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Barriers to management of Chronic Kidney Disease (CKD) CKD in a renal clinic in KwaZulu-Natal Province, South Africa – A qualitative study

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ABSTRACT

Background: The progression of Chronic Kidney Disease (CKD) and existence of comorbid conditions makes management of CKD complicated, leading to unforeseen challenges for patients and healthcare professionals. Moreover, studies exploring the barriers to management of CKD from the perspectives of healthcare workers involved in direct care or patients receiving such care are limited.

Purpose of the study: The purpose of this study was to explore the barriers to management of CKD in a Renal Clinic in KwaZulu-Natal Province, South Africa.

Methods: A qualitative research approach was used, and a descriptive exploratory design employed. The sample size was thirteen, with seven CKD patients and six healthcare providers, as determined by data saturation. A purposive sampling strategy was used to select study participants. Semi-structured interviews with open-ended questions were utilised to collect the data. Credibility, transferability, confirmability and dependability were used to evaluate the trustworthiness of the qualitative data collected. Data was analysed using a thematic framework approach. Ethical rights were observed, and informed consent and participant authorisation were sought.

Results: The side-effects of treatment, longevity of haemodialysis procedure, gastrointestinal problems, a false sense of good health, depression, lack of employment opportunities, limited in-service training, inclement weather condition, cultural and religious practices as well as uncertainties about obtaining a kidney transplant were highlighted as barriers to the management of CKD from the perspectives of both CKD patients and healthcare workers.

Conclusion: Despite the measures of state hospitals to provide CKD management, barriers to management of CKD still exist amongst the CKD population. Hence, there is need to develop specific tailored interventions to reduce such obstacles thus promoting effective management of CKD patients.

1. Introduction

Although the prevalence of Chronic Kidney Disease (CKD) is debatable in international literature, it is increasing with time, thus making the disease a global public health problem based on the current socio-demographic trends (Raghavan & Eknoyan, 2014). The international guidelines for Kidney Disease Improving Global Outcomes (KDIGO) defines CKD as decreased kidney function as shown by a glomerular filtration rate (GFR) of less than 60 mL/min per 1.73 m^2, or markers of kidney damage, or both, of at least three months duration, regardless of the underlying cause (Webster, Nagler, Morton, & Masson, 2017).

CKD progresses from stage 1 to 5, with many patients not identified until they have reached End Stage Renal Disease (ESRD), which is costly in terms of providing Renal Replacement Therapy (RRT), thus burdening the healthcare system globally (Etheredge & Fabian, 2017; Harvey, Oliver, Humphreys, Rothwell, & Hegarty, 2014). This unusual progression, the nonidentification of early stages of the disease and the existence of comorbid conditions, makes management complicated, leading to unforeseen challenges to patients and healthcare professionals.

Patients with CKD are recommended to follow dietary and fluid restriction in addition to medication and dialysis (Arici, 2016; Lynch, 2018). Nutritional therapy forms the basis for positive metabolic processes, thus preventing further renal insufficiency, and consequently slowing the progression of CKD to late stages which require dialysis (D'Alessandro et al., 2016; Stevenson, Tong, Campbell, Craig, & Lee, 2018). Medications such as angiotensin converting inhibitors have been found to be excellent in preventing the development and slowing the

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progression of CKD, in addition to lowering the comorbidity of hypertension (Thomas, 2014).

Similarly, treatment of diabetes mellitus, infections, anaemia, and mineral and bone disorders is imperative in reducing complications associated with renal failure (Arogundade et al., 2017). Moreover, fluid restriction and adequate dialysis is paramount in controlling and removing excess fluid and toxic metabolites (Geldine, Bhengu, & Manwere, 2017). The aforementioned treatments in the form of dialysis, medication, and fluid and dietary restrictions are integrated, making the management of CKD complex and suboptimal.

The availability of tertiary healthcare workers, coupled with patient self-management, were identified as key factors for optimal management of CKD (Lo et al., 2016). It is the duty of healthcare professional to screen and manage CKD, providing benefits such as early detection and treatment, the reduction of disease burden, and the opportunity to increase awareness and provide disease prevention education (Sinclair, Day, Levett-Jones, & Kable, 2017).

Nevertheless, patients are faced with many barriers, such as a lack transportation to dialysis units, holidays, cold or wet weather conditions, pain, long haemodialysis sessions, depressive symptoms and gastro-intestinal tract upsets (Chan, Thadhani, & Maddux, 2014; Ghimire, Castelino, Lioufas, Peterson, & Zaidi, 2015). The existence of comorbid conditions, coupled with the complexity of the medication regimen required, culminates in non-adherence as a barrier to management of patients with CKD (Ghimire et al., 2015). Similarly, healthcare workers experience barriers which include cultural, language, insufficient time, poor clinical competencies, a lack of policies and procedures, as well as inadequate expertise, and these factors hinder the effective management of the CKD population (Clayton et al., 2015; Narva, Norton, & Boulware, 2016; Stevenson et al., 2018).

Barriers to the management of CKD result in complications which may call for frequent hospitalisations, emergency revisits, and Intensive Care Unit (ICU)-Coronary Care Unit (CCU) admissions (Chan et al., 2014) which are consequently costlier for the healthcare system and more demanding on patients. The management of CKD in state hospitals of South Africa is bound by government as they only treat patients who have qualified for kidney transplants (Etheredge & Fabian, 2017). Despite the efforts of healthcare workers and patients to effectively manage CKD, both parties are faced with obstacles as a result of the highlighted complexity of the treatment. Moreover, studies exploring the barriers to the management of CKD from the perspective of healthcare workers involved in direct care or patients receiving such care are limited in both the international and South African contexts.

2. Purpose of the study

The purpose of this study was to explore the barriers to management of CKD in a Renal Clinic in KwaZulu-Natal Province, South Africa.

3. Materials and methods

3.1. Study design

A qualitative approach was used. A descriptive exploratory design was employed to examine the barriers to the management of CKD from the perspectives of healthcare workers and patients with CKD.

3.2. Study setting

The study was conducted at a major referral healthcare facility in eThekwin district, which is the largest regional hospital in the southern hemisphere providing regional and tertiary services for the management of CKD patients.

3.3. Study population

The study population was made up of patients with CKD attending in the selected renal clinic at the time of the study. CKD was operationalised as an irreversible condition which progresses from stage 1 to 5, resulting in the inability of the kidneys to eliminate waste products, and maintain acid base and fluid and electrolytic balance. Only patients with confirmed CKD were chosen because they have been exposed to and experienced the phenomenon of the management of the disease.

Healthcare workers, namely doctors and nurses, were used as key respondents because they have a first-hand knowledge and understanding on CKD management. In this regard, doctors and nurses working in the renal clinic at the time of the study who were operationalised as healthcare workers were selected.

3.4. Inclusion criteria for CKD respondents

All male and female CKD patients who could communicate verbally and were attending the renal clinic were eligible for selection in the study. Moreover, CKD patients aged 18 years and above were eligible for selection and this ensured coverage of all age groups in which CKD occurs. The patients had to have been in the CKD programme for at least three months. The CKD programme encompasses treatment of the disease at state hospitals in terms of medication and dialysis, coupled with self-management of dietary and fluid restrictions. CKD treatment in public hospitals in South Africa is based on the strict criteria introduced by the Department of Health as a legal measure to aid in the selection of CKD patients (Guidelines for Chronic Renal Dialysis, 2009). The main criterion for admission of patients to the CKD programme is their eligibility for a kidney transplant. Furthermore, a well-proven history of high adherence to treatment is required to qualify for the CKD programme.

3.5. Inclusion criteria for healthcare workers

In this study, healthcare workers included those who are directly involved in the management of CKD patients. These included nurses and doctors with experience in nephrology care. In addition, those who had worked in nephrology departments for at least three months were included as they were able to give information on barriers to the management of CKD.

3.6. Exclusion criteria for CKD respondents

Excluded were all patients with risk factors (hypertension, diabetes mellitus), critically ill patients, minors, and all those who have been attending the renal clinic for less than three months. Patients with risk factors were excluded because they are still not yet confirmed as suffering from the disease. Critically ill patients were excluded because they lack the ability to comprehend information about a study, make decisions regarding participation or withdrawal from the study, or communicate effectively. Minors were excluded because they were not capable of giving informed consent and lacked the ability to comprehend information about the study. Patients who did not use the study site on a regular basis were excluded from participating in the study. Moreover, kidney transplants recipients who attend the renal clinic were also excluded from the study.

3.7. Exclusion criteria for healthcare workers

In this study, all healthcare workers who are not directly involved with CKD patients were excluded from the study. In addition, those who had worked in nephrology for less than three months were also excluded, as they were not able to provide realistic information regarding barriers to the management of CKD patients.

3.8. Sample size

The sample size was thirteen (including both CKD patients and healthcare providers) as determined by data saturation levels. With regard to CKD respondents, the researcher began with only one respondent to give in-depth information on the barriers to CKD management. More participants were then selected, since new information was still emerging. Data saturation was achieved at CKD respondent number 7, at which point no new information was provided. In-depth information was obtained as the researcher conducted interviews twice with each respondent. With regard to healthcare workers, the researcher began data collection with one participant to provide input of their own perspectives regarding barriers to the management of CKD patients. Data saturation was achieved at respondent number six, where the healthcare worker could not provide any further new information regarding barriers to the management of CKD patients.

3.9. Sampling strategy

CKD study respondents were selected using a type of non-probability sampling called purposive sampling. The type of purposive sampling was maximum variation or heterogenous sampling which purposively selected CKD respondents on haemodialysis, Continuous Ambulatory Peritoneal Dialysis (CAPD) and non-dialysing treatments to provide a wide range of variation on the barriers encountered. Inclusion of CKD respondents, irrespective of the stage of disease at which they were, meant that different viewpoints were presented concerning barriers to the management of CKD. Again, purposive sampling was used to select only healthcare workers who were highly experienced and directly involved with CKD patients. The purposive expert sampling technique was used to specifically select nurses and doctors who are experts in the area of nephrology care.

3.10. Data collection instruments for CKD respondents

Semi-structured interviews with open-ended questions were held to collect data. This was an interview situation in which the researcher had a list of topics to cover on the barriers to the management of CKD. The instrument for barriers to the management of CKD was developed from an in-depth literature review. Section A comprised demographic information for the selected study respondents which included: age; gender; marital status; level of education; religion; and occupation. Section B comprised the following questions: When did you get diagnosed with CKD? How long have you been on the CKD programme? How is the CKD programme helping your illness? How do you manage your diet, dialysis, medication and fluid restriction? Are you encountering any problems regarding your medication, dialysis, fluid and dietary restriction? What are these challenges and how are they preventing you from managing your CKD? A self-reported method of collecting data was utilised. The use of open-ended questions allowed selected CKD respondents and healthcare workers to respond narratively in their own words.

3.11. Data collection instruments for healthcare workers

The instrument for healthcare workers regarding barriers to the management of CKD patients was developed by the researcher from an in-depth literature review. The semi-structured interview schedule was designed to identify barriers to the management of CKD patients. Healthcare workers were asked questions regarding their demographic information, which included: age; gender; educational levels; professional qualifications; and period of employment. The following section asked questions regarding how long respondents have worked in the renal clinic, how they are managing CKD patients, and what the barriers to the management of CKD are. Key respondent interviews were conducted face-to-face. Qualitative in-depth interviews were conducted with the key respondents to provide insight to the nature of the barriers experienced in managing the CKD population.

3.12. Data collection procedure

Following approval from the various departments and local ethics review committees, the researcher visited the selected renal clinic for data collection. Each selected respondent was taken to a private room where a rapport was begun, and an informed written consent obtained. Each respondent was then interviewed for a minimum of 30 min. CKD respondents answered the open-ended questions on the interview schedule as the researcher read the questions. The researcher recorded respondents' feedback on individual interview schedule guides. The procedure was repeated with each selected respondent on different days until data saturation was achieved.

In the data-collection process for healthcare workers, appointments were secured with them and interviews took place during their lunch breaks to avoid any interruption of service to patients. Those that gave permission were also asked for appointments outside work time, for example on their days off. Healthcare workers answered the open-ended questions on the interview schedule as the researcher read the questions. The researcher recorded healthcare workers' responses on individual interview schedule guides. The procedure was repeated with each selected healthcare worker to achieve data saturation.

3.13. Trustworthiness of qualitative data

Credibility, transferability, confirmability and dependability were used to evaluate the trustworthiness of the qualitative data obtained (Grove, Burns, & Gray, 2013). The researcher developed an in-depth understanding of the barriers to CKD management by spending time with study respondents until data saturation was achieved. Transcripts were checked to ensure that they did not contain any mistakes made during transcription. For confirmability, the researcher was careful in not allowing prior knowledge of the patients' condition to affect the way in which the interviews were conducted. With regard to transferability, the researcher provided detailed descriptive information of the research setting, the study respondents and the themes identified during the study to facilitate assessment for applicability to new situations by other prospective researchers.

3.14. Data analysis

The researcher used aspects of the thematic framework approach (Miles, Huberman, & Saldana, 2014). Firstly, the researcher organised data into easily retrievable sections corresponding to questions in the interview guide. The researcher familiarised herself with the data by reading and re-reading all the data in an active way to search for meanings and patterns as advised by Creswell (2014). After coding, the results were summarised thematically to template-style analysis, including cross-referencing themes. A coding process was used to generate a description of the themes for analysis. The emerging themes were those which appeared as barriers to the management of CKD.

3.15. Ethical considerations

The review board for the School of Nursing and Public Health at the University of KwaZulu-Natal reviewed the proposal to reduce risks to study respondents. In addition, the institutional review board, the Biomedical Research Ethics Committee (BREC), reviewed the research proposal and any problem areas identified were rectified by the researcher. Finally, the BREC gave full approval (BREC REF: 377/14) after ensuring that the proposal was ethically sound. Permission to proceed with the study was also sought from the KwaZulu-Natal Department of Health (REF: HRKM267/14). Research permission was then obtained from the selected study site: Inkosi Albert Luthuli Central

Hospital in eThekwini District, Durban (BE377/14). Approval from these various ethics committees was granted before the study could be conducted. The research was therefore found to be ethically sound since various ethical review boards had approved the study.

All interviews with respondents were conducted in a private area designated for this purpose at the study facility to maintain privacy. To ensure confidentiality and minimise the risk of accidental disclosure of sensitive information, all respondents were given a study ID number upon enrolment, and identifying information was not entered into the database created. All study databases were password protected, securely stored and transmitted only through secure means, namely password protected email.

Information document sheets were delivered to participants prior to the signing of consent forms. Anonymity was not achieved, because the researcher employed face-to-face interviews with all respondents for clarification and verification of the interview data obtained. The purpose of the study was explained to potential subjects before obtaining their informed consent, and their voluntary willingness to participate in the study was sought.

The subjects were assured that there was no risk involved in participating in the study. Subjects were informed of their freedom to withdraw from the study, should they wish to do so, at any stage without affecting their positive therapeutic relationships with the institution and the staff involved in their care programmes. An informed consent form was given to each participant with a full explanation of what was expected and the potential benefits of the study for CKD patients described. With study respondents who were willing to participate, a consent form was signed which indicated their acceptance. Signed consent forms were not attached to the data collection instruments.

4. Results

4.1. Demographic data

Table 1 contains the characteristics of the selected CKD respondents, and seven respondents were identified. Ages ranged from a minimum of 24 years to a maximum of 52 years, with an age range of 28 years. The respondents comprised more males than females. Five were married and two single. The majority (6) were unemployed and one had a professional job. More than three-quarters (6) received less than R3 000 as they were on government medical grants. Only one received a monthly income in the range of R6 001 to R10 000 from holding a job. Most (6) had family and medical grants as a means of social support, and one had only family as social support. Those with only family support were employed and could therefore not access a medical grant from the government.

Table 2 provides the biographical characteristics of healthcare workers for the CKD respondents. The healthcare workers comprised of 4 nurses and two doctors. Their ages ranged from 42 to 54 years. In terms of the gender of healthcare workers, the sample comprised more females (5) than males (1). Half of the participants (3) have diploma level qualifications, two have achieved degree level and only one has acquired a masters' level of education. Again, half (3) of the participants were employed for more than 15 years, two were employed for between 10 and 15 years and one was employed for less than 10 years.

4.2. Barriers to management of CKD as expressed by CKD respondents

This process was influenced both by the original research objectives and by new concepts generated inductively from the data. The emergent themes were translated into narrative passages, with findings emerging logically from the respondents' responses. Verbatim quotes were provided which the researcher perceived to be most descriptive of the respondents' views of barriers to the management of CKD. The barriers to CKD management are discussed as follows:

4.2.1. Unpleasant symptoms after taking oral medications and haemodialysis treatment

The side-effects of haemodialysis were reported by respondents as a barrier to haemodialysis management. During haemodialysis, these include pain in the abdomen, vomiting, low blood pressure and pain in the chest. Post-dialysis effects include loss of power, loss of interest in sex, and not being able to perform some activities of daily living. All these unpleasant symptoms result in shortened sessions, and in some cases patients find excuses not to attend their next haemodialysis session.

These points were demonstrated in the following excerpts:

> *I always do not finish my 4-hour dialysis sessions due to pain in my muscles, pain in the abdomen, chest pain and low blood pressure. After haemodialysis session, I will not be able to perform any other activities like cleaning the house as I will be feeling tired'. (Respondent 4)*
>
> *My CKD was due to hypertension and diabetes mellitus, so the medications which I am drinking are many and I feel like vomiting. Sometimes, I experience headache and not being able to pass stool when I go to the toilet after taking these medications. (Respondent 6)*

4.2.2. Lack of taste for the recommended dietary restriction

Respondents reported the unpleasant taste of the recommended diet as a barrier to dietary management. All of them complained that the food is tasteless, and they are always tempted and sometimes continue to eat a non-renal diet like the rest of their family members. Some CKD patients even thought that the Gastrointestinal (GIT) problems they experience emanate from the recommended renal diet.

> *I am having problems with this renal diet and the food does not taste at all. After eating the diet, I experience abdominal pains, nausea, vomiting and diarrhoea. Sometimes I am forced to eat non-renal diet which the rest of the family will be eating. (Respondent 1)*
>
> *I am experiencing loss of appetite and the renal diet is making it worse because it's tasteless. It also makes me feel nauseous and am always experiencing abdominal pains after eating the diet. (Respondent 3)*
>
> *Medication is not a problem at all and I am coping with it. One thing that is troubling myself is the diet which does not taste at all. I am trying but I cannot stand low-salt diet. (Respondent 6)*

Table 1
CKD participants for the study (N = 7).

	P1	P2	P 3	P 4	P 5	P 6	P 7
Age	45	50	52	43	24	50	38
Gender	Male	Female	Male	Male	Male	Male	Female
Marital status	Single	Married	Married	Married	Single	Married	Married
Occupation	UE	UE	UE	UE	Professional	UE	UE
Monthly income	Below R3000	Below R3000	Below R3000	Below R3000	R6000 – R10 000	Below R3000	Below R3000
Support systems	Family and grant	Family and grant	Family and grant	Family and grant	Family	Family and grant	Family and Grant
Type of treatment	HD	CAPD	ND	HD	ND	CAPD	HD

KEY: P – Participant, UE – Unemployment, HD – Haemodialysis, CAPD – Continuous ambulatory Peritoneal Dialysis, ND – Non dialysing.

Table 2
Health-care workers as study participants (N = 6).

	Age	Gender	Educational level	Professional qualifications	Period of employment
Health-care worker 1	42	Female	Degree	Medical doctor	6–10 years
Health-care worker 2	44	Female	Diploma	Professional nurse	More than 15 years
Health-care worker 3	43	Female	Diploma	Professional nurse	6–10 years
Health-care worker 4	47	Female	Degree	Professional nurse	More than 15 years
Health-care worker 5	49	Female	Diploma	Professional nurse	10–15 years
Health-care worker 6	54	Male	Master's	Medical doctor	More than 15 years

4.2.3. Inclement weather conditions

The study area was Durban in KwaZulu-Natal, where the weather is warm and sunny, very occasionally mixed with light, steady rainfall. In this regard, all participants mentioned hot weather as a barrier to their CKD management, especially with regard to the recommended fluid restriction, as noted in the following excerpts:

> *Fluid restriction is problematic because of the weather condition of KZN region. This area is very hot, so am always thirsty and as such I end up drinking more fluids. After drinking more fluids, my breathing becomes a problem and end up attending haemodialysis more times per week than the scheduled ones. (Respondent 4)*
>
> *I try to follow medication and diet as prescribed but there is one thing I am failing to adjust and it's fluid intake. The weather here is always summer and very hot so am always thirsty. In the end, am tempted to drink more fluid than the recommended one. (Respondent 5)*

4.2.4. Limited employment opportunities

The majority (5) of CKD respondents were not employed as they had been dismissed from their previous workplaces on medical grounds, and opportunities for reemployment are scarce. Three of them said that they could not afford the renal diet because it is too expensive for them, meaning they cannot afford to cook two separate meals in the same household, as seen in the following excerpts:

> *I do not work and am the breadwinner, need to provide for my two children. Therefore, cooking two different meals is an expense on my part so I end up eating normal diet with my children because I cannot make them suffer because of my condition. (Respondent 1)*
>
> *I have been unemployed for too long and there is ever rising of food commodity prices such that sometimes I cannot afford my restricted diet. I end up compromising and eating what is not required of me. The chances of getting another job is zero since no company will hire a person with chronic condition. (Respondent 6)*

4.2.5. Time-consuming dialysis procedure

Haemodialysis was described as time-consuming, which was thus a barrier to the management of this treatment modality. This resulted in participants having shortened haemodialysis sessions. CAPD respondents did not have any complaints about the time factor because the procedure is performed in the comfort of their own homes at their own convenient times, so long as the bag changes are done strictly four times per day. The following excerpt explained this:

> *I am an unemployed single father and have a daughter who is going to university. So sometimes I do part time jobs to try which coincides with my haemodialysis schedule and I end up not coming for few hours. (Respondent 1)*
>
> *Haemodialysis takes much of my time because I do sell fruits and vegetables to survive, yet I have to attend dialysis thrice a week. I always end up dialysing 3 h instead of 4 h because I need to get to a place where I sell fruits and vegetables. I tried CAPD but it did not work out, that is why I am on haemodialysis. (Respondent 7)*

4.2.6. False perception of good health

A false perception of good health amongst CKD respondents was cited as a barrier to haemodialysis, medication, and their diet and fluid restriction management.

> *Sometimes I do not attend dialysis thrice a week as prescribed because I will be feeling much better and stronger after two sessions of haemodialysis. This is also the time when I eat whatever I like because I feel that my body will be able to handle anything. (Respondent 4)*
>
> *I am on dialysis continuously on daily basis. When I am feeling much better and have more energy on some days, I tend to drink more fluids and eat food of my choice. (Respondent 6)*
>
> *There are situations when I produce a significant amount of urine and this is the time when I drink more fluid. I drink more fluids because I will be feeling that my kidneys will be able to handle any amount of fluid. (Respondent 5)*

4.2.7. Uncertainties about obtaining a kidney transplant

All patients on the CKD programme in state hospitals are eligible for kidney transplants if they maintain an acceptable level of adherence with their CKD management. Imbalances between demand and supply for kidney transplants resulting in prolonged waiting periods for obtaining kidney transplants were observed as a barrier to CKD management. This caused uncertainties and fear, as indicated by healthcare workers and CKD respondents and expressed in the following excerpts:

> *I have been on dialysis for long, even started with haemodialysis then switched to CAPD. Since then, I am still waiting for my chance to get a kidney which I believe these chances are slim. There is a long list even those who have been here before are still waiting for transplant. As a result, I always ask myself what's the use of engaging with my treatment if I will die without even getting the chance of getting a kidney. As you can see, I am getting older. (Respondent 2)*
>
> *I am still in the monitoring programme and my kidney function is deteriorating. Soon I will be on dialysis programme and have joined the que for kidney transplant which I am not sure when I will get a donor. Tried to find a donor within my family members but there was no match. (Respondent 5)*
>
> *There are some patients who have been on haemodialysis for long and they are still waiting for kidney transplant and some of them are even dead. It is really demotivating because I will die waiting for kidney transplant. Sometimes I wonder why I should engage with my management if I will never get a kidney in the end. (Respondent 7)*

4.3. Barriers to management as expressed by healthcare workers

4.3.1. Drug reactions and complications of haemodialysis treatment

In general, CKD patients suffer from comorbidities, which include diabetes mellitus and hypertension. Therefore, they are expected to take medications to treat any complications associated with these comorbidities. In this regard, CKD patients report unpleasant symptoms which include nausea, vomiting, headaches and sometimes constipation after taking their oral medications. This results in an inability to take the next dose of oral medication, thus worsening the complications of their CKD. Healthcare workers highlighted this as a complication of haemodialysis treatment and the side-effects of orally administered medication. This is expressed in the following excepts:

> *Haemodialysis is a very tedious procedure as the patient has to attend the sessions twice or thrice a week depending on the state of the physical health. Side-effects range from minimal to severe. Severe side-effects such as muscle cramps and hypotension cause the patient to have shortened sessions of haemodialysis. Even CAPD procedures which are done by CKD patients at home cause abdominal pains and sometimes general body weakness. (Healthcare Worker 2)*

4.3.2. Gastrointestinal problems due to pathogenesis of CKD

Healthcare workers highlighted gastrointestinal problems as a barrier to the management of diet amongst their CKD patients. Healthcare workers were able to relate the GIT problems as being physiological as they arise from the pathogenesis of the disease. These side-effects include: loss of appetite; nausea; vomiting; and abdominal pain. The healthcare workers also emphasised that although there are gastrointestinal problems which affect dietary intake due to the uremic effects of CKD, the onus is on CKD patients to make this work for their own health, and they must try harder to get used to the diet, as indicated by the following excerpts:

> *Many patients always have problems with renal diet as it is not appetizing. Again, the uremic effects of CKD have effects on dietary intake as most patients complain of nausea, vomiting and abdominal pain, as well as diarrhoea is some serious cases. As a result, they end up eating non-renal diet, thus non-engagement with their diet. However, as health workers, we always encourage them to take charge of their health and try to follow the prescribed diet no matter how hard it is to follow. (Healthcare Worker 5)*

4.3.3. Depression

Healthcare workers highlighted depression in patients with CKD as a barrier to the management of their condition. Such manifestations were stress, loss of hope and ignorance, which can even affect the family of the patient, as illustrated in the following excerpts:

> *Psychological problems that emanate from initial diagnosis of CKD patient affects patients together with their management. Patients sometimes feel depressed about being a chronic somebody and they tend to lose hope with their management. Even the families are devastated at first and they even struggle to encourage the patient to engage with his or her management modalities. (Healthcare Worker 4)*
>
> *The reason we have engaged the services of the social worker and counsellor in our renal team is for them to help us with management of psychological problems among our renal patients. We noticed that many were coming to hospital depressed and even losing hope of their comprehensive management thus affecting their adherence levels. (Healthcare Worker 5)*
>
> *Yes, the first reason for being in the CKD programme is because a patient qualifies for kidney transplant but there are situations that are beyond our control in the management of CKD. Shortage of organs for donation is a real problem even at international level. CKD patients spend years waiting to find a donor match and some even die still waiting. This alone affects patients as they end up with depression and seeing no reason to engage with their management if the possibility of finding a donor is almost nil. (Healthcare Worker 6)*

4.3.4. Poor socioeconomic status

All healthcare workers caring for patients with CKD patients cited poor socioeconomic status resulting from unemployment as being a barrier to the management of CKD, specifically with relation to diet:

> *More than three-quarters of our patients are unemployed; therefore, their socio-economic status is compromised. They are surviving on the medical grant and sometimes hand-outs from other family members, that is if the family members financially are stable as well. As a result, it is difficult for these patients to fully afford renal diet as it is expensive and worse off even to cook two meals at the same time. Medication and dialysis are usually not a problem because the government is providing them (Healthcare Worker 1)*

4.3.5. Limited in-service training

Health care professionals receive theoretical and practical education during their training to get professional accreditation and recognition in different areas of speciality. However, they are also supposed to have regular in-service education at their workplaces to keep up with the current trends in the management of chronic conditions like CKD. In this study, health care workers highlighted limited in-service training on current management of CKD. This is expressed in the following excepts:

> *Continuous in-service training is paramount in management of specialities like renal failure patients. It has been long since we received in-service training on current trends on the management of CKD. (Healthcare Worker 4)*
>
> *I have been to school 10 years ago. After completion, I started working in renal unit. Since then, I never had extra in-service training concerning the care of CKD patients. I have learnt most of the management through meeting different types of patients. (Healthcare Worker 2)*

4.3.6. Cultural and religious differences

Cultural practices are part of human nature, however they become a problem when it comes to management of CKD patients. Moreover, religious affiliations poses some barriers to management of CKD patients. This is expressed in the following excepts:

> *As you know, South Africa is a multicultural country, meaning this hospital serves everyone irrespective of cultural affiliation. As part of management, CKD patients are expected to cease taking cultural herbs, restrict to fluid and certain dietary intakes. Due to cultural differences, some people resort to traditional healers as a way of finding treatment for this condition, making the management difficult as this causes severe complications. Some even visits the apostles and they are given more holy water to drink thus mimicking the recommended fluid restrictions. (Healthcare Worker 6)*
>
> *There are practices that hinder management of CKD population. For example, some patients refuse to be transfused, but it is a known fact that CKD comes with anaemia as a complication. Some patients even want to continue eating red meat with salt, yet this will contradict their dietary intake. This becomes difficult to effectively manage the CKD population as they are always presenting with complications when they come for review. As a healthcare professional, you begin to wonder how best can you help these patients because most of them are not even willing to tell you the truth. We always get the truth from the relatives and carers of these patients. (Healthcare Worker 3)*

5. Discussion

The side-effects of the treatment, the length of the haemodialysis procedure, gastrointestinal problems, a false sense of good health, depression, a lack of employment opportunities, inclement weather condition and long waiting lists were identified as barriers to the management of CKD from the perspectives of both CKD patients and healthcare workers. Side-effects of haemodialysis which were reported as a barrier to management amongst CKD respondents included abdominal and muscle cramps, nausea, vomiting, hypotension and chest pain, which confirms the findings by Fatima, Afzal, and Ashraf (2018). Chest pain was highlighted in this study as a barrier to CKD management with haemodialysis, which is consistent with the findings of

Singh, Singh, Rathore, and Choudhary (2015), who identifies chest pain as a major side-effect of haemodialysis treatment. Pain is a major health problem in CKD, affecting half of the dialysis patients treated, with most experience a moderate to severe degree of pain (Song, 2018).

Again, hypotension was identified as a side-effect of haemodialysis treatment, which affirms the findings of Fatima et al. (2018), and this causes the shortening of haemodialysis sessions, thereby contributing to severe fluid retention and poor volume management in CKD patients. Reports of abdominal and muscle cramps as barriers to haemodialysis treatment are reinforced by the findings of Flythe et al. (2018). As a result, patients refuse to adhere to prescribed dialysis rates and the amounts of fluid to be removed, leading to mismanagement of the dialysis procedure. Lynch, Abate, Suh, and Wadhwa (2014) explain, in addition, that painful muscle cramps frequently occur toward the end of dialysis sessions, sometimes preceding hypotension, and are associated with higher fluid removal during haemodialysis. Consequently, this impacts on the quality of life experienced by CKD patients.

Gastrointestinal symptoms such as nausea and vomiting were also discovered in the study results as being barriers to management with haemodialysis, which is consistent with the findings by Singh et al. (2015), who highlight gastrointestinal symptoms as a common problem which even further affects dietary intake amongst CKD patients. Again, the presence of uraemia is a more obvious factor (Grant et al., 2017) which contributes to decreased appetite and nutrient intake, and this was mentioned by the interviewed healthcare workers.

CKD respondents also complained that their food was tasteless due to the required limited salt intake and that they are always tempted to continue eating a non-renal diet like the rest of their family members. The findings by De Borst and Navis (2016) emphasise levels of sodium intake higher than the recommended dose as being problematic. Yet reduced sodium intake is paramount in all stages of CKD as this reduces the progression to end of life stages, as well as the risk of cardiovascular disease (Meuleman et al., 2018). However, Pugh-Clarke, Read, and Sim (2017) stress altered taste perceptions amongst patients with CKD as being due to the disease's process.

The time-consuming nature of the haemodialysis procedure, as cited by study respondents, results in patients shortening the procedure. This confirms the findings by González Oquendo, Morales Asencio, and Bonill de las Nieves (2017), in which the lengthy duration of the haemodialysis procedure was seen to be a barrier amongst CKD patients. In this study, CKD patients on haemodialysis undergo the haemodialysis procedure two to three times a week, for a total of at least 10 h per week. CAPD participants did not have any complaints about the time factor because the procedure is done in the comfort of their own homes at their own convenient times, as long as the bag changes are done strictly four times per day.

CKD patients and healthcare workers for CKD patients cited unaffordability due to financial constraints and lack of employment opportunities as a barrier especially to dietary restriction management, affirming the findings of Stevenson et al. (2018), and Clark-Cutaia et al. (2018). Moreover, Tsutsui et al. (2017) concur with the findings of this study and reiterate frequent hospital visits, complications to vascular access and altered physical health as factors affecting employment in they CKD population. Light duties initially, and finally being boarded on medical grounds for having a chronic illness, were cited by CKD participants and healthcare workers as having consequences for family lives, since most CKD patients are family breadwinners. Most CKD respondents in this study were not employed, and three of them reported that the renal diet was too expensive for them since they were the breadwinners in the family and could not afford to cook two separate meals each time for the same household.

Depression was highlighted by healthcare workers as a barrier to management amongst CKD patients, and this confirms the findings of Flythe et al. (2018) and Liu et al. (2017). An interesting fact in this study is that none of the patients could not identify depression as a barrier, meaning that when a patient enters into depression, they are not even aware of the situation until diagnosed by the relevant healthcare professionals. Again, false perception of good health amongst CKD respondents was cited as a barrier to the management of their condition, and this is consistent with the findings of Chironda and Bhengu (2018). Moreover, this finding was perceived by care givers as a barrier to CKD management. In this study, a young CKD respondent gave a feeling of better physical well-being as their reason to skip CKD treatments. In addition, cultural and traditional practices were found to be challenges with fluid and dietary management, and this confirms the findings of Stevenson et al. (2018).

Hot weather conditions in the study area were given as a barrier to fluid restrictions, mainly by CKD patients, and also by some healthcare workers. Chironda and Bhengu (2018) report similar results, though their findings were from the perception of caregivers regarding the integrated management of CKD patients. These barriers prevent patients from complying with fluid restrictions, just as found in this study. In the present study, however, the high intake of fluids was reported all year round. The use of ice cubes to curb thirst is encouraged by some healthcare workers, but this will simply further aggravate fluid overload when the ice cubes melt to become water in the body.

All patients in CKD programmes were eligible for kidney transplants. The shortage of kidneys for transplant was cited by healthcare workers and CKD patients as a barrier to their condition's management, as patients may wait for many years to find a suitable donor (Clayton, Rizzolo, & Nair, 2018). In all countries, including South Africa, cadaveric and live donors are failing to meet demands for kidney transplants, despite the frameworks which have been put in place (Chironda & Bhengu, 2016). This alone causes a significant number of candidates with CKD to die whilst waiting, or to become too sick for transplants; consequently, uncertainty amongst all CKD respondents is reported in this study, with an increasing fear of never obtaining a donor kidney.

6. Conclusion

Despite the measures of state hospitals to provide CKD management, barriers to its management still exist amongst the CKD population. Dietary and fluid management, in addition to a shortage of kidney donations, have been identified as being the main problems in the provision of care to patients with CKD. Continual education to remind these patients on the importance of CKD management is paramount. Promoting engagement with healthcare management amongst CKD patients will prolong lives and increase patients' chances of securing a kidney transplant.

The use of dieticians to emphasise the proper renal diet is crucial in assisting patients to adopt the recommended healthy eating behaviours. Adjustment of medication doses are also encouraged for each patient to minimise the side-effects. Moreover, a review of haemodialysis settings, such as the ultrafiltration volume, time and pump speed, is necessary to minimise the effects of haemodialysis complications. In-service training of existing staff is required to equip them with up-to-date information on the management of CKD to provide them with a better understanding of patients' problems.

Long-term recommendations include the use of nongovernmental organisations to introduce mobile kitchens with specifically renal diets to reach CKD patients wherever they live to make it easier for patients to comply with dietary restrictions, which are an important element in the management of the condition of these patients. In addition, the government should advocate for sheltered employment to improve the financial position of CKD patients. Furthermore, the promotion of awareness campaigns to emphasise the importance of kidney donations is essential to reduce the currently lengthy waiting lists.

Conflict of interest

None.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ijans.2019.04.001.

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