302/6 Ext. 1015
Direct Line: +255-22-2151378
Telefax: +255-22-2150465
E-mail: dpgs@muhas.ac.tz

Ref. No. DA.287/298/01A/ 14th February, 2019

Emmanuel Emmachius,
Master of Science in Bioethics,
MUHAS.

RE: APPROVAL OF ETHICAL CLEARANCE FOR A STUDY TITLED: "KNOWLEDGE, PERCEPTION AND ETHICAL DILEMMA OF POTENTIAL DONORS TOWARDS LIVING RELATED KIDNEY' DONATION

Reference is made to the above heading.

I am pleased to inform you that, the Chairman has, on behalf of the Senate, approved ethical clearance for the above-mentioned study. Hence you may proceed with the planned study.

The ethical clearance is valid for one year only, from **22nd January, 2019 to 21st January, 2020.** In case you do not complete data analysis and dissertation report writing by **1st January, 2020,** you will have to apply for renewal of ethical clearance prior to the expiry date.

Dr. Emmanuel Balandya
ACTING: DIRECTOR OF POSTGRADUATE STUDIES

cc: Director of Research and Publications
cc: Dean, School of Public Health and Social Sciences, MUHAS

Appendix 6: Permission Letter to Collect Data at MNH

MUHIMBILI NATIONAL HOSPITAL

Cables: "MUHIMBILI"
Telephones: +255-22-2151367-9
FAX: +255-22-2150534
Web: www.mnh.or.tz

Postal Address:
P.O. Box 65000
DAR ES SALAAM
Tanzania

In reply please quote: MNH/TRC/Permission/2019/020 26th February, 2019

Head of Department,
Internal Medicine (Renal unit)
Muhimbili National Hospital

RE: PERMISSION TO COLLECT DATA AT MNH.

Name of students	**Emmanuel Emmachius**
Title	" KNOWLEDGE, PERCEPTION AND ETHICAL DILEMMA OF POTENTIAL DONORS TOWARDS LIVING RELATED KINEY DONATION
Institution	Muhimbili University of health and Allied Sciences
Main Supervisor	Dr. Paschal Ruggajo
Co – Supervisor	Mr. Baraka Morris
Period	26/2/2019 to 30/08/2019 (6 months)

The above named student has been permitted to collect data for the above study.
Please ensure that the researcher abide to the ethical principle and other conditions.

Sincerely,

Dr.Faraja Chiwanga
Head of Teaching, Research and Consultancy Coordination Unit

HEAD, TEACHING, RESEARCH & CONSULTANCY UNIT
P. O. Box 65000
DAR-ES-SALAAM
MUHIMBILI NATIONAL HOSPITAL

c.c DMS
c.c. **Emmanuel Emmachius**

HOD - Renal
Study site
and facilitate
him
accordingly

04/3/19