PERCEPTION AND BURDEN OF TREATMENT IN PATIENTS WITH RENAL ALLOGRAFT: UNIVERSITY COLLEGE HOSPITAL, IBADAN EXPERIENCE

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ABSTRACT

Background: Kidney transplantation is the most desirable treatment option for patients with end stage renal failure. Individuals with kidney transplant face many challenges such as coping with burdens of taking several pills on daily basis in order to prevent renal allograft dysfunction, yet many live under the constant threat of rejection.

Aims and objectives: The aim of this study was to describe the perception of the patients with renal allograft and the burden associated with its maintenance at the University College Hospital, Ibadan.

Methodology: A semi structured qualitative interview was conducted with all patients receiving treatment from January 2006 to February 2015.

Result: A total of 20 patients with renal transplant participated in the study. The participants included 13 males (65%) and 7 females (35%).Seventeen (85%) were adults while 3(15%) were paediatric cases. More than 85% of the patients with kidney transplant expressed fear of kidney rejection and burden of medication adherence.

Conclusions: Transplantation is a therapeutic modality which enhances the quality of life of the patients; most of our patients live in constant fear of rejection thus there is need for regular counselling of patients to allay fear and adherence to drug regimen.

Keywords: *Transplant, renal transplant recipient and challenges*

INTRODUCTION

Chronic kidney disease (CKD) is a universal public health issue with increasing incidence and preva-lence[1-2] and associated health careexpenses [3].

CKD is common, associated with low quality of life, treatable, and linked to other major non-communicable chronic diseases (NCDs) such as diabetes, hypertension and cardiovascular diseases (CVD) [4].

The most common and accepted treatment for end stage renal disease (ESRD) is in-centre haemodialysis worldwide [5,6]but to be free from dialysis and its associated challenges, renal transplant is necessary which leads to im-proved survival, increased quality of life[7] and lower costs compared to long-term dialysis. It is the treatment of choice for most patients [8,9].

Renal transplantationwhich may occur from a living or cadaveric donor, is consideredas the treatment of choice for individuals withESRD because of benefits such as improved long-termsurvival and quality of life compared to dialysis

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[10-12].Although there are well known benefits of renal transplantation,it may not be suitable for every candidate [13].

Successful kidney transplantation also offersincreased life expectan cy and greater physical and occupational rehabilitation compared to chronic dialysis for patients with end-stage renal disease (ESRD) [9,14-15].

Kidney transplantation has become the most desirable treatment option for patients with renal failure for its efficacy and health outcomes [16]. Although transplantation is assumed to bring recipients' life closer to normal, there are new challenges and altered life styles; each individuals' response to this altered life style depends on his background and experience in life [17].The recipients of kidney transplant are subjected to a lot of psychosocial stress which include: fear of kidney transplantrejection, worries about the risk of infection, compliance with the medication regimen,repeated hospitalizations, and changes in body appearance [18-19].Thus, renal transplant patients experience stress, distress related to side effects of medications and economic burdenwhich influence their health-related quality of life (HRQOL) [20]. Hence there is need to conduct a qualitative study toinvestigate the experiences and individual differences with renal allograft so that these issues can be addressed when developing a psychological care protocol as a part of follow-up management for the patients.

This study was carried out to describe the perception of the patients with renal allograft and the burden associated with its maintenance at the University College Hospital, Ibadan.

MATERIALS AND METHODS

Research design: A semi-Structured qualitative interview was used for the study.

Study setting: The study was conducted in University College Hospital,Ibadan**.**

Participants: The participants were all the renal transplant recipientswho received treatment between January 2006 and February 2015 at University college Hospital and they were requested to participate in the qualitative interview.Informed consent was obtained from the participants before the interview was conducted and confidentiality was assured.

Sample technique: Purposive sampling technique was used.The study recruited all recipient of kidney transplant attending follow up visit at the University College Hospital. Only one recipient refused to participate in the study.

Data collection: Data collection occurred from April to June 2015. Interview was conducted using the pre-conceived themes. The semi structured interviews were conducted in Yoruba and English language and the participants were informed about their right to withdraw from the study at any point.

The key themes that were assessedinclude: their perception of renal transplantation,self-perception, relationships and family support, fear of kidney rejection, cost and coping with the bulk usage of drugs. The themeswere discussed according to the responses of the participants using qualitative thematic (manifest) content analysis[20-21]and a comprehensive view of their collective experience was presented.

RESULT

Twenty (20) patients participated in the study;the mean age was 39.8 ±16.0 years(12-72).There were 13 males (65%) and 7 females (35%) altogether and the participant had lived with the kidney transplant for a period of 3 months to 8 years.

The demographic characteristics of the participants are outlined in the table

The themes assessed are discussed below with the participants' responses:

Theme1: Perception of Renal Transplant

Perception is the way an individual viewa particular thing/way /procedure and it is one of the factors that can influence clinical decision-making and treatment preferencesof each individual.Some of the participants acknowledged that life after transplantation has a lot of restrictions in order to safe guard the transplanted kidney.

1.1: *Restrictions*

Ø A 45 years old man who had transplant 8 years ago said*"it makes one live a normal life but you need to be cautious"*.Another recipient who had transplant 4 years ago said "*it is a*

TABLE 1: Characteristics of participants

Case no	Age	Sex	Marital Status	Occupation	Duration of Transplant
	21	Female	Single	Undergraduate	1year
	12	Female	Single	Secondary school	2years
	16	Male	Single	Secondary school	2years
	36	Male	Married	Civil Servant	6years
	40	Male	Married	Business Man	4years
	16	Male	Single	Undergraduate	2years
	37	Male	Married	Civil Servant	4years
	39	Female	Married	Civil Servant	3months
	25	Female	Married	Full house wife	1year
	43	Male	Married	Civil Servant	6years
	60	Male	Married	Retired	9months
	40	Male	Married	Civil Servant	7years
	45	Male	Married	Civil Servant	1year
	41	Male	Married	Business Man	5years
	51	Female	Married	Civil Servant	5years
	45	Female	Married	Civil Servant	8years
	65	Female	Widowed	Retired	1year
	47	Male	Married	Civil Servant	6 months
	72	Male	Married	Retired	2years
	44	Male	Married	Civil Servant	3years

lasting solution to renal failure,but there are things you cannot do because of the kidney

Ø Another recipient who had transplant two years ago said ''*Hmm..well, with this transplanted kidney...I can't focus on my business and have to avoid public meetings, fearing that I might catch an infection'.*

Ø A female recipientsaid ''*the first 4 days of the transplant was terrible but itis good for anybody that has renal failure if the person can obey rules and regulations''.*

1.2: ***Lasting solution***

Ø A 43 years old man who had transplant 6 years ago said *'you don't have a choice, the survival rate is high if you can have a match donor'*.Another recipient who had transplant 1 year ago said "it *is a sure security for those with renal failure''.*

All the participants said they can encourage others to go for renal transplantation since it is the lasting solution to renal failure.

Theme 2: Self-perception

Self-perceptionrefers to an individual's evaluation of his/her overall physical health functioning, coping and subjective wellbeing'after transplant.Majority of the participants felt very good about themselves and reported improved quality of life.

2.1: ***Happiness***

Ø Another female recipient who is 25 years old said ''*I am very,very, very happy about myself''.*

Ø 16 year old recipient said ''*I can only compare myself to my condition before the transplant and that is why I am so happy to have done transplant and a successful one...what if I had died with renal failure or stayed on dialysis*''?

2.2: ***Improved quality of life***

Ø A 40 year old man who had transplant 7 years ago said that "*I can compare myself to those who did not have transplant and are still suffering on dialysis and I feel luckier and thank God to have got a* *donor at the right time and resumed my normal life*”.

Ø 40 year old man that had transplant 4 years ago said *‘I see myself that l got my life back’*.

Ø 72 years old man who had transplant 2 years old said *“I am much healthier than before”,*while another recipient said*“my life has changed a lot”.*

2.3: *Uncertainty about self*

Ø A 47 year old man who had transplant 6 months ago said that *‘‘it is just good to be alive, not down,not happy”.*

Ø Another 43 year old man who had transplant 6 years old ago said that ‘*‘well, the truth is that l was not hopeful,until things were getting better”.*

Theme 3:Relationships and Family Support

The entire participants described how relationships have impacted their health and this has contributed to their quality of life positively.According to them, the attitude and behaviour of their family, friends, partners/ spouses and colleagues, ultimately affected their ability to cope and adjust to life pre and post-transplant.

All of the respondents replied that they had full family support which helped them to cope effectively.

3.1: *Reaction of the family members*

Ø One male recipient who was transplanted 4 years ago said“it *was like a miracle, my family members saw me as a survivor”.*A female recipient said “*my family members were very, very happy for me.*

3.2: *Support*

Ø A 12 year old girl said “I *never understood the love of my parent until I lost my kidneys and almost died during my illness, I realized how loving and caring they are and without their support I could have never made it, thanks to them”.*

Ø Another 67 years old recipient said “*I was given wholly family support, I will forever be grateful to them”.*

Theme 4: Fear of Kidney Rejection

Majority (85%) of the recipients of kidney transplant recipients expressed fear of kidney rejection.

Ø A 43 year old man that had transplant 6 years ago said “*Yes, l believe anything can happen at anytime*”.

Ø Another 60year old man that had transplant 9 months ago said “*don’t even mention that, I don’t even want to think about it”.*

Ø A 45 year old man that had his transplant 8 years ago said “*Yes l have fear of going back on dialysis”.*

Ø One 40 year old man said ‘*I had the fear initially but after series of tests, the feargot worn off*’.

Theme 5: Coping with the Bulk Usage of Drugs and Regular Medical Follow Up

Kidney transplantation requires life - long compliance and regular follow up. Maintenance immunosuppression is an integral part of minimizing the risk of rejection of the transplant kidney and improving patient’s quality of life. The discovery and development of a diverse array of these medications are major factors contributing to the notable achievements in kidney transplantation [16]. Nevertheless, since immunosuppressive therapy is a mandatory and lifelong component of post-transplant to avoid rejection of graft, theparticipants showed an attitude of concern and compliance towards medication despite the adverse common side effects.

21 year old recipient said “*I have to take these poisonous medicines, but I have no choice and have to continue taking these as long as I live...what can I do??? Nothing...but just give in to my destiny*”.

Ø A 43 year old man recipient said *‘‘l have considered it as a cross that l have to carry all my life, it is part of me and it also essential for me to visit the clinic regularly”.*

Ø A 51 year old woman responded that “*I don’t have a choice, just have to get used to it”.*

Ø Another female recipient who is married said,“to *me it is not bulky as long as it can keep my kidney safe”* while another recipient said *“the bulk of medications reduces with time”.*

Ø A man who had transplant done twice *said l don't have a choice as far as it keeps my kidney safe* while another male recipient *said " I am just trying to get used to it".* A 16 years old recipient *said "it can be stressful but what can Ido,don't have a choice but to use my drugs and come for follow up visit'.*

Theme 6: Cost of Medications

Financial burden is another challenge transplant recipients have to face. Anti-rejection medications are very costly, ranging from $2,000 to $4,000 a month. Medicare covers 80% of the cost and secondary insurance may or may not cover the remaining 20%[23].This is not the case in Nigeria because the immunosuppressive medication is not covered by theNational Health Insurance Scheme.Majority of the participants said the drugs were too expensive but they have to get the drugs.

A40 year old man *said, ' it isnot too expensive it depends on the package'* while a 67 year old man that had transplant one year ago said '*he drugs are too expensive but what can I do ,just look for the money and buy'.*

A43year old recipient said '*the drugs are too expensive and the government is not subsiding, I have no choice than to source for funds'.*

In contrast to that, another 43 year old said '*'the drugs are not too expensive, at least it is far better than dialysis,makes my life a lot better".* This is similar to the response of a 60 year old who*said,'what is the issue of money here? Idon't care how much is the drug as long as it can keep my new kidney safe".*

DISCUSSION

Organ transplantation is not merely a physical experience; rather, it influences the recipient and the family in totality. Also the way renal transplantation is perceived by the patient is a very complex combination of positive and negative factors which vary according to life cycle stage, education level and socio-economic status. Therefore, it is not possible to describe how an individual reacts or is able to cope with the renal allograft,[24]and each of theparticipants that were interviewed in this study described their experiences with the kidney allograft differently from each other.Hence, it is necessary for recipients to be counselled on the need to be aware of the challenges of life post renal transplantation.

It has been reported that recipients face many new challenges and altered life style after kidney transplant surgery such as: coping with mandatory immunosuppressive medications, uncertainty of graft survival, longevity and rejection, and fear of graft rejection. Also once the transplant is done, the patient is discharged, leaving him or her to adapt new skills and mechanisms to cope with the renal allograft,[25]. The present study also reflected similar concerns and issues as described by recipients after their kidney transplant, a trend similar to the study that was conducted in Pakistan where 20 participants were assessed about their quality of life after renal transplant and majority of the participantsshowed concern about rejection and fear of kidney rejection,[17].

In a qualitative study that was carried out to evaluate patients' knowledge and awareness of life post transplant, sixteen renal recipients were interviewed 4-6 weeks post-transplantation about content and methods in the patient education programme where they all described kidney transplantation as a 'turning point in life' [26] and the findings in this research was similar to this study in which all the participant said renal transplant was a good thing in their lives and they can encourage others to go for it.

Some of thestressors that the participants have were fear of rejection, compliance with medication, fear of infection and the cost factor. Since the cost of medication is not covered by insurance or government health services in Nigeria, issues of affordability do affect medication compliance while some individuals stated that they go extra mile looking for money in order to get the immunosuppressive drug.

Kidney transplant recipients typically have a high pill burden, and non-adherence among patients with their immunosuppressive treatment regimen which is considered a major risk factor for poor outcomes following kidney transplantation,[27-28] and this present study identified a high pill burden among the participants.

It has been identified that post renal transplant noncompliance is currently the third leading cause of renal graft loss with chronic rejection the primary cause, [29]. Also, steps that had been identified to prevent non-adherenceincludes:

identifying patients at risk, reducing the number and frequency of medication, treating depression or other psychological issues, and providing ongoing education, discussion, and counselling,[30] but it has been shown that health-related stress is not eliminated and that fear of rejection and economic factors are the most important stressful issues, [31].

A study was carried out to explore patients' perceptions of stress and QoL at different stages following a first, functioning renal graft: within six months, between one and five years and over five years later. They identified a number of concerns, of which fear of rejection was the most frequently mentioned, followed by stress generated through altered body image (a product of immunosuppressive therapy). Nevertheless, all reported a significant increase in QoL after transplantation, although improvement was least marked in patients in the intermediate group (1–5 years after surgery) who also experienced most stress [18]. All the findings of these studies were similar to this present study in which the most identified stressor was the fear of rejection, cost of medication followed by high burden of pill and frequent visitation to the hospital for medical check-up.

A qualitative study that was conducted to describe the beliefs, experiences and perspectives of renal transplant recipients on adherence suggested that considering patients' attitudes, priorities, current life events, commitments, the support systems and healthcare services can be used to plan interventions to promote concordance between prescribed medication and medicine-taking behaviours. This may improve treatment outcomes and mitigate the risks of non-adherence-related rejection, [32].

CONCLUSION

Renal transplantationincreases life expectancy and health related quality of life of individuals with renal allograft but such individuals are faced with uncertainty and constant fear of kidney rejection, hence there is need for counselling and proper education of patients on what they would encounter before undergoing transplant**.**

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