

## **EXPLORING KIDNEY TRANSPLANT RECIPIENTS' PERSPECTIVES AND EXPERIENCES POSTTRANSPLANTATION AT A UNIVERSITY HOSPITAL OF CAIRO: A QUALITATIVE STUDY**

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### **ABSTRACT**

Kidney transplantation introduces new challenges in patients' life as recipients obliged to live with a chronic life state and condition. The situation they need to adapt is complex. Therefore, this study was conducted to explore kidney transplant recipients' perspectives and experiences post-transplantation. A qualitative phenomenological design was used in this study. A purposive sample of 20 adult kidney recipients of both genders was recruited from a urology & nephrology outpatient clinic of a university affiliated hospital in Cairo. Personal and medical data structured questionnaire as well as face to face open-ended semi-structured audio-recording interviews were utilized to collect data pertinent to the study. Results revealed that; the sample age ranged from 21 to 54 years, sample perspectives and experiences were reflected through 8 main themes and related subthemes that included encountered recipient feelings, fears of uncertain outcomes, perceived impact on life, encountered medical sad life, experienced challenges, attitudes toward self care practices, gain of support and perceived needs. Feelings of happiness, rebirth, and revives, being normal, settled life, fear of uncertain outcomes and fear of their lives related donor's health were expressed by participants. To conclude kidney recipients had encountered a vast array of feelings and experiences that shaped their life posttransplantation. Encountered feelings were both toward self and their living related donors. Further qualitative and quantitative studies are recommended.

**KEYWORDS:** kidney transplantation - Recipients - Post transplantation - Qualitative design Perspectives- Feelings - Experiences - Themes- Subthemes – Living related donors.

### **INTRODUCTION**

Kidney Transplantation is a surgical procedure to transfer a healthy, functioning kidney from a living or brain-dead donors to a recipient with non-functioning kidneys (Medical Dictionary, online). The procedure is a worldwide best treatment for selected patients with end-stage renal disease (ESRD). Longer survival time, lower costs and better quality of life all make kidney transplantation a treatment of choice compared to dialysis among patients with end- stage kidney disease (Tonelli et al., 2011; Pinter et all, 2017). The treatment is considered by patients as the gateway to personal liberation, necessary for regaining control over their life and their self (Tong, Morton, Howard, McTaggart, & Craig, 2011).

Kidney transplantation has become a progressive and innovative field in the past decades. The number of adult's kidney transplants continues to increase. Survival rates of grafts and patients have also increased dramatically (Squifflet, 2011). At present, kidney transplantation is active in most countries in the region, including Egypt and many other Arab countries. The practice has found its place as the preferred method of renal replacement therapy throughout

the region (Einollahi, 2008). In Egypt 1.200 kidney transplants using live donors are carried out every year (Mersal & Ali, 2014). For a successful transplantation, the participation of nurses at all stages of the process is essential, from the care provided to the donor of multiple organs and tissues, to the care provided to patients in the post-transplantation period as these patients require experienced professionals and specialized care (Borsato & Escudeiro, 2014).

Kidney transplantation brings new challenges in the patient's life (Squifflet, 2011). Post-surgery, they have to learn to cope with such challenges as they need to adhere to a complex medical regimen following treatment, which includes close self monitoring, regular clinic visits, and compliance with medication regimen and lifestyle changes around nutrition, exercise, and weight control. This clarifies that once a transplant has been performed and the patient has been discharged with a functioning graft, the patient must continue to deal with a life of chronic illness. Researchers suggest that; recipients need to be assessed for their awareness of the challenges of life post-transplantation (Kamran, 2014). Therefore, qualitative and longitudinal studies are needed to investigate the unique experiences and individual differences in the transplant process as it requires lifelong compliance to treatment and constant care together with regular follow ups, daily life self-management activities including self monitoring of rejection and infection, so these issues can be addressed when designing care plans as a part of follow-up management. Given the importance of this phenomena to nursing practice, therefore; the aim of this study was to explore kidney transplant recipients' perspectives and experiences post-transplantation to be used as a guiding framework in the designing of a comprehensive protocol of care for such population.

## **MATERIAL AND METHODS**

### **Design**

The qualitative phenomenological design was utilized by the research investigator to achieve the aim of the current study. Phenomenological design is the best approach for the investigator to gather 'deep' information and perceptions through inductive qualitative methods such as interviews, discussions and participant observation, and representing it from the perspective of the research participants. (Rossman, 2010; Creswell, 2013; Marshall & Ponce, 2014).

### **Participants/Informants**

A Purposive sample of 20adult kidney recipients of both genders was recruited from urology & a neurology outpatient clinic of a university affiliated hospital in Cairo. Participants were selected to be a source of data for the current study based on the following criteria; (a) conscious adult who is eligible for and wish to participate in this study (b) undergone kidney transplantation at least two months since the time of surgery to obtain complete and mature perspectives about post transplantation self experiences (c) able to communicate through talking and free from mental/psychological problems or any cognitive impairments that would prevent them from expressing their self experiences (d) able to sign a consent form.

### **Instruments**

**The data pertinent to the current study were collected using the following tools;**

- A structured questionnaire. Was designed by the researcher and it covered the personal and medical data of participants such as age, gender, place of residence, level of education, occupation, marital status and support system as well as medical data such as date of surgery, type of graft received, comorbid conditions and hospital readmission.
- Face to face open-ended semi-structured interviews were conducted by the researcher using an interview guide which includes several open ended questions to facilitate full, free, extensive and deep descriptions made by kidney transplant recipients of their true experiences. Interviews were recorded using a high quality audio tape recording to ensure recording of comprehensive, accurate and true reflective descriptions of participant's experiences. All the previously mentioned tools were exposed to a group of qualitative research experts to review its content validity.

## PROCEDURE

After receiving institutional and authoritative personnel approval, data were starting to be collected from February 2016 to September 2016. Kidney transplant recipients who met the criteria for inclusion were recruited by the investigator and direct face to face contact was initiated through individual audio-recording interviews that conducted at the urology & nephrology outpatient clinic of the designated study setting. At the time of each participant's interview; the purpose, significance and the nature of the current study was explained. The majority of participants were interviewed once and some participants were interviewed twice to cover all questions pertinent to the study. All interviews were initiated using the mother tongue language (Arabic), using the slang form that is commonly used by the participants. An average time for each interview ranged between 45 minutes to 1 hour until all guided questions were covered. Kidney recipients were encouraged by the investigator to express themselves freely in their own words through the use of an interview guide; which consists of a series of open ended questions that were designed by the investigator to allow for a deeper exploration yielding a rich description and understanding of their experiences. Field notes were made immediately following the interviews. Data collection interviews were terminated as participants were exhausted by narrating and describing phenomena under study, no new codes, categories and themes were emerging and when there were repetitions of similar data among participants (data saturation).

## DATA ANALYSIS

The investigator started data analysis at the same moment of data collection; through an attitude of bracketing (separating investigator's past knowledge of the phenomenon of interest), transcripts were read repeatedly to achieve a holistic and intuitive understanding of participant's verbatim, the transcripts were then divided into discrete segments of expressions of the participant's experiences; then repeated words were removed considering that the essential experiential descriptions were not altered then they were given codes and the codes were organized into central themes which are sentences conveying discrete expressions of experiences. The data were then translated into English following the exact verbatim for the research purposes.

## RESULTS

Participants of this study had shown a vast array of feelings and life experience posttransplantation. Eight main themes and related subthemes were identified as follows; encountered feelings, fears of uncertain outcomes, perceived impact on life, encountered medicalized life, experienced challenges, attitudes toward self care practices, gain of support and perceived needs.

An example of encountered feelings theme; feeling of being normal subtheme; a 26 year old female participant, reported that “. Now, I had undergone kidney transplantation 2 months ago, am moving and walking normally, there is no any problem...”. a 31 year old female participant, expressed that “... of course the feeling is no different than when, before kidney transplantation, I was feeling tired, after kidney transplantation, it is extremely different I feel comfortable, no pain in my two sides, there is no vomiting, my face gets neither black nor yellow and my condition is always normal..”

An example of feeling, of rebirth subtheme; a 23 year old female participant, expressed that “... I swear to God, I feel as if am a new person, that in just reborn again, life is open for me...”. For the subtheme of feeling, of revivacy; a 23 year old male participant, had expressed that “ of course a beautiful feeling I felt it, I was dead then waked up, you understand what I mean?”

An example of feeling, of gratitude subtheme; a 39 year old female participant, expressed that “... It feel like someone gave you something that bring you back to life, someone creates a new identity and life for you, frankly, I thank my brother who gave me that”. For the subtheme of feeling, of settled life; a 33 year old male participant, reported that “ I was on dialysis 3 times a week; I could not feel stable or able to live, by having transplantation one's condition gets better, his psychological condition becomes stable and able to go on with life ”.

An example of the theme of fears of the uncertain outcomes; the fear to return to dialysis subtheme, a 29 year old female participant, verbalized that “...but the fear may I have that; I return back to dialysis is still inside me, more than before and it is still lasting until now...”. a 30 year old female participant, expressed the following for the same subtheme “...after kidney transplantation; I am afraid that I might go back to dialysis, that is the biggest nightmare, which happen to me 4 to 5 times a day, I get it back as I admitted to hospital and my lab investigations gets high as beyond the normal limit...”.

An example of the theme of fear of new kidney rejection; a 23 year old female participant, expressed that; “ I swear to God, am afraid that; the new kidney may be rejected, that was the most terrifying thing to me, after one month or two months I find kidney functions are getting high again and rejection occurs that is what terrify me and until now...”.

An example of the theme of perceived impact on life; planning for a new life subtheme, a 38 year old male participant, verbalized that “... after kidney transplantation, one can develop a work project or two, can travel, work, go and come, something like this...”. An example of improved physical activity and work ability subtheme, a 30 year old female participant, verbalized that “... before the transplantation, I could not even carry a cup, after transplantation I do everything, I clean carpets, mop, and sweep the floor...” An example of social life reintegration subtheme, a 23 year old female participant, expressed that “... before the transplantation, I was in certain turbulence with myself but now am with my family, sharing their happiness and sadness and I tell my opinion...”

An example of the theme of encountered medicalized life; multidrug intake subtheme, all participants mentioned that "... At the beginning, medications are as many as 12, 15, and 16 pills on the long run they get lesser; they are taken at 10 am and 10 pm..."

An example of attitudes toward self care practicestheme, obligatory fluid intake subtheme, a 45 year old male participant, stated that "... after the transplantation, I was advised to drink plenty of water as much as I can, three full bottles, one and half liters or even more, it is ok no problem..."

An example of urine monitoring subtheme, a 29 year old male participant, mentioned that "... no one asked me to measure the amount of urine when I go home following the transplantation in the hospital, they used to measure the urine for me every day, I do not measure the urine for myself, and actually I pass plenty of urine, I am ok..."

An example of body temperature monitoring subtheme, a 30 year old female participant, reported that "... I never cared to measure temperature, but I feel it myself, I know whether it is high or low, I have a thermometer, I clean it and I measure when I feel feverish..."

An example of blood pressure monitoring subtheme, a 29 year old male participant, stated that "... I follow up my blood pressure and I know it every day, but I do not record, I have an apparatus at home, and a clinic at my work place, I measure it there..."

An example of weight monitoring subtheme, a 45 year old male participant, stated that "... I did not measure my weight for three months, there is no weight measuring here..."

An example of the theme of perceived needs; financial needs subtheme, a 39 year old female participant, verbalized that "... I need help to buy our medication because it is so financially taxing..." An example of information need subtheme, the same participant reported that "... we did not know that; we will remain on lifetime medication, we did not know anything like that..." a 25 year male participant, stated that "... how to continue living with the transplantation, how we could work, is it troublesome in my work or sleep?...", A 30 year old female participant, verbalized that "... I hope that any one undergone transplantation would have someone responsible for him like a dietitian, a doctor or a nurse it does not matter, should orient him about what should be done, I used to eat bananas, after about three days I get readmitted to the hospital, no one helped me to understand that banana increases the potassium level and that is wrong..."

## DISCUSSIONS

The study of interest aimed at exploring kidney transplant recipients' perspectives and experiences post-transplantation. Kidney transplant recipients under the study had experienced positive vast arrays of feelings and emotions toward self as well as emotions concerning their living related donor's health. Feelings of happiness, feelings of being normal, feelings of rebirth, feelings of revivacy and feelings of settled life were among the positive emotions encountered toward self, while anxiety, fear and feeling of guilt were among the emotions encountered toward their related donors. Achieving a sense of rebirth and normality were important feelings expressed by participants under the study; such feelings of rebirth and being normal had motivated them to start and plan for a new life, enjoying its hopeful sweets aspects including planning for their future and a return to their social roles and relations with their families. Such finding is consistent with Tong, Morton, Howard, McTaggart & Craig (2011) as well as with Santos et al (2015). Tong and his

colleagues reported that achieving a sense of normality facilitated better functioning, social adjustment, well-being, and positive development after transplant among participants in their study while Santos and his colleagues clarified that; the feeling of rebirth is based on the notion that participants received a new kidney to get better. Feeling of rebirth represents a return to one's previous condition

Although the life of recipients under the study assumed to be closer to normal. Other feelings of anxiety, fears and guilt were also expressed by participants to be continuous. The main sources of these feelings were; fear from an uncertain return to painful dialysis sessions and rejection of the new kidney. These findings are compatible with (De Brito, de Paula, Grincenkov, Lucchetti&Pinheiro, 2015) who studied the changes and difficulties arising from kidney transplantation among 50 recipients; they reported that episodes such as infection/admission to hospital, loss of the graft and needing to return to dialysis were much cited as causes of fear. Guilt feelings were also reported by Schipper, Carina, Bakker, Sander man & Schroevers (2013) as they clarified that participants of their study had encountered the guilt feeling toward their living donor.

In relation to the theme of perceived impact on life; the study results showed that participants were exposed to both positive and negative impacts on life. Improved physical activity and work ability, social life reintegration and planning for hopeful life are narrated as positive impacts on their lives while divorce, leaving the original work and family overproduction were reflected by their words as negative impacts on their lives. These results are in harmony with Santos et al (2015) findings, which illustrated the negative and positive consequences after kidney transplantation among twenty participants. Life independency of hemodialysis treatment, a better way of scheduling their lives, defined as quiet and normal, with the feeling of well-being were among the experienced positive consequences while marital separation and the obligation of using immunosuppressive medication are perceived as negative consequences. All of these are reflected by the participants of the current study.

Regarding the theme of encountered medicalized life; the study findings pointed out that; although all participants under the study experienced multidrug intake they showed a remarkable positive attitudes including a dopting a self responsibility for drug intake by the majority of participants as study results showed strong willingness toward adherence to drug intake however the experienced side effects and reported challenges, the reasons for these willingness that were narrated by some participants were to protect the new kidney as possible and not to return back to dialysis again. These findings are consistent with Tong et al (2011) who conducted a systematic review of qualitative studies of medicine taking after kidney transplantation, among the patient views on taking medications were to protecting life and a way of demonstrating responsibility for maintaining their own health.

In relation to the theme of experienced kidney recipients' challenges; the study findings revealed that participants under the study raised their voice about the difficulties they experienced with some of immunosuppressive drugs, in particular the high cost of immunosuppressive drugs and its consequences on the affordable life expenses as well as the perceived side effects. This strategy of raising their voice comes from the belief that; they had the new kidney by not an easy way and they do not want to lose it., Such findings are consistent with Gordon, Prohaska & Sehgal (2009) and with James & Mannon (2015). Their results informed that kidney recipients experienced financial strain in their ability to purchase immunosuppressive drugs as they reported that; immunosuppressant expenses have had somewhat to great (adverse) impact on their lives.

Concerning to attitudes toward self care practices theme; the study findings revealed that; participants adopted a relatively positive attitude toward adherence to the required daily fluid intake, low salt and spicy free diet as well as adherence to fatigue free work while expressed a no actual concern toward self monitoring practices, in particular regular checking, measurement and recording of blood pressure, urine output and weight, which may be related to not having a strong belief about the seriousness of these practices to the preservation of their health. These findings are compatible with the work of Gordon, Prohaska & Siminoff (2009) whose study results revealed that attitudes towards fluid intake and maintaining a low-salt diet were mostly positive.

In relation to the theme of perceived needs and concerning information needs subtheme; the study findings showed that; participants expressed that they had no idea about medical issues concerning kidney transplantation, including the meaning of the surgery, meaning of follow up after surgery and being on lifelong medications, they added all information were gained during hospital stay from contact with other recipients. Participants had also narrated that; they need to be informed about the issue of rejection and the way of life after kidney transplantation, including work type. Participants had reported that; they need to be informed about all issues related to medication, including its effects and adverse effects, its price and the way of getting medications. Participants had narrated the need for a specialized dietitian to provide them with the necessary dietary guidelines following kidney transplantation, such findings were compatible with Ramani, Abraham, Mathew & Lesley (2014), who recommend a dietary counseling, and lifestyle changes advice to all transplant recipients, to prevent the development of diabetes and hypertension. Participants had narrated the need for self monitoring training, including urine, weight and body temperature measurement. These results are supported by the report of Ghadami, Memarian, Mohammad, & Abdoli (2012), who carried out a qualitative study among 18 kidney recipients. Ghadami & his colleagues reported that recipients need support in fields of knowledge, skills and motivations. Their study findings showed that patients' did not receive adequate knowledge about the kidney transplant process.

## CONCLUSIONS

Participants in the current study had shown positive feelings toward self after kidney transplantations, Feelings of happiness, feelings of being normal, feelings of rebirth, feelings of revivacy and feelings of settled life were among these feelings. Other feelings of anxiety and fear were also encountered toward their living related donor. Participants had perceived improved physical activity and work ability, social life reintegration and planning for hopeful life as positive impacts on their lives while divorce, leaving the original work and family overproduction were reflected by their words as negative impacts on their lives. Participants had showed strong willingness toward adherence to drug intake, however the experienced side effects and the reported challenge of the high cost of immunosuppressive drugs and its consequences on the affordable life expenses. Participants adopted a relatively positive attitude toward adherence to the required daily fluid intake, low salt and spicy free diet as well as adherence to fatigue free work while expressed a no actual concern toward self monitoring practices including regular checking, measurement and recording of blood pressure, urine output and weight.

## ETHICS STATEMENT

The ethics committee of the Faculty of Nursing Cairo University approved this study.

Before conducting the current study, all participants gave written informed consent.



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## RECOMMENDATIONS

Based on the previous theme findings of the study, the following recommendations are suggested.

- Designing and implementing patient education programs concerning the issues raised by kidney recipients' verbatim to raise the awareness for recipients and those who are expected to undergo kidney transplantation.
- Provide online education services for the educated population category to provide the necessary information pertinent to all phases of the kidney transplantation procedure.
- Designing booklets and leaflets in an attractive simplest way concerning all phases of the kidney transplantation procedure to be available to inpatients and those in outpatient clinics.
- Designing and implementing discharge plans for meeting the expressed needs for lifelong care.
- Contact community resources to aid in the provision of suitable work load to such population to substitute for work loss impacted by kidney transplantation.

## For future research

- The current qualitative study enabled us to outline specific issues and additional topics of interest for further research pertinent to kidney transplantation population, so qualitative studies should be replicated for other population in other geographical areas including the private health sectors; replication of qualitative researches for these population serve theory generation purposes.
- Conducting mixed designs. As quantitative designs will be helpful for assessing the severity of their narrated fear and anxiety and all associated factors to kidney transplantation and evaluating their impact on all aspects of life.

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