

Knowledge, Attitude, Barriers and Enablers to Kidney Donation From Caregivers' Perspective: A Qualitative Design

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ABSTRACT

Background: Globally, chronic kidney disease is a growing cause of death. Although kidney donation can help lower mortality, there is a clear organ shortage. Data on the obstacles and enablers of kidney donation, as seen from the perspective of caregivers, are scarce. **Objective:** To investigate the knowledge, attitudes, and enablers of participants towards kidney donation. **Materials and Methods:** Nine caregivers from a Nigerian tertiary hospital participated in a focus group discussion. The audio recordings were transcribed verbatim before being thematically analyzed. **Results:** The focus group participants included five males and four females with a mean age of 38.25 ± 9.53 years. Most participants agreed that kidney donation is the act of giving one's kidney to someone else who is in need of it in order to save that person's life and that most kidneys come from voluntary donors who do so out of compassion for others and for financial gain. Most participants said that they will not donate or encourage someone else to donate because of the risks associated with surgery and living with one kidney. Participants suggested that incentives including financial gains, free medical care for living donors, and public awareness of the risks and benefits of kidney donation could persuade more people to donate their kidneys. **Conclusion:** The study's findings demonstrate a high level of understanding regarding kidney donation. It draws attention to the carers' reluctance to donate and suggests tenable ideas which could motivate others to come forward as kidney donors.

Keywords: attitudes; barriers; facilitators; kidney donation; knowledge

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INTRODUCTION

Chronic Kidney Disease (CKD) affects 1 in 10 persons in the general population and is an emerging cause of death among non-communicable diseases. [1] Kidney Transplantation offers cure in the management of persons with CKD who end up in kidney failure. Despite the usefulness of this procedure, inadequate supply in the face of high demand has resulted in long waiting time and death. [2] Several factors may be responsible for organ scarcity, notable among them is the knowledge and willingness of healthy persons to donate their kidneys.

Few cross-sectional studies in Nigeria have reported that about two-third of their participants are aware of kidney donation. [3,4] These studies show that being aware does not translate to willingness to donate but highly correlated with it. [3,4] Being a medical personnel were a significant predictor of willingness to be a kidney donor. [4]

There is dearth of data on the understanding of kidney donation in Nigeria from the perspective of caregivers. Previous studies highlighted above have utilized researcher-designed questions to assess awareness and knowledge using categorical responses (yes/no answers). This has inherent setbacks as it does not necessarily allow participants to express their views with regards to the subject; rather, they are constrained to tick responses as provided by the researcher. This study aimed to bridge this gap by using a more rigorous methodology (i.e., qualitative design). Based on the foregoing, the pertinent question is: what are the perceptions, barriers and enablers to kidney donation among caregivers in a Nigerian tertiary hospital? The primary aim of this study was to explore participants' knowledge, attitudes, barriers and facilitators to kidney donation.

MATERIALS AND METHODS

Study design

Focus group discussion with content analysis was chosen as the appropriate method to obtain information about knowledge, attitudes, barriers and enablers to kidney donation among caregivers.

Focus groups were chosen because they are known to open up numerous channels of communication between participants while simultaneously lessening the researcher's impact, giving participants more power and allowing them to express their ideas and opinions in front of others. [5]

Participants, sample size and sample selection

Study participants were caregivers aged 18 years and above whose family members were admitted in the study setting. Nine caregivers were selected purposively to ensure inclusivity of various adult age groups, gender and educational attainment. One participant declined to join the study because she was busy with caregiving. However, among those who were enrolled, there were no dropouts.

Data collection

A face-to-face strategy was used to conduct the focus group in June 2023. A semi-structured discussion guide (Table 1), created by the study team served as the basis for the 45–60-minute-long conversation. Instead of acting as a rigorous questionnaire, the guide provided a flexible framework for examining study issues and eliciting unconditioned responses. The primary goal of the focus group discussion was to examine the knowledge, attitude, hurdles, and enablers of kidney donation among the participants. The secondary aim was to explore suggestions on strategies to encourage kidney donation in the general population.

In order to provide an unstructured environment free of pressures, the focus group was held in the hospital hall away from the wards. At the start of the discussion, participants were given a thorough explanation of the study's objectives. Informed consent was then obtained, and participants were given the choice to leave at any time if they felt uncomfortable or unable to continue talking. To avoid the perception of a regulated environment, ground rules were made by consensus among participants and moderator to facilitate the functioning of the focus group. Discussions were fluid and dynamic with adequate interaction among participants. The groups were conducted by a

research assistant who has a university degree in social sciences with prior experience in qualitative research, and underwent additional training for the purpose of the study. He was responsible for facilitating and guiding participation and discourse elaboration, while the content of discussion was recorded in audio formats. An additional research assistant took notes during the discussion. No relationship existed between the study participants and the research assistants prior to the interview. The recordings were played back to the participants for further comments and corrections.

Data analysis

The audio recordings were transcribed verbatim and then analyzed thematically using manual means. Transcripts were carefully read and reread by the third author, then segments of text were coded, synthesized and integrated into categories based on similarities of meaning. A general inductive approach was employed to code data and coding continued until no new concepts emerged from the data. Inductive approach was preferred because of the need to build the theme from the scratch using the study dataset. Coding consistency was checked by other co-investigators (two nephrologists) to ensure trustworthiness and theme confirmation was reached after discussion among three co-investigators. For the purpose of coding, the dataset was broken into smaller samples and read carefully. Codes were created using short phrases as new datasets were read. Where codes didn't match, new codes were created. These codes were further categorized into themes. Themes were summarized and interpreted using a contextualist approach where the context of the study setting was used to understand the perception of the participants. Ethical approval was obtained from the Institutional Review Board (CEHRAT/IRB/005/023).

RESULTS

There were nine participants, five males and four females. The mean age of participants was 38.25 ± 9.53 years. They were mostly married

(66.7%), had tertiary education (66.7%) and Christians (88.9%) as shown in Table 2.

Knowledge of kidney donation

Kidney Donation as Giving One's Kidney to Another Person Who Needs It to Save the Person's Life

All participants described kidney donation as giving of one's kidney to another who needs it to save the persons' life.

"kidney donation to me is a thing that we do, like it's a process to save life like giving one of your kidney; everybody has two kidneys so kidney donation is you giving one of your working kidney to somebody who has kidney failure who needs it, who really needs it not those who can still manage with drugs, somebody who really needs it through kidney surgery or kidney transplant. Thank you." (Participant C004)

"Yeah it's just donating one of your kidneys to a patient that needs it just to save his or her own life." (Participant C008)

Persons at the Extremes of Life Should Not Donate

Most participants agreed that persons at the extremes of life (i.e., children and the elderly) are not supposed to donate their kidneys.

"Yes babies cannot donate let's say from zero to 12 years even early teenagers at 13 cannot donate, then aged people from 60 up cannot donate it will not go well with them." (Participant C009)

Nature Made It Two, Living Well With One, I See No Possibility

Many participants felt that living well with one kidney is impossible while a few noted that living with one kidney is possible but leaves uncertainties.

"Living normal with one kidney, I'm not seeing the possibility because from the creation we have been created to have two kidneys and we are from the motivation of human being it was given to us to have two kidneys so telling me to live with one, I'm not seeing the possibility." (Participant C004)

"I can say that God gave us two kidneys so it is good donating a kidney to somebody who needs a donation but the problem is that you may donate a kidney thinking that the other one is okay, is functional is very okay when you donate one and you now have one, assuming that other one has problem what would that person do. So if that remaining kidney is okay the person can still live well but assuming that it develops problem along the line, it becomes another problem altogether. So the person may not live right as such." (Participant C007).

Sources of kidney

Voluntary Donors on Humanitarian Ground and Financial Gains

Most participants (six out of nine) stated that kidneys are usually given by voluntary donors on humanitarian grounds or for financial reward.

"Voluntary donors and people who turn into business to selling their body parts or however they want to do it and relatives who decide if their loved ones on their deathbed they can sign and say that they can take any of their functional organs. That's all I think I know about that." (Participant C005)

From Cadavers with Prior Consent

Two participants stated that kidneys could be sourced from dead persons who gave consent for their organs to be harvested to save others.

"Well we have some institutions where we have those who go there to donate parts of their body when or maybe the person is down with another ailment that does not affect the kidney or the eyes they go there to fill documents that when they are dead, parts of their body should be harvested to save lives." (Participant C003)

One participant noted that kidneys are sourced from involuntary donors who may have committed a crime.

"Some countries whenever they caught some criminals like China, China does it;

they harvest their organs like kidney and some other parts before killing them if you understand".

Attitudes towards kidney donation

Not Favorably Disposed to Donate or Encourage Another to Donate their Kidney

Half of the participants who responded to this question stated that there were not favorably disposed to donate or even encourage others to donate due to uncertainties of living with one kidney.

"I won't allow my relative to donate kidney because you're not even sure of the remaining one, it might fail you tomorrow so you may find it difficult to getting another person to donate to you. So I won't try it or support anybody." (Participant C009)

"No encouragement from me. I cannot encourage anybody, even I won't encourage myself to donate because it's full of risk."

The other half stated that kidney donation is a personal decision and won't discourage anybody from donating provided the person is fully informed.

"That one is hard o. As a natural rule, I don't convince anybody to do anything. But if I'm to say anything I'll make sure the person understands the risks and the importance of whatever he's doing. If he knows every risk that is involved and he decides to, fine. But for me to encourage... the only thing I'm going to encourage is for him to understand what he's trying to do if he understands it himself, I'll tell him to ask a lot of people around, you know, gets everything 100percent understand what he wants to do then he can go ahead and do what he wants to do." (Participant C007)

"for me, I won't encourage and I won't discourage. Kidney donation should be a personal decision. I can only help you understand what you're getting yourself into making sure you get the full details and if you choose to donate I would support you but If you choose not to donate I would also

support you. It's a personal decision because after the whole surgery you're the person who's going to be living with one kidney that is remaining I, it's not going to be me though I'll be there to support you as a family member or as a friend. Another thing why I won't directly support you to donate is when problem pops up tomorrow or when you have reasons to look for somebody to donate for you tomorrow, it will turn to you're the one that encouraged me to go and donate o. But if you choose to I'll support you but if it doesn't then I'm not going to be the forefront pusher." (Participant C004).

Barriers to kidney donation

The Uncertainty of Living with One Kidney

Almost all the participants stated that the major barrier to donating kidney is the uncertainty

"What will make me not to donate is the risk of the other kidney failing because if the other kidney fails you, you will not find somebody that will donate for you that is the main reason like when the other kidney fails you, you will start looking for somebody that will donate to you so that is the risk that's I am emphasizing on. If I donate my own when the other one that is remaining has problem the person that will donate for you may not see the person so that is what will make me not to donate." (Participant C006)

"Well what will make me not to donate is the risk involved is in fact what will discourage me from donating. The risk is too much and the other kidney if you donate the other kidney may fail you, so what are you going to do, who is going to take care of your people, your children also your loved ones you left behind so the risk involved is just what is going to discourage me from donating." (Participant C009).

Enablers to kidney donation

Only if a Nuclear Family Member is Involved

About 40% of the participants noted that they may consider donating their kidney only if a nuclear family member is involved.

"Well, if I'm to donate, if it is compulsory that I'll donate, it will be to my husband or my child... But as for any other person... laughs. I don't think I would do so". (Participant C009)

"The only thing that will make me donate is my loved ones like my husband or my child. If I should say let me donate for my husband, what of the risk surrounding it. So if the risk should arise both of us will suffer from the same thing, who is going to be caring for one another. If both of us should leave, who is going to take care of our children? So I can't do it." (Participant C002)

Love and Compassion

Another 40% noted that it is only love and compassion for the suffering person that can influence them to donate their kidneys.

"It's love, love and care. If you love such person and you want the person to stay alive you donate." (Participant C003)

".....for the love." (Participant C008)

Monetary Gains

One participant stated that the major factor that will encourage them to donate is for financial gains.

".....: Ermm. I will do it for money."

Suggested ways to encourage people to donate their kidneys

Public Education on the Risks and Benefits of Kidney Donation

Three out of nine participants were of the opinion that public education on the risks and benefits of kidney donation should be mounted to dispel ignorance and allow people make informed decisions about becoming a kidney donor.

"Well, I would advise a lot of NGOs comes in to enlighten people that can join hands, okay, I have a terminal illness I might die tomorrow, you can come to an NGO fill the form, when I'm dead you can harvest my kidney and give to somebody who needs it"

upfront. Then we can also encourage people to donate. There are ways that we understand things when it comes to explaining things to people. Okay you came to me and said you want to donate a kidney to somebody, the way I'll shout, putting fear into the person before explaining to the person what to do, it's a bad thing. So I think calming the person down to understand that it's not really a 100 percent die affair. I believe we still have those who live a good life with one kidney. Then bringing them to spotlight, bringing them to TV shows to encourage people to tell people that they live with one kidney and they live a good life with it telling them how they survive how they live you know. I think people that are, its person who wears the shoes knows where it pains them most so if they come out to sensitize the people on what it is I think people will start to see reasons why to donate. Then giving assurance after the whole scenario too, i have free medical attention at any time. I think that will also encourage people too to donate.” (Participant C004)

Two participants stated that giving free medical services to previous donors across the level of health care systems will encourage other people to donate.

“ Well to me, my own point of view, ... is to let the person know you have free medical attention. If there's any issue arising the person will not spend that money that you give that person. Free medical attention that's how I can my own or any other person, don't worry even anything that happen everything's free come to my clinic, come to my hospital or anywhere we'll handle your case without spending anything.” (Participant C003)

Giving Monetary Reward to Donors

Another two participants believe that giving money to donors may be a reasonable incentive to donate.

“What will be done like people like money; when you give them tangible amount it's can encourage the person and the person will donate that is the only thing I think and we make some body to the needs like tangible amount when you give that person and you give the person assurance that nothing will happen to the other one.” (Participant C006)

Giving Free Medical Services to Donors

Table 1. Interview Guide for the Caregivers

Serial number	QUESTIONS
1.	What does kidney donation mean to you?
2.	Can a person live normally with one kidney?
3.	Do you think there's any age limitation as to kidney donation?
4.	What do you think are the sources of this kidney donation?
5.	Will you donate or encourage your family member or relative to donate kidney?
6.	What are the things that will make you not to donate kidney?
7.	What can influence you to donate kidney?
8.	What do you think can be a way to encourage people to donate kidney?

Table 2. Socio-demographic Characteristics of the Study Participants. (N=9)

Variables	Frequency (%)	Mean (SD)
Age (years)		38.25 (9.53)
Gender		
Male	5 (55.6)	
Female	4 (44.4)	
Level of Education		
Secondary	3 (33.3)	
Tertiary	6 (66.7)	
Marital status		
Single	3 (33.3)	
Married	6 (66.7)	
Occupation		
Civil servant	3 (33.3)	
Trader	3 (33.3)	
Student	3 (33.3)	
Religion		
Christianity	8 (88.9)	
Islam	1 (11.1)	

DISCUSSION

The primary aim of this qualitative study was to determine the knowledge, attitudes, barriers and facilitators of kidney donation among caregivers in a Nigerian tertiary facility. This study to the best of the authors' knowledge is the first using this methodology to elicit these information from caregivers' perceptive. The main highlights of the findings of this study are: 1. the caregivers understood what kidney donation means; 2. majority were not willing to donate or encourage others to donate; 3. the uncertainty of living with one kidney and the risk of surgery were the major barriers to kidney donation; 4. the involvement of a nuclear family member, love and compassion and monetary gains were the major motivators to donate and 5. participants were of the opinion that public education on the risks and benefits of kidney donation, attaching financial gains and offering free medical services to living donors are the possible ways to encourage people to donate in the future.

The finding that all the participants understood what it means to donate kidney and the unwillingness to donate or encourage other persons to donate is consistent with previous reports.[3,4,6] Previous Nigerian studies have demonstrated high awareness but also noted that being aware does not translate to

willingness to donate. [3,4] Sharaan et al reported high awareness among students of health sciences but only a few were willing to donate. [6] Although our participants were not health care students but all had above six years of education and the good understanding of kidney donation reported was not unexpected.

The uncertainty of living a healthy life with only one kidney and the risk of surgery were the major barriers cited by majority of the participants. The fear that the remaining kidney may malfunction in the future and there may be nobody available to donate a kidney to them was expressed by almost all the participants.[7,8] Kang et al reported that complications and possible deterioration in health after donation were the most significant reason for reluctance to donate. [8]

Involvement of a nuclear family member was the major motivation to consider donating kidney among the participants. This reinforces the observation that African families are increasingly evolving from the traditional extended family structure to nuclear families.[9] Another important motivator to donate is love and compassion and monetary gains. Dopelt et al reported high levels of altruistic behaviors among organ donors in Israel while Friedman suggested that payment for living organ donation should be legalised to allow living

donors benefit from their gift.[10,11] This echoes the suggestion of the participants that some benefits such as money and free medical services should be given to living donors to encourage others to donate. Only one tertiary facility was used in this study, and it is unclear if similar perceptions are shared among caregivers in other facilities across the country. As with all qualitative studies, the proposed study suffers the limitation of extrapolation beyond the context of the study. Other potential limitations include the non-inclusion of persons with lower level of education as this may affect people's perception and attitude.

CONCLUSION

The study findings indicate that caregivers demonstrate an optimal understanding of the meaning of kidney donation. On the other hand, their interest in either donating their kidneys or encouraging others to donate is abysmally low. The provision of financial reward and free medical services to living kidney donors may encourage people to donate their kidneys. Furthermore, public enlightenment campaigns on the risks and benefits of being a kidney donor would be helpful in this regard.

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Data availability: The data used to support the findings of this study are available from the corresponding author upon reasonable request

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