

DOI: 10.21767/1791-809X.1000527

# Motivators and Barriers to Self-Management among Kidney Transplant Recipients in Selected State Hospitals in South Africa: A Qualitative Study

Hillary Ndemera\* and Busisiwe Bhengu

School of Nursing and Public Health, University of KwaZulu-Natal, Durban, South Africa

\*Corresponding author: Hillary Ndemera, School of Nursing and Public Health, 5th floor Desmond Clarence Building, Howard College Campus, University of KwaZulu-Natal, Durban, 4041, South Africa, Tel: +27836555449; E-mail: ndemerah@gmail.com

Received date: 21 September 2017; Accepted date: 14 October 2017; Published date: 23 October 2017

Copyright: © 2017 Ndemera H. This is an open-access article distributed under the terms of the creative Commons attribution License, which permits unrestricted use, distribution and reproduction in any medium, provided the original author and source are credited.

Citation: Ndemera H, Bhengu B (2017) Motivators and Barriers to Self-Management among Kidney Transplant Recipients in Selected State Hospitals in South Africa: A Qualitative Study. Health Sci J. Vol. 11 No. 5: 527.

## Abstract

**Background:** Kidney transplantation is the most recommended treatment modality for many patients with end stage renal disease. Kidney transplant recipients need integrated care to provide continuous and coordinated care from pre-transplant to post-transplant phase. Kidney transplant recipients are motivated to adhere to the health care recommendations to improve on the graft life. However, to effectively implement strategies that enhance adherence, it is important to understand the motivators and barriers to self-management among recipients.

**Objectives:** To explore motivators and barriers to self-management among kidney transplant recipients in selected state hospitals in South Africa.

**Methods:** A qualitative case study design was adopted. Purposive sampling method was used to select the study participants. Data was collected through semi-structured interview schedule developed from in-depth literature review. Data was analyzed through thematic template approach. Thematic codes were created based on central research questions during data collection and analysis.

**Results:** The motivators included kidney transplant recipient, physiological, psychological, different support systems and healthcare system related factors. The barriers included kidney transplant recipient, physiological, psychological, healthcare system and socio-economic status related factors.

**Conclusion:** Exploration of motivators and barriers to self-management among kidney recipients resulted in identification of gaps in kidney transplant management. Understanding the motivators and barriers among kidney transplant recipients towards self-management may allow healthcare professionals to tailor interventions. In addition, the study would inform strategies to promote self-management and behavioral change among kidney

transplant recipients towards management. Furthermore, the specific interventions may contribute to improvement of long-term graft survival post kidney transplantation, enhancing improved health status and quality of life.

**Keywords:** Kidney transplant recipients; Motivators for self-management; Barriers for self-management; Self-management; Self-management for allograft survival; Transplant management

## Introduction

Kidney transplantation is the best possible treatment for many patients with end-stage renal failure, but progressive dysfunction and eventual allograft loss with return to dialysis is associated with increased mortality and morbidity [1]. According to Gordon et al. [2], there has been greater emphasis on improving the management of renal transplant recipients to prevent complications after renal transplantation and insure proper graft functioning and long-term patient survival. Moreover, transplantation outcomes are largely determined by the capacity of transplant recipients to adhere to a complex and ongoing self-management regimen to minimize the risks of transplant loss and future comorbid conditions [3]. However, according to the same authors, patient perspectives on self-management, which might explain adherence and other self-management decisions and behaviors, are less well understood [3].

According to Griva et al. [4], transplantation confers a survival and quality-of-life advantage and is more cost-effective than dialysis. Non-adherence to immunosuppressant has been found to be related to age, employment, income, and transplant vintage as well as psychological factors [4]. In addition, factors such as emotional distress/depression, stress and feelings of indebtedness, perceived side-effects and symptom burden, attitudes and medication beliefs are also related to non-adherence [4]. Obi et al. [5] reported that non-adherence is a major risk factor for long-term allograft failure in kidney transplant recipients. The same author reported risk factors for non-adherence, especially for treatment with

immunosuppressant, as a history of adverse side effects, financial distress, lack of knowledge about treatment and complex medical regimens, involving taking immunosuppressive drugs at strictly scheduled times and monitoring blood levels [5].

According to Morales et al. [6] adherence with treatment is influenced by several factors related to patients' lifestyle, socio-demographic and psychosocial characteristics or to the treatment regimen itself. These factors may act as either barriers or facilitators and constitute the main predictors of medication adherence. Treatment adherence generally includes regular intake of medications, monitoring vital signs undergoing diagnostic tests, following dietary and exercise protocols, abstinence from substance abuse, and regular follow up [7]. The kidney recipients continue to live with a chronic condition, thus, these patients need to take responsibility for their own care after transplantation [8]. However, self-management has been recognized on a worldwide basis as an important aspect of successful health care [8]. According to Weng et al. [8], patients with greater self-efficacy have been shown to practice more self-management behaviors, leading to better disease control, better physical function and better quality of life. Self-efficacy is a psychological construct defining a person's confidence in performing a particular behavior and in overcoming barriers to that behavior [8].

Pinter et al. [9] stated that elderly transplant patients valued the chance to extend life with a kidney transplant. In addition, the kidney transplant was perceived as restoring vigor, improving daily functioning, life participation and psychosocial well-being [9]. Gratitude and appreciation for the kidney transplant led to moral responsibility to keep recipients motivated to adhere to the 'sacred' medical regimens and lifestyle recommendations [9].

However, Chisholm-Burns et al. [10] reported that evidence supports using behavioral contracts as an effective adherence intervention that may improve healthcare outcomes and lower costs. Evidence further indicates that greater availability and/or higher quality support throughout the transplant process is associated with better psychological adjustment in patients, more optimal adherence behaviors, and longer survival [11]. According to De Pasquale, et al. [12] integrated and multidisciplinary care should include uniform criteria and procedures for standard assessments for patient autonomy, adherence to therapy, new coping strategies and the adoption of more appropriate lifestyles. Adherence with healthcare recommendations to self-management among kidney transplant recipients is greatly achievable with enhancing motivators and combating barriers.

## Methodology

### Purpose of study

To explore the motivators and barriers to self-management among kidney transplant recipients in selected state hospitals in South Africa.

### Specific objectives

To identify and analyze motivators to self-management among kidney transplant recipients in selected state hospitals in South Africa.

To identify and analyze the barriers to self-management among kidney transplant recipients in selected state hospitals in South Africa.

### Research questions

How do motivators affect self-management among kidney transplant recipients in selected state hospitals in South Africa?

How do barriers affect self-management among kidney transplant recipients in selected state hospitals in South Africa?

### Research design

A qualitative case study design was used to gain an in-depth insight into issues of engagement with transplant management focusing on motivators and barriers from the perspective of selected cases of kidney transplant recipients.

### Study setting

The study was carried out at four state hospitals. The four state hospitals were selected from the only four provinces offering kidney transplantation in South Africa. The four state hospitals identified serve the whole population of 54 million in South Africa. State hospitals were selected because the same legislation and National Department of Health govern them.

### Study population

The population comprised of kidney transplant recipients attending the selected state hospitals in South Africa at the time of the study. Each selected kidney recipient constituted a case. The inclusion criteria were kidney transplant recipients with a failed or functioning graft attending transplant follow-up visits at selected clinics, both male and female, live related, live unrelated and cadaveric transplant recipients. In addition, they must have been at least be one year post transplantation. The kidney transplant recipients must have been 18 years and older. The exclusion criteria were deceased kidney recipients, those below 18 years, the critically ill and those who were less than one-year post transplantation. Those below 18 years were not in a position to give informed consent, the critically ill may not have been in a position to fully complete interviews and the state of mind may not have permitted full cooperation. Those less than one-year post transplantation may not have had a realistic perception of engagement behaviors in transplant management.

### Sample size

A purposive sampling method was used to select cases of transplant kidney recipients. A guiding principle in adequacy of

this qualitative case study was data saturation. The researcher started with two cases from each site to give in-depth information on their own perceptions with motivators and barriers to with self-management among kidney transplant recipients. Seventeen more cases in total of kidney transplant recipients were added hence data saturation for this qualitative inquiry was achieved at case number nineteen, where the last selected kidney transplant recipient provided no new information.

## Data collection methods

Face-to-face semi-structured interviews were conducted to elicit responses from kidney transplant recipients. The interview-schedule was developed from in-depth literature review using concepts from the Chronic Care Model. The semi-structured interview schedule was designed to elicit in-depth information on perceptions of kidney transplant recipients about self-management among kidney transplant recipients. Kidney transplant self-management was assessed using indicators of adherence to medication, follow-up appointments, diet, lifestyle modification, hygiene, exercise and recommended treatment by the healthcare professionals.

## Ethical considerations

Permission to carry out the study was sought from the Department of Health, KwaZulu-Natal Province, Free State Province, Gauteng Province and Western Cape Province. Permission from the four selected state hospitals was also sought. Ethical clearance was sought from the Biomedical Research Ethical Committee of the University of KwaZulu-Natal. Informed consent was obtained from participants. The right to self-determination, privacy, fair treatment, anonymity and confidentiality was observed.

## Trustworthiness

Four measures of trustworthiness identified for this study were credibility, dependability, conformability and transferability as indicated by Miles et al. [13]. Credibility was achieved as the researcher spent time with selected cases of kidney recipients and developed an in-depth understanding of their perceptions during data collection until there was data

saturation as elaborated by Polit et al. [14]. A detailed case study protocol with a set of questions to be addressed by the researcher and data base with field notes and documents was set in the data collection process so that other researchers can follow the procedures thus facilitating dependability as emphasized by Yin [15]. Verification of interviews was conducted with the selected cases of kidney recipients to confirm that the information collected was a true reflection of their perceptions. The researcher provided detailed thick descriptive information of the research setting; study participants and themes identified in the study to facilitate assessment for applicability to new situations by prospective researchers in other various fields thus enhancing the transferability of the qualitative case study as elaborated by Yin [15].

## Data analysis

In this study, thematic codes were created based on central research questions during data collection and analysis. Then a sample of transcripts were read and coded using the skeleton codes and new codes were added as themes emerged in each transcript. This iteratively generated a standard codebook to be used across all transcripts. Ultimately, all transcripts were coded using the final codebook to ensure consistent application of the codes on all transcripts. After coding, results were summarized thematically to template style analysis, including cross-cutting themes and individual quotations and/or experiences as suggested by Yin [15].

## Results

### Selected cases of kidney transplant recipients

**Table 1** displays the selected kidney transplant recipients. Age ranged from a minimum of 28 years to a maximum of 71 years. The sample comprised of seven females and twelve males. There were eight married, eight single, two widowed and one divorced. Most (13) received monthly income of less than R3000 because of unemployment, casual work or received the pension grant. A minority (5) were fully employed and earning above R3000. The self-employed (1) earned between R3000-R6000.

**Table 1** Kidney recipient participants.

|               | Age | Gender | Marital Status | Occupation                                    | Monthly income |
|---------------|-----|--------|----------------|---|----------------|
| Participant 1 | 53  | Male   | Married        | Access control specialist –Full time employed | Above R10000   |
| Participant 2 | 28  | Male   | Single         | Unemployed Disability grant                   | Below R3000    |
| Participant 3 | 42  | Male   | Single         | Full time employed-educator                   | Above R10000   |
| Participant 4 | 47  | Female | Married        | Unemployed Disability grant                   | Below R3000    |
| Participant 5 | 39  | Female | Single         | Unemployed                                    | Below R3000    |
| Participant 6 | 38  | Male   | Married        | Full time employed-marketing                  | Above R10000   |
| Participant 7 | 65  | Male   | Married        | Pensioner                                     | Below R3000    |

|                |    |        |          |                                       |              |
|----------------|----|--------|----------|---------------------------------------|--------------|
| Participant 8  | 67 | Male   | Widowed  | Pensioner                             | Below R3000  |
| Participant 9  | 71 | Female | Single   | Pensioner                             | Below R3000  |
| Participant 10 | 41 | Male   | Single   | Personal Assistant-Full time employed | R3 000-R6000 |
| Participant 11 | 50 | Female | Married  | Unemployed                            | Below R3000  |
| Participant 12 | 39 | Male   | Single   | Unemployed                            | Below R3000  |
| Participant 13 | 49 | Female | Single   | Unemployed-Disability grant           | Below R3000  |
| Participant 14 | 55 | Male   | Married  | Employed-machine operator             | R3 000-R6000 |
| Participant 15 | 53 | Male   | Married  | Unemployed                            | Below R3000  |
| Participant 16 | 59 | Female | Divorced | Unemployed                            | Below R3000  |
| Participant 17 | 39 | Female | Single   | Casual worker                         | Below R3000  |
| Participant 18 | 58 | Male   | Widowed  | Unemployed-Disability grant           | Below R3000  |
| Participant 19 | 42 | Male   | Married  | Self-employed                         | R3 000-R6000 |

## Description of themes identified from selected kidney transplant recipients

This process was influenced both by the original research objectives and by new concepts generated inductively from the data. The emerged themes were made into narrative passages and the findings emerged logically from the participants' responses. Verbatim quotes were given and they were used to give the reader an idea of how the main and emerging themes evolved during the process of data analysis in this case study.

## Motivators to kidney transplant recipient self-management

Motivators as perceived by kidney transplant recipients are aspects of self-management, which influence the recipient positively in managing himself or herself, taking full responsibility of their condition. The main themes were kidney transplant recipient, physiological, psychological support systems and healthcare system related as displayed in **Table 2**.

**Table 2** Summary of the main themes and emerging themes of motivators.

| Target population | No of Participants | Main theme        | Emerging themes   |
|-------------------|--------------------|-------------------|---|
| Kidney recipients | 19                 | Recipient related | Scheduled routine<br>Independence<br>Adequate Knowledge                                   |
| Kidney recipients | 19                 | Physiological     | Few/no side effects   |
| Kidney recipients | 19                 | Psychological     | Fear of graft loss<br>Positive sense of well-being  |
| Kidney recipients | 19                 | Support Systems   | Peer<br>Family<br>Community Healthcare professional- Positive staff attitude<br>Financial |
| Kidney recipients | 19                 | Healthcare system | Effective Process<br>Effective Health Education   |

### Kidney transplant recipient related

The emerging themes were scheduled routine, independence and knowledge.

#### Scheduled routine

Most of the participants - 13 indicated that a planned scheduled routine of when to take medication was a

motivator. The participants confirmed that, the usual routine is to have the medication with breakfast and supper respectively. The participants admitted that after sometime of doing it, it becomes second nature. These were expressed in the following excerpts:

Participant 1: It is my daily routine; it has become part of my breakfast and supper. In addition, I have an alarm reminder on my phone.

Participant 3: I have a routine which I follow; I take my medication first thing in the morning after breakfast and at night after supper. I am so used to it there is no way I can forget.

Participant 7: I have no problems taking my medication, I have a pill box, making sure all my pills are organized according to days, and I take my medication at breakfast and supper time. There is no way I can forget, because I have been doing it for more than ten years.

## Independence

Findings revealed that there is nothing as rewarding as regaining one's independence. Participants - 12 confirmed that independence is a strong motivator, having the freedom to lead almost a normal life motivates one to stick to recommended health care behaviors. The participants described independence as performing activities of daily living without being a burden to others as indicated in the excerpts below:

Participant 4: I actually enjoy my independence; am not planning on letting it go. Every time I think of the dialysis days I always push myself to eat right and to take my medication.

Participant 7: I am now free to do most of the things I never did before the transplant and am not yet prepared to give up my freedom.

Participant 10: There is nothing as rewarding as being independent, being able to work and being productive for a change. I was given a second chance in life, I have to appreciate that.

## Knowledge

Findings highlighted that a few participants - 6 were motivated because of adequate knowledge and insight on the type of medication and how to manage the side effects. Being well informed of self-management and all the dynamics involved motivated the kidney transplant recipient to adhere to healthcare recommendations. These were expressed in the excerpts below:

Participant 1: I follow everything the staff at the hospital told me, I was informed about the best way to manage myself, to avoid most complications and even losing the transplanted kidney.

Participant 8: I know most of the things on kidney transplantation, through the hospital staff, internet and other patients. I avoid all the things which can contribute to the new kidney failing.

Participant 11: I know a lot on kidney transplantation, after being diagnosed with kidney failure, I could see that transplantation was my only and best option. I read and did a lot of research on the whole process.

Participant 13: I have read a lot on kidney transplantation, which is the only thing which keeps me going, knowing that I can actually contribute to the success of this transplant.

## Physiological motivators

Physiological motivators were aspects which were perceived to promote the normal function of the body. Physiological motivators emerging theme was few or no side effects.

### Few or no side effects

Findings revealed that transplant recipients with few or no side effects of medication tend to be motivated to continue treatment as prescribed. The participants - 7 indicated that having few or no side effects motivated them to continue with taking their medication as scheduled as indicated in the following excerpts:

Participant 2: I absolutely had no side effects, which made me take my medication as prescribed.

Participant 16: There was no need for me not to take the medication, I had very few side effects which I managed myself at home.

Participant 17: Not having any side effects encouraged me to take my medications religiously; I never skipped a day.

## Psychological motivators

These were psychological aspects perceived as positively motivating self-management among kidney transplant recipients. Emerging themes were fear of graft loss and positive sense of well-being.

### Fear of graft loss

Data reflected that most participants - 14 had fear of graft loss. Fear of going back to dialysis also played an important role, fear of losing freedom, going back to food restrictions and being rejected by the family motivates kidney recipients to stick to healthcare recommendations as expressed in the following excerpts:

Participant 6: The truth is that I have fear of losing my kidney that is why I try and do whatever I was told to do.

Participant 11: I can't lose my freedom, and the thought of going back to dialysis actually haunts me. I don't want my family to reject me after all it's my brother who donated this kidney, I wouldn't want to disappoint him.

Participant 13: Wee! I am afraid of losing my kidney and so I take my medications as prescribed and I never miss my follow-up visits.

Participant 16: I have fear of losing my kidney, because I dialyzed for eight years and those were the worst years of my life. I am so paranoid in managing myself in such a way that I do my own cooking and cleaning to avoid problems.

### Positive sense of well-being

A few participants - 5 revealed that a positive sense of well-being especially if the transplant is doing well was a strong motivator to make the recipients engage with self-

management. The feeling of living almost a normal life was a strong motivator as indicated in the following excerpts:

Participant 2: I feel positive now after transplantation. I feel I can attain my goals because now I don't feel tired like before.

Participant 17: I feel good about myself, at least now I am working and am helping my family.

Participant 18: My family seems to appreciate me, now that I can do things for myself and am no longer a burden, it makes me feel good.

## Support systems

A significant number of participants verbalized some form of support which motivated them to take full responsibility for their management. Some of the support system highlighted included peer support, family support, community support, healthcare professional support and financial support.

### Peer support

Most participants - 13 confirmed that peer support was a strong motivator to transplant management. Participants indicated that support groups where people with the same interests met, were beneficial and there was a lot of support for each other. Furthermore, participants indicated that people with the same condition understood each other and most problems were resolved. These were expressed in the following excerpts:

Participant 1: I look forward to coming for my follow-up visits; it is the only time I get to talk to people in the same situation as myself. I always feel encouraged to take my medication and do the right thing when I see others doing so well.

Participant 4: We now have WhatsApp group, started by a doctor in the clinic. We discuss problems among ourselves and the doctor only intervenes when there is a problem we cannot resolve. I look forward to receiving messages from people who know and understand the condition.

Participant 18: There is nothing as rewarding as meeting and talking to someone in the same situation. This is the thing, which keeps me going; if others can do it, I can also do it. The thought makes me commit myself to all the right habits so that my kidney can function for as long as I live.

### Family support

Findings reflected that participants - 8 valued family support as a strong support system. Participants indicated that they are doing well because of their family; most common was support between spouses. The participants confirmed that family support is vital as "no man is an island" as one echoed. This was expressed in the following excerpts:

Participant 2: Without a family, I do not think I was going to survive. I value my family so much especially my mom, somehow she always senses it when I am not feeling okay. My

siblings have also been supportive reminding me on follow-up visits and when to take my medication.

Participant 3: My wife is my pillar, from the time I was diagnosed with kidney failure to post kidney transplantation; she has been on my side. She reminds me to take my medication, makes sure I eat healthy food and always keeps the house clean. Again, even the times I felt low she would say something to uplift my spirit.

Participant 12: My family has always been there for me and I believe that no man is an island. They are protective of my new kidney in such a way that they will not allow sick relatives to visit. My mom will not allow me to eat junk food and always reminds me about what the nurses said post transplantation.

### Community support

A few participants - 4 revealed that the community's support was essential in transplant self-management, as they would assist to keep the environment conducive for transplant management as highlighted in the following excerpts:

Participant 12: In my community, all my neighbors are aware that I had kidney transplantation. They do not call me to join them in community gatherings because they know that I have to avoid infection by all means otherwise I may lose my kidney.

Participant 16: The whole neighborhood, know how I suffered before transplantation. They are supportive in making sure my new kidney functions for many more years. I get donations from my church and their constant support makes me have the urge to carry on.

### Healthcare professional support

Findings revealed that most participants - 12 treasure the support of healthcare professionals because one remains a patient for life. The positive, supportive healthcare professionals, according to findings, assist in motivating patients to report to the clinic as soon as a problem is identified. This was expressed in the following excerpts:

Participant 3: I do not hesitate to present myself at the transplant clinic with any minor problem, the staff there is very friendly, approachable and always willing to assist. Sometimes even when am feeling low, I just phone the clinic and talk to the staff on duty. They always have time for us.

Participant 5: I always feel motivated to take my medication and follow all the recommendations by the healthcare professionals because I do not want to disappoint the nurses and doctors, because they really do care for us. They treat us like family.

Participant 8: The nurses and doctors here are super, they are God sent, and they are very nice but are firm with us if we do not do what is recommended. I like them, they make me feel appreciated and that keeps me going. They are always there to listen and advise when necessary.

Participant 11: I love the staff in this clinic; Sr Nancy (not her real name) is the best though the whole team is good. She is

very approachable, friendly and always smiling. I always look forward to my follow-up visits.

### Financial support

Participants - 9 revealed that financial support to transplant recipients still unemployed assisted with adherence to healthcare recommendations. According to the findings after transplantation, the government disability grant, if not withdrawn assists a lot in sticking to healthcare recommendations such as eating a healthy diet and transport for follow-up visits. This was revealed in the following excerpts:

Participant 12: My parents support me financially. I stopped working when I got sick. The financial support has kept me going. It makes it easy to follow doctors' orders when you are financially supported.

Participant 13: I am so grateful that my government disability grant was not withdrawn after transplantation. I have not yet found work and so the money I get assists me in eating healthy meals and I am able to go for my follow-up visits.

Participant 18: The most important thing which keeps me going is that I get financial help from my husband and I am also receiving the disability grant. The money I get motivates me to manage myself making sure I do as per doctors' orders.

### Healthcare system motivators

Healthcare system motivators were aspects involving the whole process in kidney transplant management, offered by the healthcare facility to promote self-management to kidney transplant recipients. Effective process and effective health education were identified as the emerging themes.

### Effective process

A significant number of participants - 11 confirmed that an effective healthcare system, reflecting a smooth process from the time one walks into the hospital premises to the time one leaves was a strong motivator. The participants revealed the most institutions had effective processes except for a few hiccups expected in state hospitals. This was expressed in the following excerpts:

Participant 2: I am very happy with the process, which takes place in this institution, the records are retrieved in time, investigations are done on time, the doctors see us on time, however, they are delays in pharmacy where there is mixing of patients but it does not bother me much because this is a state hospital. Again, the urine room where they test our urine, it can be very messy. That does not stop us from coming for review because all other things are okay.

Participant 6: The system at this hospital is super, considering that it is a state hospital I think it is doing well. I am happy to come for my visits here because I get all investigations done and I get all my prescribed medication. At least we have access to everything needed when we come to follow-up visits.

Participant 9: This hospital is well organized. I look forward to coming for my follow-up visits, from the time I enter the hospital to the time I leave I have nothing bad to say. The only issue is that if I am not wearing a mask to show that am a transplant patient then I am not prioritized and so I have to join the long queues to be registered.

### Effective health education

Data sources revealed that effective education, delivered in a language the kidney recipient understands was a strong motivator to self-management. The participants - 9 echoed that health education starting well before transplant and continued post-transplant was very effective. This was indicated in the following excerpts:

Participant 2: I was informed about transplant management before I had my transplant done and the emphasis was on keeping the new kidney working. The education continued even after transplant, this made me realize that if I follow the recommendations my kidney may survive for a long time.

Participant 15: The health education given to me post-transplant was so intensive and understandable. It motivated me to read more on kidney transplant and management. I always do things, which may contribute to the survival of my transplanted kidney.

Participant 16: Both the nurses and doctors give health education. I was only discharged after I revealed that I knew my medication well and I knew about self-management at home. The language used was clear and understandable. Knowing most of the information about my condition motivated me to stick to all the dos and don'ts of kidney transplantation self-management.

### Barriers to kidney transplant recipient self-management

Barriers as perceived by kidney transplant recipients are aspects of self-management, which influence the recipient negatively in managing himself or herself or even taking full responsibility of their condition. The emerging themes were kidney transplant recipient, physiological, psychological, healthcare system and low socio-economic status related as displayed in **Table 3**.

**Table 3** Summary of the main themes and emerging themes of barriers.

| Target population | No of Participants | Main theme        | Emerging themes  |
|-------------------|--------------------|-------------------|--|
| Kidney recipients | 19                 | Recipient related | Busy work schedules<br>Lack of knowledge/ignorance<br>Unhealthy lifestyle habits |
| Kidney recipients | 19                 | Physiological     | Severe side effects<br>Poor Health   |

|                   |    |                           |   |
|-------------------|----|---------------------------|---|
| Kidney recipients | 19 | Psychological             | Lack of support<br>False sense of wellbeing   |
| Kidney recipients | 19 | Healthcare system         | Lack of self-monitoring equipment<br>Inadequate health education<br>Negative staff attitude |
| Kidney recipients | 19 | Low socio-economic status | Lack of financial support<br>Poverty<br>Unemployment  |

## Kidney transplant recipient related

Emerging themes under kidney transplant related were busy work schedule, lack of knowledge/ignorance and unhealthy lifestyle habits.

### Busy work schedule

Findings reflected that a few participants - 6 echoed busy work schedules as a barrier to self-management. They further mentioned that the strict schedule to be followed when taking immunosuppressant was difficult to adhere to; contrary to most participants who advocated that a scheduled routine was a motivator to self-management. This was expressed in the following excerpts:

Participant 14: I am so busy at work, in such a way that when the time for taking medication has come, I am unable to leave the machine running without any one to hand over to. I only get to take my medication well after the scheduled time.

Participant 17: After transplant, I started some part time work, and because I work for different people, I sometimes become so busy and never get an opportunity to take my medication in time, an effort not to disappoint anyone.

Participant 19: I cannot follow the strict schedule of taking immunosuppressant. They want us to stick to the times for the treatment to function well but with my busy work schedule, sometimes we have no tea break and I end up taking my immunosuppressant well after scheduled time.

### Lack of knowledge/ignorance

Findings revealed that lack of knowledge on kidney transplant self-management was a huge barrier. Furthermore, participants - 8 mentioned that lack of formal education maybe a barrier to self-management as one would never comprehend on why certain things should be done in certain ways, in addition health education focused more on medication adherence only and not lifestyle modification as expressed in the following excerpts:

Participant 4: I went as far as grade seven, sometimes I stop doing things, which they say I must do because I do not understand the benefit. After transplantation there was a time, I stopped taking my medication as prescribed because I was passing urine well and I was feeling okay. When I went for my checkup, I was informed that my blood results revealed

that the kidneys were not functioning too well, that is when I confessed to not taking my medication properly.

Participant 9: I was sick but I did not seek help immediately, when I felt pain on my operation site, followed by flu-like symptoms. Later this was followed by drop in urine output that is when I presented myself at the renal clinic. Nobody really emphasized on signs of kidney rejection during health education.

Participant 12: I feel the knowledge I have on kidney transplant management is not enough. The person who educated me on management post transplantation focused mostly on medication, what you are asking me about exercise, eating healthy meals, watching out for rejection signs in order to seek assistance early and self-monitoring at home, am hearing this for the first time.

### Unhealthy lifestyle habits

Very few participants - 5 confirmed that unhealthy lifestyle habits such as drinking alcohol and using drugs maybe a strong barrier to transplant management as one might forget to take medication or even take overdose. One may even forget about follow-up clinics. These were indicated in the following excerpts:

Participant 2: I like clubbing because I am only 28 years old but once I take more than 3 bottles of beer then I forget to take my medication. I know alcohol is not good for me but that is the only thing, which makes me not to worry about many things.

Participant 14: I know I am not supposed to use drugs but a friend of mine is doing very well taking a bit of recreational drugs, and I have never seen him admitted to hospital unlike myself. I have now started using a bit of drugs and the problem is I sometimes forget to take my medications completely.

Participant 17: Last month I skipped my follow-up clinic because I had taken a bit the previous night. The nurses were so upset with me when I presented myself on the unscheduled date. It was not even a transplant clinic day.

### Physiological barriers

A significant number of participants mentioned physiological barriers to transplant management. Emerging themes for physiological barriers indicated were severe side effects and poor health.

### Severe side effects

A few participants -6 revealed that severe side effects such as severe diarrhea, warts, ulcers, skin cancer, tremors etc. were a strong barrier to engagement with management. Participants confessed to stopping medication without even informing the healthcare professionals because of the severe side effects. These were indicated in the following excerpts:

Participant 4: I was so sick post transplantation due to immunosuppressant, I developed severe abdominal pains, I



also had diarrhea and oral ulcers and furthermore am now diabetic. I stopped taking medication even before I informed the doctor. My immunosuppressants were changed and now I feel much better. I still present with a few side effects but they are manageable.

Participant 8: Immunosuppressant which I first took for my transplant made me develop warts all over my body, you can see for yourself even after stopping, I still have them though I am much better.

Participant 10: Severe side effects of immunosuppressants made me cut back on the doses of immunosuppressants; I was having severe headaches and dizziness. After visiting the clinic my immunosuppressants were changed and now I feel a bit better. My blood results revealed that my urea and creatinine was slightly elevated.

### Poor health

A few participants - 5 revealed that poor health could be a barrier to transplant management, as one is not able to attend to all activities of daily living. This was highlighted in the following excerpts:

Participant 5: The only time I do not do things as recommended is when I am sick and depending on someone to assist me. I hate it when I am sick.

Participant 11: The time I was not feeling well I could hardly keep anything down my stomach that made me to stop drinking as I am supposed to. I could not take medication on an empty stomach.

Participant 14: At one point I was very sick; I could not shower or brush my teeth without assistance. That really disturbed my routine because I always want to keep the good standards of hygiene to prevent infection.

### Psychological barriers

Findings highlighted that lack of psychological support is a barrier to transplant management. A few participants - 6 indicated that lack of psychological support from family, healthcare professionals and community was a barrier to self-management. These were expressed in the following excerpts:

### Lack of support

Participant 2: I do not have anyone to remind me on anything. I stay alone, and make sure I remember my medication and clinic days. After transplantation, my family took it that I can now manage on my own. Nobody seems to care now making me so sad that I do not feel motivated to take care of myself.

Participant 19: I frequently have mood swings I am sure due to steroids, which is part of my treatment. I feel there is lack of psychological support even from the hospital; nobody refers you to a psychologist let alone talk about one. I always feel depressed at times and there is no one to talk to. I feel demotivated, sometimes eat unhealthy food.

### False sense of well-being

A few participants - 5 indicated that the false sense of well-being could be a barrier to self-management. When one starts feeling normal, they may stop treatment thinking all is well as indicated in the following excerpts:

Participant 4: After the transplant, I felt all was well, I was passing urine well, regained my energy levels and somehow I felt there was no need to attend the follow-up clinic, when I finally presented myself at the follow up clinic I was informed that my therapeutic blood levels for immunosuppressant were very low.

Participant 9: This feeling of being so well sometimes makes us ignore the recommendations by the medical staff. I sometimes take things for granted and eat unhealthy or forget to take medications as prescribed.

Participant 14: I feel so good post-transplant in such a way that sometimes I do not see the reason to be compliant with all follow-up visits.

### Healthcare system related barriers

Healthcare system related barrier is what the hospital is failing to do thus contributing negatively to self-management among kidney transplant recipients. Emerging themes were lack of self-care monitoring equipment, inadequate health education and negative staff attitudes.

### Lack of self-care monitoring equipment

Findings revealed that almost none of the participants had equipment to monitor themselves at home. The participants - 13 indicated that lack of equipment for self-monitoring at home was a barrier if one was fully immersed in transplant management. This was highlighted in the following excerpts.

Participant 6: I would like to monitor my sugar and blood pressure but I cannot afford to buy the equipment to use, I only have my blood pressure and sugar checked when I go for my checkups. Last visit the nurses said that my blood pressure was very high but I could not tell except that I had headaches a few times.

Participant 14: I am gaining a lot of weight now that I have regained my appetite after transplantation. Having a scale would assist me in monitoring my weight closely. Unfortunately, the hospital did not provide one and I cannot afford it.

Participant 18: I do check my temperature at home when I am feeling feverish but as for the weight and blood pressure I do not have the equipment.

### Inadequate health education

Participants 9: Indicated that inadequate health education was a strong barrier to self-management. The poor personal hygiene, failure to adapt to the new lifestyle post transplantation and the non-compliance to medication were

all attributed to lack of effective health education. This was expressed in the following excerpts:

Participant 9: When you are asking me now I realize the education I got was not adequate, not everything important was covered. Exercise and signs of kidney rejection were not emphasized.

Participant 15: I did not know why good hygiene and compliance to medication was emphasized. The action of immunosuppressant was left out and yet once one understands they would take their immunosuppressant on time.

Participant 17: Health education was only given to me three days before discharge after transplantation. I was not confident when I left the hospital. They did not even invite my wife at least, the lady who taught was white and my English is not very good.

### Negative staff attitudes

Findings from a very minute number of participants - 3 revealed that negative staff attitude would definitely not contribute to effective transplant management. Staffs that are unapproachable, unfriendly and rude would make the patient think twice on being compliant with follow-up visits as indicated in the excerpts below:

Participant 7: There was one visit the sister was very rude to me, if it was not for my wife I was to stay at home and never come back.

Participant 10: There are some staff members who are not approachable; I sometimes do not query anything because you are afraid on what may come onto you.

### Low socio-economic status

Data collected reflected that kidney recipients who are unemployed with no source of income had problems adhering to transplant management. Participants - 9 revealed that, money to have a well-balanced meal, to attend follow-up visits and to maintain high standards of hygiene may not be available. Unemployment, poverty and lack of financial support were highlighted in their responses as follows:

Participant 13: I am not working and so a well-balanced meal is not possible. The disability grant I am getting also supports my siblings.

Participant 16: I am sharing a one-roomed house with five other relatives. I cannot move because I cannot afford. I eat whatever is available; I do not have much choice.

Participant 18: I am not educated, I do not have a course and so I can hardly get a good job and so I rely on temporary jobs. These are not always available.

## Discussion

### Motivators to self-management

Most of the participants indicated that a planned scheduled routine of when to take medication was a motivator, taking during breakfast and supertime was common. This was consistent with studies done by Chisholm-Burns et al. [16], Griva et al. [17], Gordon et al. [2] in which establishing a daily routine improved adherence. Most participants mentioned regaining ones' independence as a strong motivator. Similarly Thomas [18] stated that a successful kidney transplant results in freedom from dependence upon the machine, fluid bag or caregiver; freedom from fluid and dietary restrictions. Furthermore, a few participants verbalized that adequate knowledge and insight on kidney transplantation through effective health education was a strong motivator. This was supported by a study done by Low et al. [19] which demonstrated the feasibility of creating a consumer driven video that supports medication adherence in an engaging way. A few participants, also indicated that, few or no side effects of medication motivated recipients to be adherent to health care recommendations. This is consistent with a study by Kung et al. [20] in which, adherence to medication regimens correlated negatively with drug-related symptoms and perceived susceptibility to rejection.

Fear of graft loss and having a positive sense of well-being especially if the transplant is doing well as indicated by a significant number of participants is a strong motivator to make the recipients adhere to transplant management. This concurs with a study done by Griva et al. [17] which reported that being aware of the negative consequences associated with non-adherence served as a deterrent and motivated patients to align their behavior with the treatment recommendations. Furthermore, according to Jamieson et al. [3] anxieties about rejection, complications, and comorbid conditions can also strongly motivate kidney transplant recipients to remain vigilant in self-management. About half the participants highlighted that positive staff attitudes made kidney recipients look forward to their next follow-up visit, which made recipients adhere to follow-up visits. This is supported by a study done by Zhao et al. [21] which, demonstrates the patients' physical functioning, social functioning, treatment, subjective satisfaction, and total points of quality of life were affected by adherence to follow-up.

Most kidney recipients appreciated peer and family support. This was supported by study done by Clarke et al. [22] in which participants appreciated being surrounded by peers of similar capabilities, and this was perceived to be mutually supportive, educational and a way of improving confidence. Furthermore, studies done by Griva et al. [17] and Prihodova et al. [23] reported that family support primarily served as a direct facilitator to follow treatment recommendations. According to the same authors, support was extended by providing cues to action, direct assistance in administering medications or preparing meals, reinforcement and advice or reminders to control fluid and dietary intake [17,23]. Kidney transplant

recipients treasured community support and support of healthcare professionals especially the positive staff attitude. Lin et al. [24] reported that the importance of healthcare provider support in improving health promotion behaviors was found to be a major contribution. A significant number of participants reported financial support to transplant recipients while still unemployed as a facilitator with adherence to healthcare recommendations. A few unemployed appreciated the government disability grant they were still getting. Participants indicated that an effective healthcare system, reflecting a smooth process promoted adherence among kidney transplant recipients. A significant number of participants were happy with kidney transplant management in their respective institutions, however, the few hiccups mentioned, according to participants were acceptable since these are state hospitals.

### Barriers to self-management

A significant number of participants highlighted busy work schedules among kidney recipients as a barrier to management. According to Weng et al. [25] patients' personal schedules and routines were barriers to adherence with recommendations. Participants indicated that lack of knowledge and formal education as huge barrier to transplant management as Obi et al. [5] confirmed. Similarly, a study done by Demian et al. [26] indicated that worse adherence was associated with poorer overall health literacy. Inadequate health education was a strong barrier to self-management. Participants blamed poor personal hygiene, failure to adapt to the new lifestyle post transplantation, and the non-adherence to medication on lack of effective health education. In addition, participants felt health education was focused more on medication adherence only neglecting all other aspects of self-management. This was supported by a study done by Brown et al. [27] in which the majority of patients agreed that they did not receive enough information about kidney transplant from their dialysis teams, or that the information they received was often not helpful. Very few participants confirmed that unhealthy lifestyle habits such as drinking alcohol and using drugs maybe a strong barrier to transplant management as one might forget to take medication, overdose or even forget about follow-up clinics. This was supported by a study done by Israni et al. [28] in which, alcohol use, distractions and falling asleep before taking evening dose was a barrier to health care recommendations.

Participants indicated severe side effects and poor health as a barrier as one is not able to attend to all activities of daily living. This is consistent with study by Lee et al. [29]. Furthermore, Muduma et al. [30] reported that some participants verbalized side effects to be so severe that new job roles were required. However, there was a feeling of gratitude for the new kidney [30]. In contrast a study done by Lennerling and Forsberg [31], side effects were not increased in the non-adherent group. Lack of psychological support from family, healthcare professionals and community was a barrier to management. Russell et al. [32] and Lennerling and Forsberg [31] concurred that the extent of support from family and friends was significantly more often classified as minor by

the non-adherent patients, indicating that social support might be a predictor for non-adherence among kidney transplant patients. A few participants echoed a false sense of well-being as a barrier to transplant management. Furthermore, the participants revealed that some recipients do well and intentionally stop following healthcare recommendations.

Most participants had no equipment (blood pressure machine, glucometer, temperature probe and scale) to monitor themselves at home. The participants indicated that lack of equipment for self-monitoring at home was preventing early detection of ill health. Agena et al. [33] and van Lint et al. [34] assert that blood pressure control in kidney transplant recipients might be better achieved through home blood pressure monitoring. Furthermore, according to van Lint et al. [34] self-monitoring enhances patients' high levels of satisfaction. Participants highlighted negative staff attitude as attributing to ineffective transplant management. This concurs with a study done by Lin et al. [24] in which there were a dramatic decline in healthcare provider support perceived by recipients in the third post-transplant year. The unemployed with no source of income had problems adhering to health care recommendations. This was supported by a study done by Ortiz et al. [35] in which, health-related quality of life was better in employed kidney recipients.

### Conclusion

Identified motivators were scheduled routine, fear of graft loss, effective health education, different support systems and an effective healthcare system as most prominent. The most prominent barriers included inadequate health education, low socio-economic status, severe side effects, poor health and lack of self-monitoring tools. A multi-disciplinary team approach may assist to develop an intervention model to improve on long-term graft survival.

### Relevance to Clinical Practice

Understanding the motivators and barriers to self-management among kidney transplant recipients may enhance more vigilant attention to their needs by healthcare professionals. Focus may be paid to those at high risk for non-adherence to self-management.

### Recommendations

To conceptualize research findings on motivators and barriers to self-management among kidney transplant recipients, and use them to develop and promote evidence based practice to improve on graft survival.

### Acknowledgement

This project received financial support from the College of Health Sciences, School of Nursing and Public Health of the University of KwaZulu-Natal. The research article is part of a PHD thesis towards the development of an intervention model

to improve on long-term graft survival post kidney transplantation in state hospitals in South Africa.

## References

- Nankivell BJ, Kuypers DR (2011) Diagnosis and prevention of chronic kidney allograft loss. *The Lancet* 378: 1428-1437.
- Gordon EJ, Wolf MS (2009) Health literacy skills of kidney transplant recipients. *Prog Transplant* 19: 25-34.
- Jamieson NJ, Hanson CS, Josephson MA, Gordon EJ, Craig JC, et al. (2016) Motivations, challenges and attitudes to self-management in kidney transplant recipients: A systematic review of qualitative studies. *Am J Kidney Dis* 67: 461-478.
- Griva K, Davenport A, Harrison M, Newman SP (2012) Non-adherence to immunosuppressive medications in kidney transplantation: Intent vs. forgetfulness and clinical markers of medication intake. *Ann Behav Med* 44: 85-93.
- Obi Y, Ichimaru N, Kato T, Kaimori JY, Okumi M, et al. (2013) A single daily dose enhances the adherence to immunosuppressive treatment in kidney transplant recipients: A cross-sectional study. *Clin Exp Nephrol* 17: 310-315.
- Morales JM, Varo E, Lázaro P (2012) Immunosuppressant treatment adherence, barriers to adherence and quality of life in renal and liver transplant recipients in Spain. *Clin Transplant* 26: 369-376.
- Kumar BA, Mattoo SK (2015) Organ transplant & the psychiatrist: An overview. *Indian J Med Res* 141: 408-412.
- Weng LC, Dai YT, Huang HL, Chiang YJ (2010) Self-efficacy, self-care behaviours and quality of life of kidney transplant recipients. *J Adv Nurs* 66: 828-838.
- Pinter J, Hanson CS, Craig JC, Chapman JR, Budde K, et al. (2016) 'I feel stronger and younger all the time'-perspectives of elderly kidney transplant recipients: Thematic synthesis of qualitative research. *Nephrol Dial Transplant* 31: 1531-1540.
- Chisholm-Burns MA, Spivey CA, Zivin JG, Lee JK, Sredzinski E, et al. (2013) Improving outcomes of renal transplant recipients with behavioral adherence contracts: A randomized controlled trial. *Am J Transplant* 13: 2364-2373.
- Rodrigue JR, Mandelbrot DA, Pavlakis M (2010) A psychological intervention to improve quality of life and reduce psychological distress in adults awaiting kidney transplantation. *Nephrol Dialysis Transplant* 26: 709-715.
- De Pasquale C, Veroux M, Indelicato L, Sinagra N, Giaquinta A, et al. (2014) Psychopathological aspects of kidney transplantation: Efficacy of a multidisciplinary team. *World J Transplant* 4: 267-272.
- Miles MB, Huberman AM, Saldaña J (2014) Fundamentals of qualitative data analysis. *Qualitative data analysis (3rd edn.)*, Sage, Thousand Oaks, CA. pp: 69-104.
- Polit DF, Beck CT (2012) Resource manual for nursing research: Generating and assessing evidence for nursing practice. Wolters Kluwer Health/Lippincott Williams & Wilkins. Participation in paid work after organ transplantation: Perceptions of kidney transplant recipients. *J Occup Rehabil* 25: 38-51.
- Yin RK (2014) Case study research: Design and methods. Sage Publications, UK. pp: 1-53.
- Chisholm-Burns M, Pinsky B, Parker G, Johnson P, Arcona S, et al. (2012) Factors related to immunosuppressant medication adherence in renal transplant recipients. *Clinical Transplant* 26: 706-713.
- Griva K, Ng HJ, Loei J, Mooppil N, McBain H, et al. (2013) Managing treatment for end-stage renal disease—a qualitative study exploring cultural perspectives on facilitators and barriers to treatment adherence. *Psychol Health* 28: 13-29.
- Thomas N (2008) Renal nursing. Elsevier Health Sciences.
- Low JK, Crawford K, Manias E, Williams A (2016) A compilation of consumers' stories: The development of a video to enhance medication adherence in newly transplanted kidney recipients. *J Adv Nurs* 72: 813-824.
- Kung PC, Yeh MC, Lai MK, Liu HE (2017) Renal transplant recipients: The factors related to immunosuppressive medication adherence based on the health belief model. *J Nurs Res* 25: 392-397.
- Zhao L, Yan J, Yang GL, Liu Y (2017) A study on adherence to follow-up, quality of life, and associated factors among renal transplant recipients in China. *Transplant Proceedings* 49: 1285-1290.
- Clarke AL, Young HM, Hull KL, Hudson N, Burton JO, et al. (2015). Motivations and barriers to exercise in chronic kidney disease: A qualitative study. *Nephrol Dialysis Transplant* 30: 1885-1892.
- Prihodova L, Nagyova I, Rosenberger J, Majernikova M, Roland R, et al. (2014). Adherence in patients in the first year after kidney transplantation and its impact on graft loss and mortality: A cross-sectional and prospective study. *J Advanced Nurs* 70: 2871-2883.
- Lin SY, Fetzer SJ, Lee PC, Chen CH (2011) Predicting adherence to health care recommendations using health promotion behaviours in kidney transplant recipients within 1–5 years post-transplant. *J Clinical Nurs* 20: 3313-3321.
- Weng FL, Chandwani S, Kurtyka KM, Zacker C, Chisholm-Burns MA, et al. (2013) Prevalence and correlates of medication non-adherence among kidney transplant recipients more than 6 months post-transplant: A cross-sectional study. *BMC Nephrol* 14: 261.
- Demian MN, Shapiro RJ, Thornton WL (2016) An observational study of health literacy and medication adherence in adult kidney transplant recipients. *NDT Plus* 9: 858-865.
- Brown L, Gardner G, Bonner A (2016) A randomized controlled trial protocol testing a decision support intervention for older patients with advanced kidney disease. *J Adv Nurs* 72: 1191-1202.
- Israni A, Dean C, Kasel B, Berndt L, Wildebush W, et al. (2016) Why do patients forget to take immunosuppression medications and miss appointments: Can a mobile phone app help? *JMIR Public Health Surveill* 2: e15.
- Lee SY, Chu SH, Oh EG, Huh KH (2015) Low adherence to immunosuppressants is associated with symptom experience among kidney transplant recipients. *Transplant proceedings* 47: 2707-2711.
- Muduma G, Shupo FC, Dam S, Hawken NA, Aballéa S, et al. (2016) Patient survey to identify reasons for non-adherence and elicitation of quality of life concepts associated with immunosuppressant therapy in kidney transplant recipients. *Patient preference and adherence* 10: 27-36.

31. Lennerling A, Forsberg A (2012) Self-reported non-adherence and beliefs about medication in a Swedish kidney transplant population. *Open Nurs J* 6: 41-46.
32. Russell CL, Moore S, Hathaway D, Cheng AL, Chen G, et al. (2016) MAGIC study: Aims, design and methods using System CHANGE™ to improve immunosuppressive medication adherence in adult kidney transplant recipients. *BMC Nephrol* 17: 84.
33. Agena F, Prado EDS, Souza PS, Silva GVD, Lemos FBC, et al. (2011) Home blood pressure (BP) monitoring in kidney transplant recipients is more adequate to monitor BP than office BP. *Nephrol Dialysis Transplanta* 26: 3745-3749.
34. van Lint CL, van der Boog PJ, Wang W, Brinkman WP, Rövekamp TJ, et al. (2015) Patient experiences with self-monitoring renal function after renal transplantation: Results from a single-center prospective pilot study. *Patient Prefer Adherence* 9: 1721-1731.
35. Ortiz F, Aronen P, Koskinen PK, Malmström RK, Finne P, et al. (2014) Health-related quality of life after kidney transplantation: Who benefits the most?. *Transpl Int* 27: 1143-1151.