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**Investigating the reasons for the differences in the  
accessibility of renal replacement therapy in the public  
and private healthcare sectors in South Africa**

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**This thesis is presented in partial fulfilment of the degree of Master of Business Administration to the Faculty of Commerce, Law, and Management, University of the Witwatersrand.**

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### 3 DECLARATION

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I, Zubair Mahomed Asmal, declare that this research report entitled “Investigating the reasons for the differences in the accessibility to renal replacement therapy in the public and private healthcare sectors in South Africa” is my own unaided work. I acknowledged, attributed, and referenced all ideas sourced elsewhere. I am hereby submitting it in partial fulfilment of the requirements of the degree of Master of Business Administration at the University of the Witwatersrand, Johannesburg. I have not submitted this report before for any other degree or examination to any other institution.



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Signed at Johannesburg on 23 August 2022

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## 4 ABSTRACT

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Thesis title: Investigating reasons for the differences in the accessibility of renal replacement therapy in the public and private healthcare sectors in South Africa

The number of patients with kidney failure is increasing. This increase is secondary to an increase in the risk factors resulting in kidney disease, and will result in an increase in the number of patients requiring renal replacement therapy (RRT). South Africa has a two-tiered healthcare system, a public and a private sector. At present, there is a significant disparity in the number of patients receiving RRT in the two sectors with more in the private sector. This disparity has been attributed anecdotally to a lack of resources in the public sector and specific legislation, although no research have been done to confirm this. Health disparity in general is complex and involves an interplay between multiple factors, including historical, political, economic, legislative and environmental factors. The hypothesis is that the disparity in RRT is complex, based on multiple factors, and cannot be ascribed to only two factors. To test the hypothesis, we interviewed the stakeholders in the RRT industry regarding their perspectives of the causative factors. In total, 33 interviews were conducted, recorded, transcribed and analysed using the grounded theory from a constructivist angle. The objective of the analysis was to determine which factors contributed to the number of patients receiving RRT in the public sector, compared with the private sector. As the renal transplantation programme is managed collectively by the two sectors, it was considered separately. Based on the interviews, five themes were extracted to explain the disparity. These themes follow the journey of a kidney failure patient from the factors that contributed to the condition, to being diagnosed and ultimately treated. The themes are the prevalence of kidney disease in the two populations, the decision-making process of who receives RRT, the accessibility of receiving RRT, the resources available for RRT and the impact of the transplantation. Each theme has subthemes and combined they form a holistic explanation to account for the disparity. This study identified possible causative mechanisms to explain the disparity. It is hoped that by uncovering these mechanisms, corrective

measures can be implemented, a more equitable and just healthcare service can be offered to all citizens and in the process save a multitude of lives.

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## 8 DEDICATIONS

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I dedicate this research to all the doctors in this beautiful country that strive to better the lives of everyone. I give thanks to the Almighty, without whose help nothing is possible.

The MBA is a taxing course and I would not have come this far were it not for the support of my wife, Sumaiya Adam.

May Allah (SWT) grant her best of successes and the highest stages in paradise.

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## 9 DEFINITION OF KEY TERMS AND CONCEPTS

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Cadaveric donor: Donation from a recently deceased patient who is certified brain dead

Chronic kidney disease (CKD): Any dysfunction of the kidney that persists for more than three months. May range from mild dysfunction to life threatening.

Chronic renal/kidney failure (CRF): A condition in which the kidneys, for whatever reason, fails to function adequately to the point where intervention is necessary to save a life.

End-stage-renal-disease (ESRD): A form of renal disease in which renal replacement therapy (RRT) is needed to preserve life. Synonymous with end-stage-kidney-disease

Haemodialysis (HD): A form of renal replacement therapy (RRT) where blood is suffused through a filtration system to cleanse it. This usually occurs three times a week in a hospital setting.

Health disparity: In this review, health disparity refers to difference in the number of patients being treated between the public and private sector with respect to renal replacement therapy (RRT).

Health equity: A commitment to reduce and eliminate health disparity and its determinants

Incidence: The number of new cases of the disease or condition that occurs in a specified period of time, usually taken to be a year.

Live donor: Altruistic donation of a kidney from a living person. Usually, a family member or close friend.

Medical aid: Medical insurance companies operating within the Republic of South Africa.

Medical insurance: Insurance taken by members to cover medical costs. Usually, members pay a premium every month to cover the costs of any potential medical treatment.

Morbidity: Suffering that occurs as a result of a disease or health condition.

Mortality: “Death, especially on a large scale.” (Dictionary.com)

Peritoneal dialysis (PD): A form of renal replacement therapy (RRT) whereby the blood is cleansed by infusing fluid into the abdomen. Patients are required to infuse the solution on a daily basis at home.

Prevalence: The number of people who have a disease in a specified population at a given time, which includes new and old cases

Private sector: A health sector managed independently of the government of South Africa. It consists of multiple stakeholders, including hospital groups, healthcare workers, medical insurance companies and their members.

Public sector: This is the health sector operated and funded by the government of the Republic of South Africa and is synonymous with the public sector.

Renal replacement therapy (RRT): Refers to the modalities used to treat patients with kidney failure. In essence, the therapy performs the function of the kidney. Three types of renal replacement therapy (RRT) exist, including haemodialysis, peritoneal dialysis, and kidney transplantation.

Renal: Refers to the kidney, an organ in the body that functions to detoxify and maintain the body composition within certain parameters.

“Slots”: Refers to the allocation of a dialysis machine to a patient. Each dialysis machine can only dialyze 5 patients per week. Therefore only 5 slots per machine is available for patients.

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# 1. INTRODUCTION TO THE RESEARCH

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## 1.1 Background

South Africa has a two-tiered health system comprising of a public or public sector and a private sector. The public sector services about 71% of the population and accounts for approximately 50% of the total health expenditure. Funding for this sector is derived mainly from government funds. The private sector services 27% and is largely funded through individual payments to medical insurance companies, an industry called “medical aid” in the country (Rensburg, 2021). A small proportion of private healthcare (less than 15%) is funded by the personal contributions of citizens. This translates to a small proportion of the population having access to more resources, while most of the population has limited access to healthcare. Though this disparity is felt throughout the health sector, its effects is most starkly visible in kidney diseases.

Kidney diseases are unique as it is the only condition that is chronic (lifelong) and amenable to therapy, although costly. Conditions such as cancer or infectious diseases are either amenable to cure or are terminal (*patients die of the disease*). The duration of treatment for these conditions are short term. Diseases such as liver or respiratory failure have a high mortality rate as there is no cure. These patients die early and do not expose the healthcare sectors to excessive funding. Patients with chronic diseases, such as human immunodeficiency virus (HIV), hypertension or diabetes mellitus, require lifelong therapy but the treatment is cheap and the benefit longer lasting. Patients with kidney failure respond positively to renal replacement therapy (RRT), a form of treatment that provides the function of a kidney in patients whose kidneys are non-functional. However, this therapy is highly specialized, requires expertise, and expensive. Patients can live for years with the condition and this results in the consumption of significant resources. In addition, the nature of the therapy is time consuming with patients are often required to spend a substantial part of their day being treated, with less time available for social and vocational activities. Due to this, patients contribute little to the economy. Kidney patients consume substantial resources with little contribution to the economy.

The result of the high cost with little or no economic contribution makes authorities reluctant to provide kidney disease patients with RRT. If these were the only reasons, this reluctance should be experienced in both the public and private health sectors. However, though the number of patients

receiving RRT therapy in the public sector has declined, the number of patients receiving RRT in the private sector has increased exponentially over the last two decades (Davids et al., 2021). The main reason for this discrepancy could be a lack of resources, although there is no evidence. (Etheridge & Fabian, 2017) suggested that the discrepancy is due to unfair legislation pertaining to the public and private health sectors. This study aimed to take a deeper look at the industry and to ascertain the causes for the discrepancies in the access to RRT.

## **1.2 Context**

The study was conducted in the context of a worsening disparity between the number of patients receiving RRT in the two health sectors in South Africa. The consequences of this are increasing morbidity and a higher mortality rate in the public sector. The reasons for this disparity have not been studied comprehensively and this study will provide insight in rectifying this imbalance.

## **1.3 Research conceptualisation**

### **1.3.1 The research problem statement**

There is an increase in the prevalence of risk factors that predispose to kidney disease (Naicker, 2019). Similarly, there is a global increase in the number of patients with kidney disease, including South Africa, with a prevalence 10.4% (George et al., 2019). The increase will result in a increase in the number of patients with end-stage-renal disease (ESRD) requiring RRT. To date, there is no documented planning in South Africa to manage the escalation in kidney disease or for the provision of RRT for future generations.

Kidney disease causes kidney failure which requires RRT. Patients with kidney failure and no access to RRT have a higher morbidity and mortality rate. RRT is a life-saving procedure and the survival rate is higher for patients receiving this therapy (USRDS, 2018). In addition, the quality of life of patients on dialysis is higher compared to patients requiring dialysis but not receiving it (Shu-Fen & I-Chuan, 2005 ). RRT is essential to decrease the overall mortality and morbidity rate in the population.

The differences between the number of patients receiving RRT in the public and private health sectors are documented in the South African Renal Registry, an annual publication that compiles the

statistics of these patients (Davids et al., 2019). The latest report of this registry indicated that the total number of patients on RRT in 2017 was 10 744 with 7 582 patients in the private sector (58.2%) and 3 162 in the public sector (41,7%). It should be noted that the number of patients in the private sector represents only 27% of the population. Despite this, more than double the number of RRT is provided to patients in this sector when compared to the public sector.

The reasons for this discrepancy have not been fully investigated. It is thought, not proven, that the sole reason for this difference is a lack of resources in the public sector. Another potential reason may be unfair legislation which pertains to the two sectors (Etheredge, 2017). If the cause is exclusively due to these two reasons, then correction would alleviate the disparity. However, health disparity in general is more complex and it is probable that reasons for the disparity in RRT are multi-layered and multi-faceted. These reasons need to be fully elucidated to truly understand the scope of the problem. Determining all factors contributing to the disparity would provide a first step in addressing this imbalance.

This thesis aimed to explicate the causes for the disparity in RRT in the two health sectors in South Africa. It is hoped that by highlighting these causes, planning can be done to improve and prolong the lives of patients with kidney failure.

### **1.3.2 Research purpose statement**

It is known that a disparity exists between the number of people receiving RRT in the two health sectors in South Africa. The reasons for this difference have not been investigated. This qualitative study investigated the reasons for the disparity between the number of patients on RRT in the public and private sectors in South Africa.

An exploration of both sectors was done through interviewing stakeholders in both sectors. These stakeholders included all people involved in the provision of these services either directly or indirectly, as well as the recipients of the service, the patients themselves. The purpose was to explore the causes that regulates the number of patients treated in each sector. It is believed that the best people to explain the disparity are those involved in the industry. By comparing both sectors and the dynamics of how they operate, themes were generated that could explain the discrepancy in the number of people with access to RRT in the two sectors.

The exploration was done by interviewing the stakeholders about their views on RRT in South Africa. These interviews were done mainly via online platforms and recorded for future transcription and analysis. Transcripts of these interviews were typed and analysed. The structure of the interview was open-ended to gain an understanding of the deeper issues and new insights in the industry. Using an open-ended approach provided more detail as well as the sentiments and feelings of the participants.

After the exploration, the sectors were compared to highlight the similarities and differences. Themes were generated to explain the possible differences between the two sectors, which may be used as the basis of planning to alleviate the problem.

### **1.3.3 The aim of the research**

The aim of the research was to determine the reasons for the differences in the number of patients receiving RRT in the public and private health sectors in South Africa.

### **1.3.4 Research objectives**

Objectives for this research included the following:

- To understand how RRT is managed in the private sector and the factors determining the number of patients receiving RRT.
- To understand how RRT is managed in the public sector and the factors determining the number of patients receiving RRT.
- To compare the two sectors to identify the reasons for the difference in RRT.

### **Research objectives framed as research questions**

1. Which factors contribute to the determination of the number of patients receiving RRT in the private health sector in South Africa?

To answer the above question, interviews were conducted with the relevant stakeholders and their statements analysed qualitatively to gain an understanding of the renal sector in the private health sector.

2. Which factors contribute to the determination of the number of patients receiving RRT in the public health sector in South Africa?

To answer the above question, interviews were conducted with relevant stakeholders and their statements analysed qualitatively to gain an understanding of the renal sector in the public health sector.

3. How do the factors differ in the two sectors?

A comparison of the factors may help in determining the cause of the disparity.

#### **1.4 Delimitations and assumptions of the research study**

The delimitations of the study are as follows:

- The study was conducted online and included a comprehensive list of stakeholders involved in RRT. However, as most of the stakeholders are people involved in the healthcare industry, some could not be interviewed due to time and work commitments secondary to the COVID-19 pandemic. Although saturation was reached, it may be possible that new themes may have emerged if more people were interviewed.
- The study is limited to South Africa as it has a unique health system which cannot be extrapolated to other areas.
- The study is limited to the period in which the study occurred. The findings of this study are highly dependent on existing factors at a particular point in time. Circumstances may change in the future which may alter the findings of this study.
- The study is dependent on the views expressed in the interviews. These views are subjective and are the opinions of the interviewees. Although these views reflect the life experiences and emotions of people, they are not factual as experiences can be interpreted differently. The participant's rationale, emotions and perceptions at the time of the interview may play a role in the outcome of the study. The views expressed may be biased and thus the conclusions derived may also be biased.
- As the study is qualitative, interpretation is limited. Observations and conclusions may have been influenced by personal knowledge and experience.

- Due to the qualitative nature of the study, the results and conclusions cannot be verified.

The assumptions of the study are as follows:

- That participants who respond to the interview are honest and truthful in their responses.
- The people interviewed are knowledgeable about RRT in South Africa.
- The multiple perspectives attained in this study are representative of all possible perspectives with respect to the provision of RRT in South Africa.
- The inductive process of analysis precisely describes the reasons for the disparity in number of patients receiving RRT in the two sectors.
- The research conclusions accurately describe the status of RRT within the study period. The analysis of the data used to make inferences and correlations are accurate within an acceptable margin of error.

### **1.5 Significance of the research study**

There is a significant difference in the number of patients receiving RRT in South Africa in the private and public health sectors. The risk factors for the development of kidney diseases are increasing in both sectors. The assumption is that the number of patients requiring RRT should be high in both sectors. A large proportion of people requiring RRT in the public sector do not receive treatment (Moosa et al., 2016), and die without adequate treatment.

The reasons for these patients not receiving therapy are unknown. Although lack of resources is assumed to be a factor, there are most likely multiple factors involved. By elucidating the causes of the disparity, corrective measure can be adopted which would alleviate the problem.

In addition, some of these factors are likely to play a role in the disparity of other disease entities as well. By elucidating these factors and devising corrective systems, a more just and equitable healthcare system can exist in the country. With more patients receiving therapy, the mortality and morbidity rate will decrease. As a substantial number of patients are in need of this therapy, treating all patients will result in an overall decrease in mortality and morbidity in the population.

## **1.6 Organisation of the research report**

Listed below are the chapters in this thesis:

### Chapter one: Introduction:

This chapter provides a background and the context of the study and states the research problem and purpose statement. The aims and objectives are described, followed by the limitations and assumptions of the study. Finally, the significance of the study is stated.

### Chapter two: Literature review:

This chapter serves to provide a holistic literature review of the problem, the past studies and the conceptual framework.

### Chapter 3: Methodology:

Discusses research strategy, design, procedures, reliability and validity measures as well as limitations.

### Chapter 4: Data Findings:

Presentation of the empirical results obtained from the research instrument.

### Chapter 5: Data Analysis and Recommendations:

This chapter is a deep analysis of the findings in relation to the interrogation of the research questions and formulation of pertinent recommendations.

### Chapter 6: Summarises and concludes the research:

This chapter provides a summary of the research and is followed by recommendations in the conclusion.

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## 2. LITERATURE REVIEW

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### 2.1 **Introduction**

This literature review is based on the research problem analysis. We commenced by exploring the scope of kidney disease, how it results in an increase in kidney failure, and the number of patients requiring RRT. The review then focused on the current situation related to RRT and health disparity in general, as well as disparity specifically within the public and private healthcare sectors and the contributing factors.

The literature review analysed the research gap by exploring what other factors may contribute to the disparity. This is followed by the theoretical framework which explains the reasoning behind the design and analysis of this study. The chapter concludes with a short summary of the literature review.

### 2.2 **Research problem analysis**

#### 2.2.1 Increase in kidney disease

Chronic kidney disease (CKD) is defined as the presence of an abnormality in kidney function or structure (Levey et al., 2015). Globally, CKD is increasing with the World Health Organization (WHO) estimating a prevalence of 220 million (Niang et al., 2018). In Africa the prevalence of CKD is approximately 13.9% (Etheridge & Fabian, 2017) which is similar to the global prevalence of 8-16% (Jha et al., 2018). South Africa had a consistent increase in the incidence and prevalence of CKD (George et al., 2019). A meta-analysis of 98 studies done by Kaze et al. (2018) indicated the prevalence of CKD as 15.8% in Africa and 10.4% in South Africa. However, it is known that the prevalence of CKD is underestimated as patients are often undiagnosed (Naicker, 2010).

This rise in CKD is the result of multiple factors. There is a rising burden of both communicable diseases such as HIV and non-communicable diseases such as hypertension, diabetes and aging, all of which are risk factors for developing CKD (Naicker, 2010). Sub-Saharan Africa has the highest prevalence of hypertension in the world and the number is increasing (Peer & George, 2019). A similar trend is seen for diabetes mellitus with approximately 2.3 million South Africans affected in 2015 (Beukes et al., 2019). The prevalence of CKD secondary to diabetes mellitus, the most frequent

global cause for CKD, was similar to Africa in general (Piotie et al., 2015). Hypertension has progressed from being the fifth leading cause of death globally in 2013 to the second in 2015 (Mutiyambizil et al., 2019). The development of CKD is a major complication of hypertension. The HIV prevalence was 20.4% in 2018. The mortality rate and the incidence of HIV have decreased significantly (UNAIDS, 2020). However, the decrease in deaths resulted in an increase in the prevalence, which makes HIV a major contributor to the future risk CKD (Rosenburg et al., 2015).

Expanding urbanization, with its concomitant lifestyle, increases the risk of hypertension and diabetes mellitus, factors which are the main contributors to kidney disease (Jagannathan & Patzer, 2017). A poor socioeconomic status of mothers augments the risk of kidney failure in their offspring (Lucyx & Brenner, 2005). Finally, the high penetrance of the apoprotein L1 gene, a gene known to increase renal failure in susceptible individuals, of 10-30% in our population increases the risk of developing kidney failure (Drummer et al., 2015). The incidence and prevalence of CKD is expected to increase due to an increase in the contributing factors.

Table 1 summarizes reasons for the increase in kidney disease. All conditions listed in the table are risk factors for the development of kidney disease.

*Table 1: Summary of causes in the increase in CKD*

Increase in hypertension
Increase in diabetes
Higher prevalence of HIV despite a decrease in incidence
Expanding urbanization
Poor socio-economic factors
Genetic: high penetrance of apo1 gene which predisposes to kidney disease
Aging population

### 2.2.2 Increase of End Stage Renal Disease (ESRD) and the need for RRT

ESRD is defined as a form of renal disease requiring RRT to preserve life (Greenburg, 2009). CKD is a precursor of ESRD which necessitates RRT (Elshahat et al., 2020). Poorly managed patients with CKD increases the likelihood of the development of ESRD (Greenburg, 2009). Untreated CKD increases the risk of ESRD and the need for RRT.

There is a paucity of data comparing the change in CKD incidence and prevalence with the ESRD incidence. A comparison between the United States Renal Data System (USRDS) and the National Health and Nutrition Examination Surveys (NHANES) indicates that the incidence of ESRD is increasing faster than the prevalence of CKD (Hsu & Vittinghoff, 2004). Factors which may explain this phenomenon include the improved survival from non-renal disease, especially cardiovascular disease and improved diagnostic capabilities.

The prevalence and incidence of CKD or ESRD is difficult to estimate as many patients die without being diagnosed or treated (Naicker, 2010). The prevalence of ESRD varies globally depending on the state of healthcare in a country. In the United States, the age-gender-adjusted incidence rate is 357 per million per year with a prevalence rate of 2023.6 per million per year (USRDS, 2018). Although the incidence (new cases) has levelled off in the last decade, the prevalence (total number of cases) has continued to increase as a consequence of better therapy and patients living longer (USRDS, 2018). A Canadian study showed that the lifetime risk of developing ESRD in adults over 40 years of age was 2.66% for men and 1.76% in women (Turin et al., 2012). It is estimated that 0.1% of the global population will require RRT (Hill et al., 2018). A systematic review in 2010 estimated that the number of patients with ESRD globally was between 4.902 million using a conservative model and 9.701 million using a high estimate model. The number of people requiring RRT is expected to more than double to 5.439 million people by 2030, with most of this growth occurring in developing countries (Liyanage et al., 2015).

The prevalence of ESRD in South Africa may be higher as there is a marked racial difference in the prevalence of ESRD, with a higher probability in the black population. (Peralta et al., 2006). In the United States, the prevalence of ESRD for Caucasians was 268 per million, 355 million in Asian-Americans and 991 million in African-Americans (Peralta et al., 2006). Whether this race differential will be applicable in South Africa is not known.

The risk factors for CKD or ESRD vary significantly between different racial groups. Though diabetes is the main cause of ESRD in all groups, hypertension has a higher percentage in non-Caucasians with an age and gender adjusted ratio of African-American: Caucasian of 6:1 (USRDS, 2018). The incident rate of diabetes mellitus and hypertension progressing to ESRD is higher in non-Caucasians. The reasons for this are unknown. The higher presence of the APOL1 gene, a gene known to increase the risks of developing ESRD, may partially explain this difference (Dummer et al., 2015). However, the two most frequent causes of ESRD, diabetes mellitus and hypertension, are modifiable conditions and other factors, such as access to healthcare and proper management of CKD, may play a role (Crew et al., 2019).

The higher rate of ESRD in the black population is not supported by data reflecting the racial breakdown of patients receiving RRT in South Africa. Table 2 reflects a disproportionate number of patients in each racial group with the prevalence in the black population a third of the next racial group despite comprising 80% of the population (Davids et al., 2019).

Table 2: Ethnic breakdown of patients receiving RRT in South Africa. (Source: South African Renal Registry, 2019).

<b>Ethnicity</b>	<b>Prevalence (patients per million -pmp)</b>
Blacks	111
Mixed ancestry	318
Indian/Asian	765
White	368

Based on the higher prevalence of the risk factors for CKD in the black population and the reasons given above, the prevalence of ESRD and the number of people on RRT are expected to be much higher. The reason for this low prevalence of black patients with CKD is not known. It is more likely not due to the low prevalence of ESRD in this population but rather an inability of the health system to provide RRT in an equitable manner. Thus, many patients who need RRT are not receiving it.

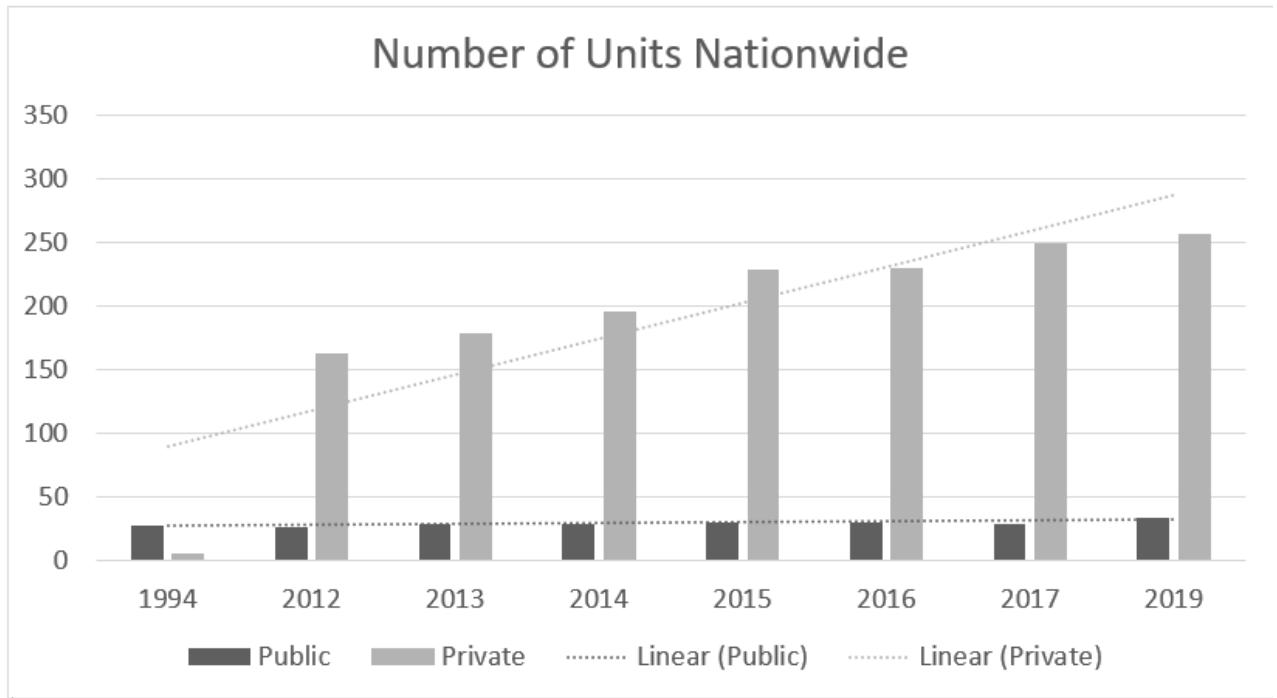
To summarize, the true incidence and prevalence of ESRD in South Africa is not known. The premise is that a substantial number of patients are not diagnosed or misdiagnosed (Naicker, 2010). The number of ESRD cases of requiring RRT will likely increase in future as a result of the escalation of the risk factors causing kidney disease. This is supported by the South African Renal Registry Data that indicates an increase in RRT over the last decade. The number of patients receiving RRT in the public sector in 2019 was 9937, compared to 2843 in 1994 (Davids et al., 2019).

### **2.2.3 Current state of RRT in South Africa**

RRT is provided by both the public and private healthcare sectors. Despite serving a larger proportion of the population, only 13.2% of the centres offering RRT are in the public sector (Davids et al., 2019). An analysis of the growth of centres in the two sectors is shown in Figure 1. It illustrates that the number of RRT centres in the public sector have remained stagnant for the last 25 years while growing exponentially in the private sector from 5 units in 1994 to 257 units in 2019 (South African Renal Registry, 2022).

*Figure 1: Growth in RRT centres in the private and public sectors. Data compiled from South African Renal Registry.*

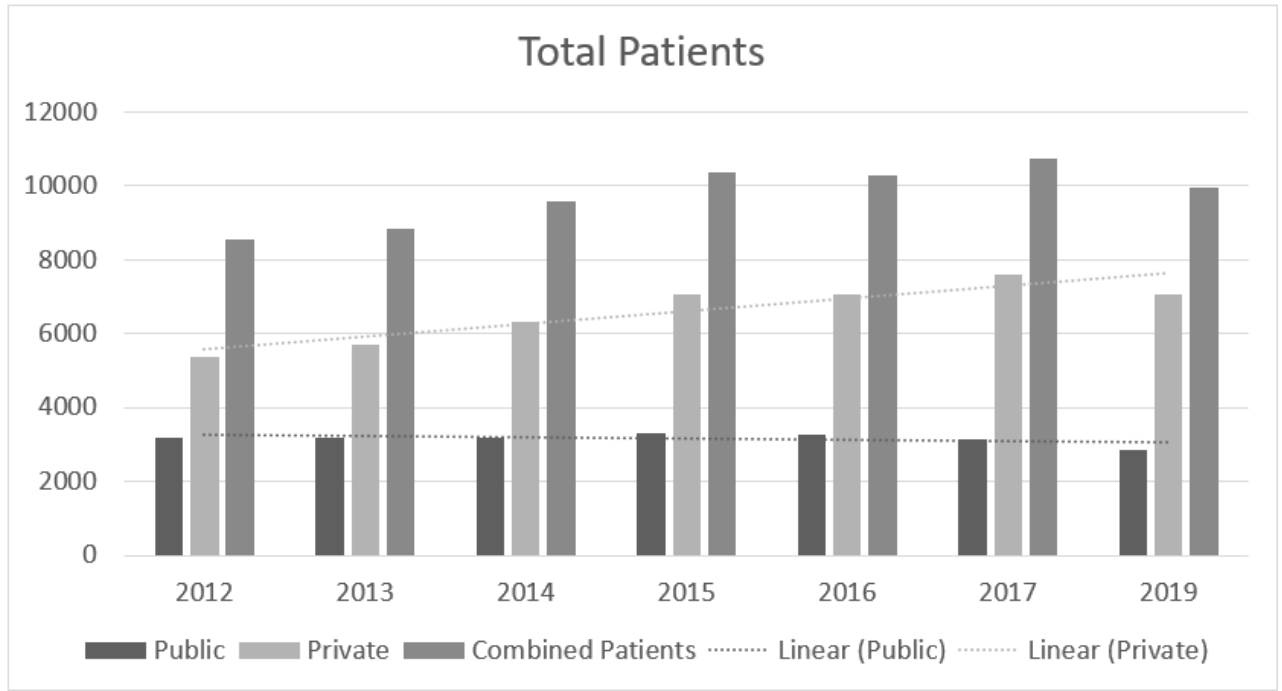
**NUMBER OF UNITS**



The higher number of RRT centres in the private sector is as a result of increased demand. The number of patients treated with RRT has increased from 2843 in 1994 and has plateaued at about 10 000 for the last 5 years. However, the percentage of patients has shifted markedly from the public to the private sector with the decline in patients treated in the public sector and an increase in the number of patients treated in the private sector (Figure 2).

*Figure 2: Number of patients in public and private sectors receiving RRT over the last 7 years (Data compiled from South African Renal Registry)*

**CURRENT STATISTICS (RRT)**



The static number of patients treated in the public sector should be considered in the context of an increasing population. As a result, when comparing the number of patients treated in relation to the population, there is a marked decline in the number treated in the public sector. Similarly, due to the exponential rise in treatment in the private sector, the number of patients treated relative to the population size has escalated. The prevalence per million population, an indicator of number of people treated corrected for population growth, for the two sectors is in Figure 3.

*Figure 3: Prevalence of RRT in people per million in public versus private sector. Data compiled from South African Renal Registry.*

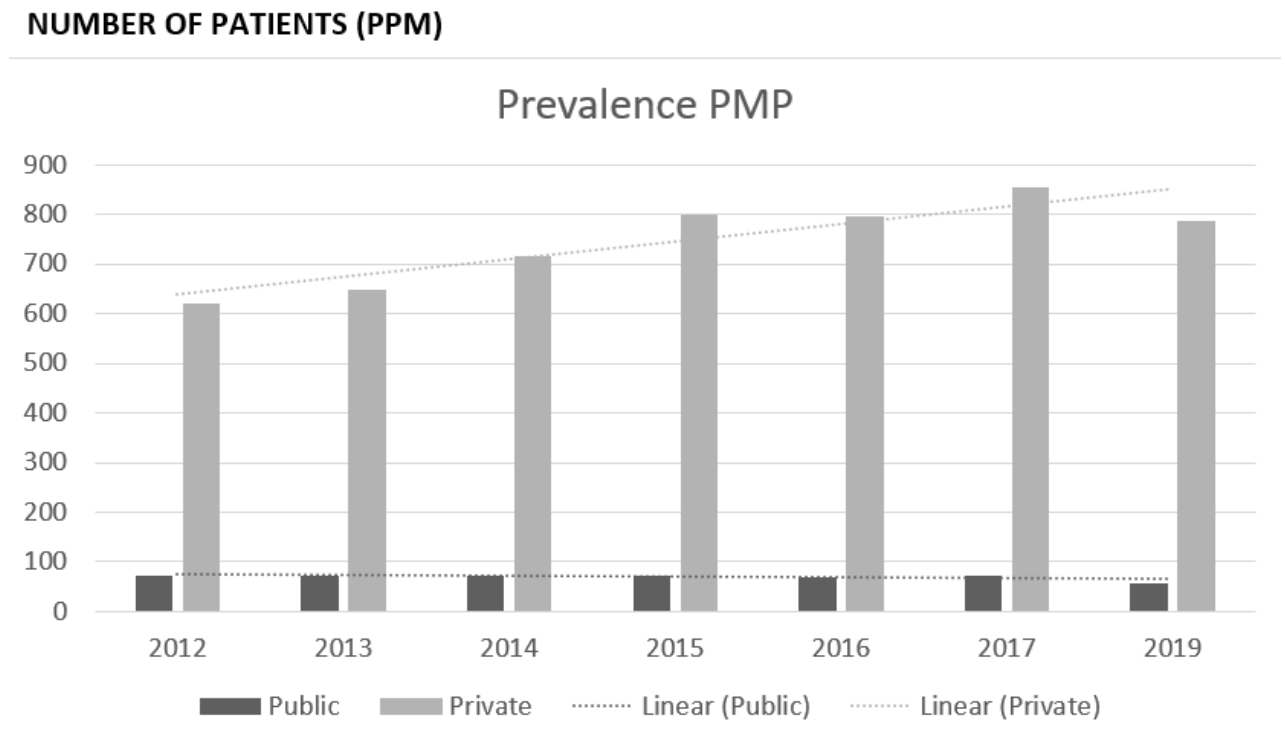


Figure 3 indicates that in the public sector, the number of patients treated has declined by 22% in real terms despite a low starting base. At the same time, in the private sector, the number of patients increased with 26.9%. In 2019, the latest available statistics for RRT in South Africa, the private sector treated 14 times the number of patients compared to the public sector, when corrected for the population in both groups. In absolute numbers, the private sector had 4217 more patients despite serving a quarter of the population of the public sector.

In conclusion, CKD and ESRD is increasing with a concomitant increase in the number people requiring RRT, as evidenced by the increasing number of patients receiving RRT in the private sector. However, the number of patients in the public sector resulting declined in a widening disparity between the two sectors. This begs the question what the reasons are for this disparity.

## **Health disparity in general**

Health disparity is a complex issue which can be explored from various perspectives. Examining the literature is difficult because the definition of health disparity varies between publications (Braveman, 2014). Disparity has been defined both as a difference between two groups which may not necessarily be unjust as well as perceived unjust aspects of healthcare.

Disparity in the literature is described from different aspects. These range in terms of whom it affects, how it affects a particular group, proving that it exists and the causes of the disparity. These aspects have been studied, such as assessing the number of people receiving healthcare, health coverage, types of treatment received between groups, quality of treatment, biases in healthcare, and health outcomes (Wasserman, 2019). The disparities being compared are usually based on race, gender, sexual identity, social economic status and education level (Nelson, 2002).

Most literature focusing on these issues attempts to prove that a disparity exists between two groups. These papers are mainly quantitative studies comparing two groups and using various health indices as outcome measures. As most research, health disparity research is highly influenced by the conceptual model of the hypothetical causes of the disparities (Roux, 2012).

The current research concentrated mainly on the causes of a disparity. This can be divided into several categories (Braveman, 2014). Biomedical causes include differences in genetics, molecular biology, diagnostic techniques and treatment responses in population groups. Social causes would include social issues, economic status, behavioural patterns and environmental concerns. Other papers investigated policies and geopolitical factors affecting health groups and their outcomes (Johnson, 2020; Towne, 2017). Finally, structural issues affecting healthcare systems and how they contribute have been explored by various authors (Brown et al., 2019; Gee et al., 2020; Nef et al., 2020).

South Africa is unique in that all the issues are present. Genetically and biologically, the population of the country is diverse and the disease patterns are non-homogenous affecting groups differently. (Petersen et al., 2013). Increasingly, it is becoming clear that diagnostic and treatment techniques previously employed may be erroneous and newer techniques may be needed (Fabian et al., 2019). Social issues affecting the country are also well known. As a developing country, it has the same

concerns as other nations with respect to economic resources (Rodrik, 2008). All these components necessarily mean that health disparity is highly likely.

However, given its history of colonization, apartheid and the post-apartheid era, South Africa also has unique challenges. The latest World Bank report shows South Africa to be the most unequal country with the highest GINI co-efficient (measure of disparity in income and consumption) in the world (Worldbank, 2022). Injustices due to apartheid such as land claims, transformation, affirmative action, education imbalances, entrenched culture differences, crime and corruption, and unemployment has led to marked social instability, political impasses, economic imbalances and environmental issues (HRW, 2021). These undoubtedly play a part in health disparity.

Added to this is the emergence of the HIV pandemic which has put a strain on the economic resources. South Africa spends R35 billion on HIV medication alone (Blecher et al, 2016). This is in addition to the unknown amounts spent on the complications experienced by patients secondary to HIV as well as the opportunity costs lost for sick patients. The reasoning behind such a huge financial layout is the cost-effectiveness of treatment but may have an influence on treatment of other diseases. Collectively, South Africa has multiple general and unique challenges which is prone to the development of health disparities.

Kidney diseases has unique risks. Treatment of disease is dependent on the duration and efficacy of treatment. Diseases can be divided into two groups: short term illnesses or acute conditions and long-term illnesses or chronic conditions. The latter is usually lifelong. Treatment of acute conditions tend to be more expensive but few patients have the condition. Treatment of a chronic condition, although with a substantial number of patients is cheaper, which makes it cost effective. Treatment of a condition attempts to prevent complications which inherently have higher morbidity, mortality and cost. HIV is a chronic condition which is easy and inexpensive to treat. Cancers are usually acute conditions that are expensive but treatment and costs are short term. Kidney failure is the only condition that is chronic, amenable to treatment and expensive. This makes it a unique predicament for funders and patients with kidney failure are the most vulnerable.

In conclusion, health disparity is complex and involves a multitude of factors. South Africa has its own general and unique factors which contribute to this disparity. Within the health disparity spectrum, kidney disease is also unique making it particularly vulnerable.

#### **2.2.4 Current reasons for disparity of RRT**

Hardly any literature probes the cause of the discrepancy of RRT in the two sectors. The literature review identified only two papers. According to the papers, the main reason is a lack of resources in the public sector (Wearne et al., 2019). Although generally believed to be true, no evidence is available to support the assumption. The lack of resource argument was tried in the Constitutional Court of South Africa. On 27<sup>th</sup> November 1997, and the court upheld a judgement in the high court in the case of Subramoney versus the Ministry of Health (Chaskalson, 1997). In the case, Thiagraj Subramoney, a terminally ill patient, claimed his constitutional right to health had been violated when he had been refused RRT treatment at a public facility. The court ruled renal failure was not a medical emergency and the obligation of the state to treat non-emergencies is dependent upon what resources are available as stated in sections 27(1) and (2) of the constitution. The constitution further states in section 27 (2) that “The State must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights”. The court added it would not interfere in decisions taken in good faith by political and medical authorities and accepted that rationing of resources was central to health service delivery in the public sector, even if this might contribute to growing inequities between the public and private sectors. The court finally stated that as per the constitution, the State should attempt to “progressively realize” the rights of its citizens. No studies have been done to analyse what resources the State has and how it is been utilized. It is generally believed, but not proven, that no policies exist to gain additional resources in an attempt to “progressively realize” the health rights of renal failure patients and the lack of resources is the only reason for declining numbers of patients.

This landmark judgement has since been used as a directive to draw up guidelines that rations dialysis in the public sector to use the limited resources in the best possible way. The effectiveness of these guidelines was studied by Moosa et al. (2016) and showed that they effectively limited the number of patients on RRT by refusing treatment to more than 50% of patients who required it. The reasons for refusal were mainly social rather than medical.

The second reason was proposed by Etheridge & Fabian (2017). Their reason for the discrepancy is a legally sanctioned injustice that exists which perpetuates the problem. Rationing of RRT can occur in the public sector as a consequence of the Soobramoney ruling. However, rationing is not possible

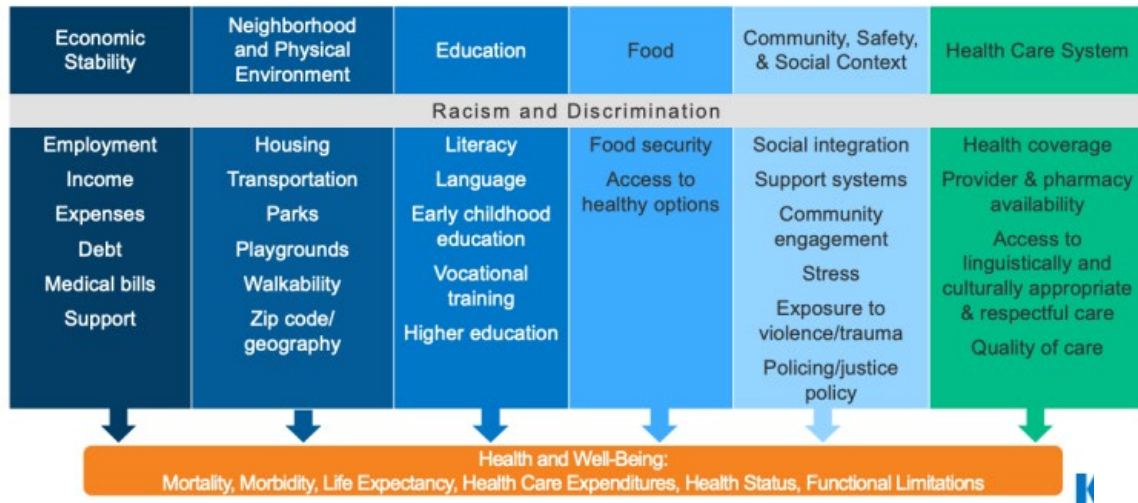
in the private sector as it forms part of a set of conditions known as Prescribed Minimum Benefits (PMBs). It is mandatory for medical aids (insurers) to pay for PMBs as set out by the Medical Schemes Act 131 of 1998, regardless of the financial contributions made by the beneficiary. (Medical schemes act no.131, 1998). Therefore, medical insurers cannot refuse RRT to any of its members and there is an obligation to pay for it. This dichotomy of policy has resulted in a growing divide in the number of patients with access and arguably the quality of treatment between the public and private sectors.

### **2.3 Research knowledge gap analysis**

Although lack of resources and unfavorable legislation have been blamed for the lack of services in the public sector, they have not been fully investigated. Other reasons for the disparity have not been explored and no literature focused on other possibilities.

As stated previously, health disparities originate from broader inequities. They are related to historical and current geopolitical, social, economic and environmental events (CDC Report, 2011). Riley (2012) describes health disparities as a “complex and multi-factorial construct” that affects not only access to healthcare but also treatment options and quality of care, which ultimately affects outcomes. Issues affecting the inequities cannot be considered in isolation but in the broader context of what and how the environment operates. In addition to the direct issues relating to health provision, factors beyond the health system sustain and perpetuate the disparity. Figure 4 (Ndugga & Artiga, 2021) illustrates some of these issues.

Figure 4: Drivers of health disparities (source: Disparities in Health and healthcare, Ndugga and Artiga, 2021)



In the context of South Africa’s long-standing history with apartheid and massive political shifts in the last two decades, it is inconceivable that this would not influence health equity. Historical and current issues result in structural and systemic differences that are both physical as well as intangible. These aspects need to be investigated to fully appreciate the causes of the inequity, which has not been done in terms of RRT. This study aimed to fully understand the causes of the disparity related to RRT in the two sectors by using a holistic perspective and to generated themes which may explain the differences.

The rationale for doing this study was to gain a better understanding of the dynamics involved. The morbidity and mortality rate of patients receiving RRT is high. Patients with ESRD have a worse overall survival compared to the general population. However, patients receiving RRT have a lower mortality rate compared to the group not receiving RRT (Murtagh et al., 2003). The mortality rate in patients receiving RRT consistently improved with the USRDS data showing a decline in mortality of 29% from 2001 to 2016. In contrast, inadequate RRT or no therapy increased morbidity and mortality (USRDS, 2018). The size of the renal unit (Yan et al., 2013), high case load (Harley et al., 2013) and the years on therapy (Chertow, 2000) contributed to this phenomenon. Access to RRT is important to decrease the mortality of these patients and improve their quality of life.

In conclusion, the RRT disparity cannot solely be explained by a lack of resources or legal ambiguity. Many more factors may play a role and these need to be investigated to gain a full understanding of the reason underpinning the imbalance. This may reduce the mortality and morbidity of these patients.

#### **2.4 The theoretical framework of the study**

The literature supports understanding the context of the research, identifying the research problem or question, advocate for the research, and locate the research and knowledge gaps. We need to identify the frameworks to interpret the research findings and finally to develop the conceptual framework (Wotela, 2016).

As described, health disparity is a large and complex topic, associated with diverse aspects. Proving the existence and causation of each disparity would require the performance of multiple quantitative studies. The disparity studied is vast and include the number of people being treated, quality of care, diagnostic differences and treatment options. In addition, the causative mechanisms and impact of health disparities are numerous and to comprehensively investigate health disparity in RRT is beyond the scope of this study. Therefore, this study only explored the causation of the disparity in this industry.

Evidence of a disparity in RRT in the two healthcare sectors is available (Davids et al., 2021). The causes of the disparity have not been fully interrogated and no research has been done in this area. Two main causes have been reported in literature. Etheridge (2017) wrote an opinion piece on the root cause being disparate legislation between the two sectors. Moosa (2016) highlighted a lack of resources but no objective research has been done, and no literature is available. To develop a conceptual framework, we used literature related to health disparities in general.

As discussed, factors leading to health inequities in general could be biological, social, geopolitical and/or structural. Ascertaining biological inequities would require determination of a difference in biological components between the two populations, for example, a difference in genetic composition. This is generally done by large expensive randomized controlled trials which is beyond the scope of this report. We chose an indirect determination by performing a qualitative study and

interviewing stakeholders familiar with RRT. Similarly, aspects of the social, geopolitical and structural causative mechanisms could be done via quantitative or qualitative studies (Roux, 2012)

Exploring each aspect individually would require interrogating multiple variables within a category. For example, social factors would require exploring social aspects such as economic stability, education, healthcare, environment and the community context: the so-called social determinants of health – a framework proposed by the World Health Organization (Braveman & Gottlieb, 2014). Geopolitical factors could be determined by the government, geographies, international interests, policies, governmental objectives and relationships (Persaud et al., 2021). Structural interrogation would require an analysis of the demographics, health systems, funders and data analysis (Cantor & Poh, 2018). Each of these variables can be subdivided and further analysed quantitatively to determine the impact on health inequality in terms of RRT. This would be complex and require resources beyond the scope of this paper. We chose to do a qualitative study to gain an overview of the causes, which could be investigated in future research.

There are five types of qualitative research methods (Vashishtha, 2019). Ethnography involves the researcher embedding himself into the lives of the participants to experience their lives. It is severely restricted by geographical constraints. Phenomenology research is used to study an event or activity as it happens. It is mainly an experienced or perception-based method in which people's experiences of a phenomena are explored. It is used to describe the "essence of things" (Moustakas, 2011). Narrative research explores human experience and their meaning of certain individuals through their stories. It is done to gain insight, reduce commonly held perceptions and to give participants a feeling that their stories are heard. Narrative research interprets the stories people tell (Vashishtha, 2019). Case studies are used to gather in-depth information of any entity, organization, event or country. It can be exploratory or explanatory. Grounded theory starts with the collection of data and through analysis, repetitive ideas or elements are coded and categorized to form theories.

The aim of the study was to gather information on the possible causative mechanisms for RRT in the two South African healthcare sectors. An in-depth comparative study framework was required. The researcher decided to use a case study and grounded theory as the most appropriate methods as this would provide the most insight in the "themes" that would explain the disparity. This framework

has been used by other researchers studying health disparities (Draucker et al., 2014; Plaza et al., 2013; Poteat et al., 2013).

#### 2.4.1 Grounded theory

Grounded theory was the methodology chosen for this qualitative study, specifically, grounded theory from a constructivist perspective. Grounded theory is a research method that generates or grounds a theory from the data collected (Noble & Mitchell, 2016). In contrast to other quantitative research, grounded theory is based on an inductive process where a general principle or theory is produced from several observations, rather than a deductive process where observations are used to prove a theory. In the current study, we aimed to generate themes that would explain the disparity in RRT between the private and public healthcare sectors in South Africa.

Grounded theory has evolved over the years and now consists of several main types (Sbraini et al., 2011). In the “classic grounded theory”, Glaser proposed that the theory be constructed purely based on the data collected without any preconceived ideas or notions. Emphasis is placed on the emergence of the theory based on the researcher’s insights within a clear frame of stages (Kelle, 2005). Strauss and Corbin’s grounded theory (Strauss, 1987) proposed the use of a well-defined “coding paradigm” which explores causation, context, intervening conditions, action strategies and consequences which drives the data rather than creating codes as they emerge from the data. Charmaz and Bryant developed the theory based on “constructivism” in which the theory is constructed by the researcher because of the interaction between the researcher and the data. It assumes that the theory is not discovered but rather constructed by the researcher based on his/her experiences (Mills et al., 2006). “Discovered” differs from “constructed” in the sense that the latter suggests that themes did not exist prior to any event but are created when the event occurs as a result of the environment. Discovered assumes that the themes always existed and are merely “discovered” as a result of the unfolding of the events in the environment. In the “post-modern situational analysis” developed by Clarke, the context in which decisions are made assumes importance in the interpretation of events. As situations and contexts change, so too will social decisions as well as the theory trying to explain phenomena. Wilson (1970) wrote “In the interpretive view of social interaction...the meanings of situations and actions are interpretations formulated on occasions and...subject to reformulation. To compensate for this, Clarke attempts to provide a framework to

formulate theories across the board. In her article, Clarke describes drawing situational maps and analyzing according to three maps: maps of situation, maps of social worlds and arenas and maps of positionality (Clarke, 2003).

In these frameworks, Glaser uses a broad, non-stringent approach to data collection, analyses and theory formation. In his approach, data is not limited and everything is considered potential data. The importance of extracting relevant data is dependent on theoretical sensitivity, a concept where the experience and rationale of the researcher is important. This method of research is more liberal but very subjective. Strauss and Corbin's approach is more stringent and prescriptive in its methodology. It specifies specific steps or procedures to be followed to arrive at a theory. Charmaz is a compromise between Glaser and Strauss. The researcher acts as a co-constructivist to give meaning to the data. Therefore, meaning is not objectively extracted but co-constructed with participants. Charmaz is open to the theoretical sensitivity and data comparison of Glaser but also has aspects of Strauss and Corbin's methodology of coding. There is a focus of context and complexity but is not as structurally procedural as Strauss and Corbin. There is a possibility for multiple meanings and therefore multiple theories. Clarke's situational analysis attempts to create a theory based on social worlds or arenas. It allows researchers to draw together various studies of a diverse nature (such as action, history and context) and analyze complex situations. Situational analysis allows researchers to draw together different studies of discourse and agency, action and structure, image and text, context, history and the present moment to analyse complex situations broadly. Thus, it can support researchers from heterogeneous backgrounds pursuing a wide array of projects.

The current study used Charmaz's framework as Glaser's original methodology was considered to be too broad, non-committal and lacking in direction. Strauss and Corbin's interpretive framework was felt to be too stringent with a possibility of missing out key concepts and ideas. As the study is fairly unique to the South African setting and limited to a specific period, we felt Clark's "post-situational analysis" would not be applicable. Hence, Charmaz's "constructivist" grounded theory was the most appropriate framework.

The study aimed to offer an explanation or theory behind certain events using interviews and existing documents. In the scenario, the aim is to provide explanations/themes that would clarify the causes of the large disparity that exists in RRT between the public and private sector in South Africa. The study intended to develop a theory rather than proving an existing theory. It used specific observations to make broad generalizations. To do this the researcher used the components of grounded theory (Table 4).

*Table 4: Components of grounded theory (adapted from Sbaraini, 2011)*

<b>Component</b>	<b>Stage</b>	<b>Description</b>
Openness	Throughout study	Inductive process. Attempts were made to develop theories or reasons for the discrepancy in RRT. Thus, the need for openness as the theory evolve as more data is collected.
Analysis is immediate and continuous	Analysis and data collection	Analysis was continuous and began immediately. It ran parallel to data collections and allowed for theoretical sampling (see later).
Coding and comparing	Analysis	Coding was done where the data were broken down, separated into different groups and labelled. This was done by comparing data from interviews, documents and focus groups. The groups were then be compared and further segregated into categories.
Memo writing	Analysis	Notes were taken after every data collection. These memos were used to develop thinking and look for patterns to enhance coding and categorization.
Theoretical sampling	Sampling, Data collection	Coding and categorization resulted in insights which necessitated additional data collection from specific avenues which developed the theory.

Theoretical saturation	Sampling, data collection, analysis	We continued to sample and collect data until no further insights were obtained. Thus, all the new data collected fitted in an existing category.
Production of theory	Analysis and Interpretation	We related and explained the categories and concepts into a theory which fully explained the data.

## **2.5 Summary and conclusion of literature review**

The literature revealed that there was an increase in CKD due to an increase in the risk factors leading to kidney disease in South Africa. This increase in CKD will result in more patients reaching ESRD, which necessitates RRT.

At present not all patients who require RRT are receiving it, especially in the public sector. Comparing the public and private sectors, it is clear that more patients are receiving RRT in the latter. The reasons for this have not been elucidated fully and to date only two reasons have been given, namely, a lack of resources and a State Act. However, considering health disparities in general, we note there are complex issues at play. We assumed that these issues may play a role in the disparity of RRT in the two sectors. We used grounded theory to generate at “themes” that could explain the disparity. We used Charmaz’s “constructivist” method as the most appropriate method to analyse our data.

It is hoped that by finding accurate causes for the disparity, we would be able to address this imbalance and improve the lives of many current and future kidney patients.

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## 10 RESEARCH STRATEGY, DESIGN, PROCEDURE AND METHODS

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### **3.1 Introduction**

This chapter describes the research approach, design and the procedures and methods employed to collect, collate, and analyse the data. This chapter describes the research strategy (Section 3.1), the research design (Section 3.2), and the procedure and methods (Section 3.3). Reliability and validity measures are described in Section 3.4 and the technical and administrative limitations in Section 3.5.

### **3.2 Research strategy**

A research strategy is defined as the techniques that is used to achieve the purpose of the research (Kothari, 2004). A research strategy, also known as a research approach or research paradigm, focuses on the research design and approach. It denotes the approach to data collection and analysis (Maree & Pietersen, 2016). The research strategy, either be qualitative, quantitative or mixed, can only be chosen when the research problem has been defined.

The research strategy describes the steps taken to achieve the objectives in the study, that is, to determine how RRT occurs in the private and public sectors and to compare these two objectives to determine why a disparity exists between the two sectors. To do this, we need to answer the research questions pertaining to the above objectives. Answering the following research questions would support the analysis:

1. Which factors contributes to the determination of the number of patients receiving RRT in the private health sector in South Africa?
2. Which factors contributes to the determination of the number of patients receiving RRT in the public health sector in South Africa?
3. How does the factors differ in the two sectors?

To answer the above questions, interviews were conducted with relevant stakeholders and their statements analysed qualitatively to understand how each sector operates and what contributes to the

number of patients in each sector. To assist in this analysis, the following questions were posed to realize the objectives:

- What are the determinants for RRT in the public and private sector?
- Who determines who receives RRT in public and private sectors?
- How is RRT implemented in each sector?
- How do the determinants and implementation described above affect the number of people being treated with RRT in each sector?
- What is the understanding of stakeholders regarding the number of patients treated in each sector?
- What are the policies pertaining to transplantation?
- How does transplantation affect RRT in each sector?
- Is resource (especially organ) allocation equitable between public and private sectors?

A comparison of the two groups would facilitate the identification of the reasons for the disparity. To answer the above questions, we have three available research strategies. These are a qualitative study (interpretive data), quantitative study (statistical data) and mixed methods (interpretive and statistical data) (Cronje & Du Plooy-Cilliers, 2014).

The researcher chose to do a qualitative study. The reason for this is the study is more exploratory and the purpose is to gain an understanding of why the disparity exists. It offers the following advantages over a quantitative study (Cronje & Du Plooy-Cilliers, 2014). Firstly, as the causation is multifactorial and multiple, a qualitative study would allow for the discovery of more causative factors compared to a quantitative study. Secondly, doing a qualitative study would allow gathering as much data as possible from a relatively small sample size. Thirdly, it would allow us to see reasons for the disparity over time. Fourthly, the less restrictive and more flexible method of qualitative studies would allow for more insight into the industry. Lastly, a qualitative study is more likely to show context as opposed to a quantitative study.

### **3.3 Research design**

“A research design is a plan or strategy that moves from underlying philosophical assumptions to specifying the selection of participants, the data-gathering methods to be used and the data-analyses

to be done.” (Nieuwenhuis, 2016) pp 72). Alok and Mishra (2017) indicate that the research design is linked to the research problem. Research design therefore outlines the framework for the collection, measurement, and analysis of data and is determined by the research problem. It ensures that the data obtained is able to effectively and efficiently address the research problem logically and as unambiguously as possible.

Research designs comprises of five different types namely: experimental design; longitudinal design; case study design, comparative design and cross-sectional or survey design (Bryman, 2012). Experimental studies involve the introduction of an intervention. Longitudinal studies examine the same individuals over a period of time. Case studies analyses data to arrive at an in-depth, multi-dimensional understanding of a complex issue in its context. A comparative design compares two or more groups with the intent of discovering something about the thing being compared. Cross-sectional study analyses data from a population subset at a particular point in time.

The key question to consider when selecting the most appropriate study design is to consider whether it is formally possible to allocate participants in a control and study group and then introduce an intervention of an issue or whether to gain a more naturalistic understanding (Crowe et al., 2011). The former is used in an experimental design while the latter in a case study. The researcher’s questions lend itself more to a case study. Yin (2009) describes case studies as a way to “explain, describe or explore events or phenomena” in the context in which they occur. This type of study lends itself well to understanding the “how”, “why” and “what” questions to explain phenomena, the context in which they occur and also provide insights of gaps in our knowledge. This is the objective of this study. To study what causes the disparity between the sectors, why do they occur and how to possibly overcome the problem.

Case studies are designed according to the epistemological perspective of the researcher which can either be critical (questioning one’s own assumptions), interpretive (trying to understand individual or shared social meaning) or positivist (studying a variable and seeing if it fits into one’s findings) (Doolin, 1998). In this instance, the researcher’s questions are more easily answered by adopting an interpretivist’s perspective. According to Stake (1995) there are three main types of case study: intrinsic, instrumental and collective. Intrinsic studies are undertaken to explain a unique phenomenon. Instrumental studies use a particular case to gain a broader understanding of an issue.

Collective case studies involve studying multiple cases simultaneously or sequentially to gain insight into an issue. The researcher thought that this study is more instrumental in nature as understanding disparities in RRT between the two sectors may be indicative of broader inequalities in other sectors of health.

To understand the disparity in the two sectors, the study aimed to compare the factors between the groups. Thus, the study needs to be comparative in nature. Comparative studies analyse phenomena and then analyse points of differentiation and similarity (Shahrokh & Miri, 2019). The focus of comparative research is to explore differences and similarities between the groups (Holt & Turner, 1970). By doing so it is hoped that the causative factors for the disparity can be elucidated.

As the factors were assumed to be large and unknown, the researcher used an inductive rather than a deductive process. After the collection of the data, the analysis involved the generation of variables or themes to explain the disparity rather than using variables to prove a hypothesis. As explained previously, the methodology used was grounded theory using Charmaz's framework. Similar studies using grounded theory to investigate the causative factors for health disparity had been done by Draucker, et al. (2014); Johnson & Nemeth (2014); and Vanedistine & Apparicio (2019).

The researcher thus committed to conducting a comparative, instrumental case study using grounded theory for the analysis. The reason for this combination is that by comparing the two health sectors the researcher hoped to gain an in-depth understanding of how and why disparities occur in the two sectors.

#### **3.4. Research procedure and methods**

This segment of the report focus on the research procedures and methods the researcher used in choosing the target population, collect and collate data, and to process and analyse the empirical data. Method is defined as the approach and manner in which research data is obtained and analysed (Saunders et al., 2009). The methodology section identifies the target population, units of analysis and the sampling method and sample size.

### **3.4.1 Research data information collection instruments**

Collection of data is one of the most important aspects of any type of research as it has a profound bearing on the overall results of a study. To do this, a data collection instrument is required which is relevant to the study (Bhattacharjee, 2012). There are three types of instruments; observation, interview schedule and survey schedule. This study used a schedule interview.

A interview schedule can be structured in a way that allows the researcher to conduct interviews with interviewees through questions and answers that can be fully structured, semi-structured or unstructured (Kabir, 2016). The data collection instrument structure used for this study was an unstructured interview. This was done in keeping with the principles of grounded theory which attempts to avoid theoretical preconceptions (Noble & Mitchell, 2016). By asking open-ended questions, it was hoped that the researcher would avoid preconceptions and gain a deeper understanding of the factors at play. Unstructured interviews would also be more likely to result in more responses with the possibility of providing newer and unexpected insights. More detail can be obtained which supports the discovery of the causative factors and to understand the processes at play (Weller et al., 2018).

Due to the COVID-19 pandemic and concomitant severe restrictions, interviews were mainly done online using video conferencing platforms such as Zoom and Microsoft Teams. With the permission of the participants, these interviews were recorded and then transcribed using Microsoft Word and analyzed. In keeping with the principles of grounded theory, the analysis and interviews occurred simultaneously to gain insights and direct further interviews (Tie et al., 2019).

### **3.4.2 Research target population and selection of respondents**

#### **3.4.2.1 Research target population**

A target population is defined as “*the entire aggregation of respondents that meet the designated set of criteria*” (Burns & Grove (1997), pp. 236). The target population must be items or people who share similar characteristics (Bhattacharjee, 2012).

The target population chosen was any stakeholder involved in the provision or acceptance of RRT in South Africa. This can be either directly or indirectly. Direct involvement would comprise of

participants who deal primarily with provision of services either by providing or receiving treatment or in the administration of such activities. Indirect involvement would be participants who do not deal directly with RRT per se but whose decisions impact the provision of the service. This target population was chosen as they are most likely to provide insight into the disparity as opposed to the general population who have no understanding and awareness of the issues involved. The method chosen for sampling was purposeful sampling.

#### 3.4.2.2 Sampling or selecting respondents from the target population

A sample is defined as "the people (respondents) that you can gain access to within the population" (Davis, 2014, p.97). The researcher initially chose purposeful sampling as opposed to random sampling. This was followed by theoretical sampling. The reason for the initial purposeful sampling is it is the most effective way to identify and select information using the least resources (Patton, 1990). Purposeful sampling strategies depend on the aims of the research. The strategies used could be emphasis on similarity, emphasis on differences or a nonspecific emphasis (Palinkas et al., 2015). This study aim is theory-based and attempts to identify all causes for the disparity of RRT in the two sectors. The population was chosen based on the potential that the participant would be able to contribute to the theoretical construct or to provide concepts which could be explored further. In keeping with the principles of purposeful sampling, the researcher chose individuals or groups of individuals that are knowledgeable and/or experienced with RRT (Creswell & Plano-Clark, 2011). These included healthcare workers, patients, administrators, funders, ethicists, lawyers, transplant co-ordinators and researchers. As the topic of interests refers to South Africa, participants had to be involved directly or indirectly with the health system in the Republic of South Africa. In addition, the participants had to have no pecuniary interest and be unbiased in their accounts. Additional criteria were availability, accessibility and willingness to participate (Bernard, 2002) and to communicate effectively in an articulate and reflective manner.

The purposeful sampling was followed by theoretical sampling. Theoretical sampling is defined as "the process of data collection for generating theory whereby the analyst jointly collects, codes and analyses his data and decides what data to collect next and where to find them in order to develop his theory as it emerges" (Glaser & Strauss, 2012). Though the initial purposeful sampling was determined by the researcher prior to the study, subsequent theoretical sampling was determined by

the provisional data analysis. Theoretical sampling differs from other sampling techniques as it aims to generate and develop theoretical data, rather than being representative of a population to test a hypothesis. It attempts to “discover categories and their elements and ascertain the interrelationships between them” (Dudovskiy, 2018). Theoretical sampling was done to gain more insight, to confirm information from prior interviews or to disprove concepts from interviews. The participants chosen through theoretical sampling were either recommended by previous participants or chosen due to analysis of prior participant’s accounts. This was a form of validation for the data collected where theories could either be confirmed or disproved.

Qualitative studies usually intend to achieve depth of understanding (Paton, 2002). The most effective way of doing this is to continue sampling until theoretical saturation is reached (Miles & Huberman, 1994). This is the point where further data does not yield any more information. Different approaches to theoretical saturation exist. The researcher attempted to follow this principle both in identifying the target population as well as the number of respondents.

The researcher used the framework of Saunders et al., (2017). To apply this framework, three questions needed to be answered: In what way is saturation defined? For what purpose should saturation be sought? At what stage is it sought and how can we assess if it has been reached? The answers to these questions are as follows: Saturation was defined as the point at which all possible interviewees would be interviewed, all possible data collected and analysis reveals no new codes.

By answering these questions, three levels of confidence can be achieved. At the first level, all stakeholders in the industry needed to be interviewed as an omission may not provide a comprehensive overview. At the second level, the content of data collected also determined saturation. The degree to which data is repeated and new data found also determined saturation. Lastly, the analysis of the data may determine saturation and sampling would stop if no new codes and themes are discovered.

In answering these questions, the researcher defined saturation as the point at which further interviewing, data collection and data analysis did not contribute any new insight. The purpose of attaining saturation is to provide a comprehensive overview of the factors leading to disparity in RRT, to provide a quality assurance that all factors have been considered and as a means of

validation. To conclude, saturation would be achieved after all known types of stakeholders have been interviewed, no new information had been gleaned from further interviews, no new data emerged in subsequent interviews and the analysis revealed no new themes

Andrade (2020) gives the following disadvantages to purposeful sampling. He suggests that the samples may not be easily defensible as being representative of populations due to the potential subjectivity of the researcher; it is more difficult to draw factual material as the sample material is also subjective; and the population size can be limited by the researcher making generalisations of the topic area inconclusive. It is hoped that reaching theoretical saturation may alleviate these disadvantages.

Khanyile (2008) used a sample size of approximately 30, and could draw reasonable conclusions from the study. In keeping with precedents of grounded theory the minimum number attempted will be at least 20-30 interviews (Palinkas et al., 2015). This would allow for the fulfilment theoretical saturation principles.

### **3.5 Ethical considerations**

Research ethics must be adhered to and maintained (Steneck, 2007). Ethical issues are of importance throughout the research and require ethical integrity from the researchers, the participants and the Research Ethics Committee. It extends to areas such as plagiarism and scientific misconduct (Blanche et al., 2006).

The researcher was committed to the adherence of stringent ethical principles and to act with integrity by practicing research in a respectful and accountable manner. The researcher conducted the research as partial fulfilment for the degree of Master of Business Administration with the Faculty of Commerce, Law, and Management, University of the Witwatersrand and fully abided by ethical principles as set out by the University. The researcher, although a practicing nephrologist in both health sectors, has no pecuniary interest in the findings of this report and has not received sponsorship by any individual or organization. The integrity and anonymity of participants was and will be strictly enforced. The researchers honoured patents, copyrights and other intellectual properties and would not use unpublished data, methods or results without permission. Care was taken to acknowledge all contributions and to avoid any form of plagiarism.

The researcher acknowledges that ethics are integral and failure to comply with ethical principles would potentially affect the participants and other stakeholders.

Below are a number of highly important ethical issues which were addressed when conducting the research:

#### University approval

The researcher applied for ethics clearance from the University of the Witwatersrand before commencing data collection. The protocol number is WBS/BA9202460R/767.

#### Informed consent

Participants were informed both verbally about the purpose and aim of the study. This was reinforced by signing the consent form in Appendix A of this paper. The participants were assured of anonymity and that every attempt would be made to protect their identities. Participants could withdraw their support at any time with no negative consequences. They were reassured that the results of the study would be used for academic purposes only and may be published in an academic journal. The University reviewed the study and provided approval.

#### Avoiding harm

Maltreatment, injury or harm was avoided in all participants. Participants were not placed under stress, duress and their self-esteem were preserved in every way.

#### Deception

The researcher guaranteed that participants were not deceived intentionally. Participants were fully aware of the intent of the study, what it entails and how their data will be used.

## **10.6 Research data and information collection process**

Data collection is defined as “the process of gathering and measuring information on variables in an established systematic fashion that enables one to answer stated research questions, test hypotheses, and evaluate outcomes” (Kabir, 2016, p. 202). It is one of the most important steps in conducting research as the quality of the data collected has a profound impact on the study’s research questions and ultimately on the research objectives. The modes of research data collection are participant observation (ethnography), interviews (face-to-face, telephone, internet-based, surveys) and focus group discussion. This study used interviews.

The study began by telephonic or text communication with a request for an interview. In the request, participants were informed of the study, the intent of the study (MBA thesis), the aims and objectives of the study and the potential of the study to change lives. Anonymity was guaranteed at the request. Confirmation of the interview and signage of consent forms was done via secure email. Subsequently, an appointment was made for the interview. The interviews were conducted either in-person or through video conferencing platforms such as Zoom or Microsoft Teams. The use of these platforms was essential as the COVID-19 pandemic severely restricted face-to-face interviews. The advantage of these platforms was a saving of time and money and improved efficiency. Scheduling of appointments was also easier. Interviews were also able to be easily recorded. The disadvantage was the interview tended to be less personal and occasionally network issues occurred. Collaborative interviews or joint interviews were not done deliberately as the researcher thought this may add a bias when one interviewee influences the views of another.

All interviews were recorded either through the video conferencing platform or through a recording device (iPhone 11 pro). Permission for recording was obtained from each interviewee prior to it being recorded and anonymity reiterated. The content of each interview was dictated by the expertise of the interviewee. For example, healthcare workers were interviewed according to their perception and experience and were mainly health related, while the content of funders would primarily deal with the financial aspects. All interviews were open-ended with no standard questionnaire. This was done to gain more insight, avoid the biases of the researcher and to understand the true feelings and attitudes of the interviewee.

The recording was stored securely on a password protected MacBook Air laptop computer to be transcribed at a later date. All interviews were transcribed by the researcher and stored as a Microsoft Word document on the same laptop computer to be analysed. The data collection and storage process were a once-off process and occurred over a six-month period.

The interview process and analyses occurred simultaneously in keeping with the principles of grounded theory (Glaser & Strauss, 2012).

## **10.7 Research data and information processing and analysis**

### **3.7.1 Research data and information processing**

Research data processing is the process of converting raw data into data for analysis purposes (Bhattacharjee, 2012). The processing of data collected should be translated correctly in order not to negatively affect the data output (Pearlman, 2019). Processed data is more amenable to interpretation and analysis.

The information processing technique necessitates a number of steps. These include transcription, data entry, data cleaning and data coding (Niewenhuis, 2016). Transcribing is the practice of replicating and revising information into a visual or written format for analysis (Bezuidenhout & Cronje, 2014). Data entry onto a computer is the process of entering data onto computer-based files to store and analyse data (Niewenhuis, 2016). The data from the oral interviews were transcribed into Microsoft Word Documents awaiting further processing. Data cleaning is the process of improving the quality of data by modifying, removing duplicated or irrelevant records within the database (Allen, 2017). The researcher cleaned the data by analysing the transcripts and keeping data of relevance and deleting inconsequential data. The relevant data was entered into Microsoft Excel worksheets waiting further analysis. Data coding is the process of meticulously reading through the transcribed data and classifying it into consequential analytical units (Niewenhuis, 2016). The data in the Microsoft Excel document was coded into themes.

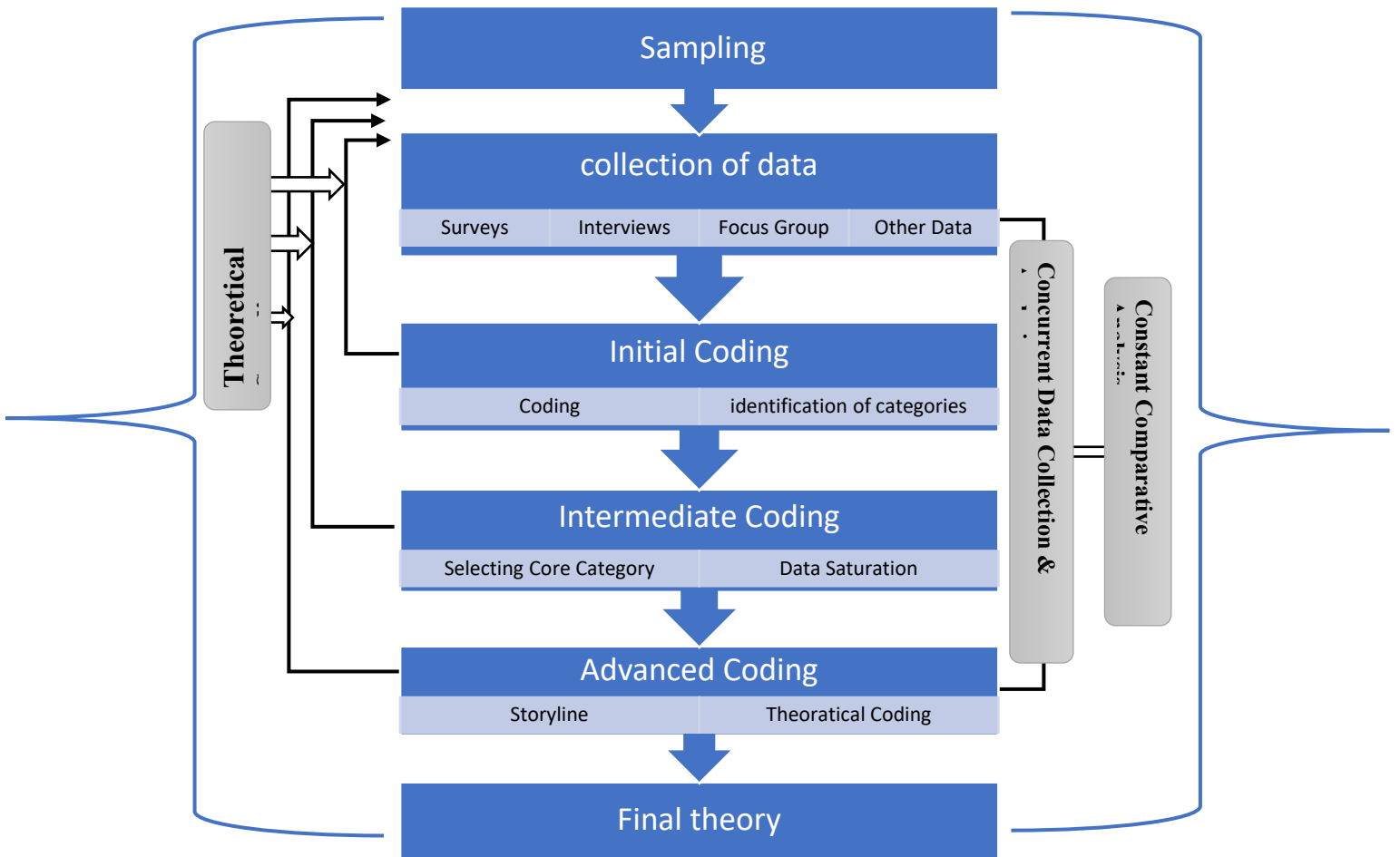
The process of data accumulation, transcription, entry, cleaning and coding occurred simultaneously. All the documents were stored safely on a password protected MacBook laptop computer owned by the researcher. The computer is further protected by Firewalls.

### **3.7.2 Research data and information analysis**

Research data analysis is defined as “the process of evaluating data using logical and analytical reasoning to carefully examine each component of the data collected or provided. Once data has been collected, it is then reviewed and analysed to make informed decisions” (Perez, 2019).

The data from this research was analyzed using grounded theory. This is an inductive process whereby hypotheses are constructed through the collection and analysis of data (Glaser & Strauss, 2012). Grounded theory has previously been discussed in depth (Chapter 2). Figure 5 (taken from Tie et al., 2019) illustrates the steps taken in the analysis of the data.

Figure 5: Research framework for grounded theory: (Tie et al., 2019)



The transcribed data was analysed and cleaned. All data related to RRT was transferred to a Microsoft Excel Worksheet. This data was coded into categories based on similarities of experience and knowledge. The coding separated the data pertaining to public and private healthcare. This was the initial coding step. These initial codes were grouped further according to the categories and the process was continued until no new categories could be formed (intermediate and advanced coding). At this stage, the data for private and public se

ctors were still separated. At the final categorization, the themes were labelled for each category. These themes were re-analysed via a relationship building exercise to create an explanation to describe the theme and understand how these themes contributed to the number of patients receiving RRT (storyline and theoretical coding). The themes from the public and private sectors were then compared and similarities and differences noted to form a final theory or theories to explain the reasons for the disparity between the sectors.

The gathering of data and analysis occurred concurrently. Analysis of previous interviews provided themes, ideas and questions for subsequent interviews. Data from earlier interviews were compared with later interviews and differences and similarities noted. Data was collected until new data could not be isolated into a new category (theoretical saturation).

### **3.8 Reliability and validity measures applied**

Research validity is defined as the extent to which variables are measured accurately, that is, how well a research instrument measures what it is intended to be measure (Dudavskiy, 2018). Validity can be difficult in qualitative studies as it requires “humans to understand humans” which is necessarily subjective (Leung, 2015). To ensure validity in qualitative research, he suggested that researchers examine the “appropriateness” of their tools, processes and data. Therefore, the research question must be appropriate to the outcome, the methodology should be appropriate for the research question, the design appropriate for the methodology, the sampling and data analysis appropriate to the methodology and the conclusions based on the analysis the analysis. The research design was meticulously considered to ensure “appropriateness” and each section was carefully constructed. This ensured reliability and validity.

Reliability represents the accuracy of the data instrument to produce the same results consistently (Heale & Twycross, 2015). Validity is defined as how well the results obtained from study participants can be extrapolated to similar populations (Heale & Twycross, 2015). Silverman (2009) proposed five processes in ensuring reliability: refutational analysis, constant data comparison, comprehensive data, inclusion of deviant case, and the use of tables. Another way to maximize validity and reliability is to use triangulation. Triangulation is defined as the “use of multiple methods or sources in qualitative research to cultivate or enhance the understanding of a phenomena” (Patton, 1999). Four types of triangulation exist: method, investigator, theory, data source (Patton, 1999).

Table 5 lists the methods the researcher implemented to minimize inaccuracy (and hence increase validity) and increase reliability by considering the above principles.

Table 5: Validity and Reliability measures. Included in parenthesis are the reasoning underpinning the measures.

Minimizing personal bias in conducting open ended interviews: ( <i>comprehensive data</i> )
Interviewing a spectrum of multi-disciplinary participants with differing experience and knowledge from: ( <i>data source triangulation</i> )
Comparing data from participants to determine accuracy: ( <i>constant comparison</i> )
Using purposeful sampling in the selection of participants who are experts in their field: ( <i>Data source</i> )
Interviewing multiple people with the same expertise to ensure reliability: ( <i>data source triangulation</i> )
Using theoretical sampling to confirm or refute data and ( <i>refutational analysis</i> )
Theoretical saturation ensures that all data including outliers is noted (“ <i>inclusion of deviant case</i> ” and “ <i>comprehensive data</i> ”)

Using a neutral supervisor not conversant with health and therefore with no personal bias: ( <i>data analysis appropriateness</i> )
Comparative case study: further comparison of factors discovered can easily be verified in subsequent studies: ( <i>Appropriateness of design</i> )

### **3.9 Technical and administrative limitations**

Limitations, within the research context, attempts to detect factors which the researcher is unable to control (Enslin, 2014). They are constraints in the research study which are outside of the researcher's control, such as access to information and time (Enslin, 2014).

The technical limitation of this study is its highly subjective nature. Data gathered from interviews are opinions of people which may or may not be true. The analysis and conclusions are therefore dependent on subjective data which need to be verified with subsequent objective studies. Personal biases may exist in the researcher as he, as well as participants, are nephrologists by profession. Purposeful sampling may be prone to self-selective bias. A further limitation was the sample size. While every attempt had been made to gain as much data as possible, the relatively small number of stakeholders makes this difficult. An example of this would be the presence of only one medical ethicist involved in RRT.

The administrative limitation included a time limitation and the COVID-19 pandemic. COVID-19 posed a rare risk and affected data collection in an effective and efficient manner. It impacted economic, health and social parameters and may have affected many people's mindsets, especially healthcare workers who were the main participants of this study. This may affect the data content. It also prevented personal contact and therefore essential nuances through body language may have been missed. In keeping with regulations, data was collected electronically as far as was practically possible.

### **3.10 Conclusion**

The research strategy, design, procedures and methods used to achieve the research aim of the study, that is, investigating the reasons for the differences in the accessibility to renal replacement therapy in the public and private healthcare sectors in South Africa, was comprehensively explained.

The researcher depicted each component of the research in detail and committed to a choice of what to do in each component. The choice was justified using existing literature, feasibility and fulfilling the aims objectives of the study. In addition, the benefits and disadvantages of the research design, strategy, procedures and methods were outlined. Validity and reliability measures were elucidated together with the limitations of the study.

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## 11 PRESENTATION OF THE RESEARCH RESULTS

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### **4.1 Introduction**

The collection of data is a vital aspect of any research as it has a profound impact on the overall results of a study (University of Wisconsin, 2016). To reiterate, a significant discrepancy exists between the number of patients receiving RRT in the private and public sectors. Based on literature, many patients are not receiving RRT in the public sector, which results in excess mortality and morbidity, as supported by Moosa et al. (2016). The causes for this discrepancy are largely unknown. We interviewed stakeholders in the industry, compared the two sectors and through using grounded theory, generated themes.

### **4.2 Demographic profile of the Interviewees**

In total of 49 people were approached for interviews (Table 6). There was one inclusion criterion, namely knowledge or experience in the provision of RRT in South Africa.

*Table 6: Number of people approached for interviews and reasons for refusal*

<b>Number approached</b>	<b>Acceptance Rate</b>	<b>Reasons for non-acceptance</b>
49 approached	33 accepted (67%)	1 COVID pandemic
	16 not interviewed (23%)	4 Lack of expertise
		6 No reply
		5 Awaiting permission from higher authorities

### **Description of the research respondents**

An attempt was made to involve all RRT stakeholders in South Africa. This proved difficult during the pandemic for two reasons. The first is that many stakeholders were involved directly in the

provision of healthcare during the pandemic and could understandably not afford time for an interview. The second is the group not involved directly could not be reached due to the lockdown laws. Offices were closed and personal details could not be obtained. Given the circumstances, 67% of the prospective respondents were interviewed. Table 4 lists the type of stakeholder and the number of interviews per stakeholder category.

*Table 7: The number and professions of people interviewed*

Doctors (including nephrologist)	12
Nephrologists	10
Nurses	6
Patients (2 private, 2 public, 1 transplant)	5
Public Health Medicine Specialist	2
Clinical ethicist	1
Transplant coordinator	2
Medical aid administrator	2
Health advocacy group	1
Chief financial officer of an academic hospital	1
Treasury officer	1

There was a slight female preponderance with 19 females (57%) and 14 males (43%). Twelve of the interviewees were doctors (36%), 10 of which were nephrologist (30%). The non-nephrologist doctor are a clinical manager of a major academic institution and a member of the treasury. Four nephrologists were either previous or current head of departments in various academic institutions

(33% of nephrologists). Eight nephrologists were exclusively in the private sector (66% of the nephrologists). Two nephrologists practiced in both the private and public sectors (17% of the nephrologists). Two nephrologists worked solely in the public sector (17% of nephrologists).

Six professional nurses were interviewed (18% of total interviewees). All nurses worked in the renal departments of various institutions. Two nurses were involved with peritoneal dialysis (33% of the nurses). One nurse was the matron of a cluster of departments of which renal was a component. Three nurses were involved in hemodialysis (50% of the nurses). The nurses who worked in primary healthcare did not respond to the invitation for an interview.

Five patients were interviewed, two from the public sector, two from the private sector and one transplant patient.

Two public health specialists were interviewed (6% of the interviewees). There was only a single clinical ethicist involved with renal care and transplantation (3%). Two transplant coordinators were interviewed (6%). Two interviews involved the administrators of two major medical aid (medical insurance) companies (6%). One interviewee was a member of the only non-governmental organization known to provide renal replacement therapy in South Africa (3%). One interviewee was a member of a health advocacy group (3%). One interview was a member of the treasury (3%). The final interview was a chief financial officer of a major academic hospital (3%). Members of all race groups were represented.

Although the number of interviews is low, it should be noted that the industry is small and the number of personnel limited. Several potential interviews could not be done due to the reasons described above.

### **4.3 Interviewing process**

Informed consent was obtained from all participants prior to the interview process. All interviewees gave their consent freely without any reservation. Eleven interviews were conducted in person. The remaining 22 interviews were conducted via video conferencing online platforms, either Microsoft teams or zoom, depending on the preference of the interviewee. The average time of the interviews was 65 minutes. The shortest interview was 35 minutes with the longest 88 minutes. No monetary compensation was given to any participant.

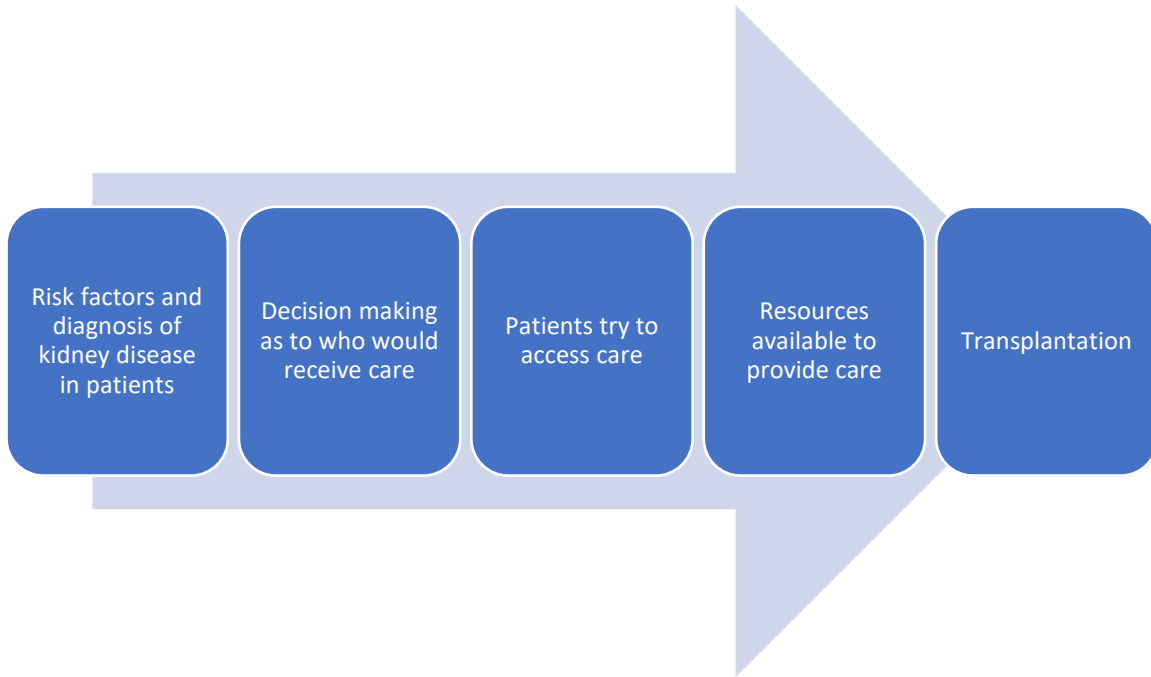
The recorded interviews were transcribed in Microsoft Word and loaded into Microsoft Excel to organize for data analysis. The principal investigator analysed the data using grounded theory, which began with open coding with labels assigned to sections of the transcripts. The initial open codes contained the participants' actual words. The total number of open codes at this stage was 374. Subsequent coding involved demarcation of the open codes into categories based on similarities and differences. This provided a more conceptual framework of the data. A total of 124 codes were created. These were then codified into 19 categories. These categories were analyzed to provide a more focused coding. A final analysis of comparison of similarities and differences led to the generation of five final themes.

The interviewing process and data analysis occurred concurrently until theoretical saturation was achieved. In this study, this occurred at the 30<sup>th</sup> interview after which no new themes could be identified. Three more interviews were done to ensure no new codes emerged.

#### **4.4 Analysis**

Analysis of the interviews, using grounded theory, revealed five main themes with several subthemes. These themes are arranged in an explanatory framework that sequences the journey kidney patients undergo from their diagnosis until possible transplantation. Figure 6 illustrates this progression:

Figure 6: The journey of patients with kidney failure



The number of patients receiving RRT is initially dependent on the number reaching ESRD. The total number of patients on RRT is the prevalence of RRT and consists of existing and new (incident) patients. Once a patient reached this stage, a decision must be made whether he/she will receive dialysis. If the decision is made to provide RRT, the actual treatment process will only occur if it is accessible to the patient and if resources are available. Finally, transplantation plays an important role in “curing” patients and therefore decreasing their reliance on RRT.

The above process has been conveniently divided into the five themes listed below:

1. The prevalence of kidney disease in the public versus private sector populations
2. The decision-making process in the public and private sectors related to whom will receive RRT
3. The accessibility of patients to renal replacement in the public versus private sector units
4. The resources available for renal replacement therapy
5. Transplantation

This process occurs in both the public and private sector. Each of these themes have subthemes and the impact of the subthemes determines the number in each sector. This difference is what causes

the disparity. A detailed analysis of all the themes and subthemes in each sector is presented below as per the study objectives.

#### **4.4.1 ANALYSIS OF OBJECTIVE 1: TO UNDERSTAND HOW RRT OCCURS IN THE PUBLIC SECTOR AND WHAT ARE THE FACTORS THAT DETERMINE THE NUMBER OF PATIENTS RECEIVING RRT IN THIS SECTOR**

The five themes described appropriately answers the research question.

##### **4.4.1.1 Theme 1: Prevalence of RRT in public sector**

*“The true prevalence of kidney disease in South Africa is unknown. Many patients die at home without being diagnosed and as a result there is a massive underestimation of the actual number.”*

Another interviewee stated, *“Due to lack of data regarding prevalence, future planning cannot be done. The lack of data is often used by the public sector as an excuse not to provide resources for RRT.”*

The quotes from the interviewees indicates what the participants thought about the prevalence of kidney disease in South Africa. The subthemes of prevalence are categorized based on the principles of prevention, which are divided into three tiers. Primary prevention aims to prevent disease before it occurs, such as minimizing and controlling the risk factors. Secondary prevention aims to decrease the impact of a disease once it has happened. This occurs by detecting the disease as early as possible to stop or slow its progression. Tertiary prevention aims to improve the lives of people once they have the disease.

##### **A: Primary Prevention**

*“So, it's not like diabetes is a disease of affluence in South Africa. Diabetes is a disease of poverty, actually, in South Africa, it's because the foods are unhealthy and cheaper. So, the access to exercise, the access to a healthier diet, the access to advice, the access to dietary advice, and so forth is more a secret. All evidence seems to indicate that we have an epidemic of non-communicable diseases in South Africa, related to poor diet, poor physical activity, and at the same time, we have an epidemic of HIV in South Africa, and both of those would tend to lead to a high incidence of chronic kidney disease and a substantial proportion of those patients would progress towards end stage renal*

*failure. So, if anything, it will be in the poorer population, you would actually expect there to be a higher prevalence of dialysis patients compared to richer populations.”*

The major risk factors for the development of kidney diseases are hypertension, diabetes, and HIV amongst others. There are no non-governmental organizations or governmental initiatives that specialize in controlling risk factors that cause renal disease (an exception to this is HIV). These risk factors are increasing and contributing to an increasing prevalence. This is especially true in the public sector.

The following reasons were given by interviewees for this rise. These reasons contribute to the subthemes. Lack of education of the public sector was highlighted as the main contributor to the increase in risk factors. This lack of access to education is compounded by an absence of formal prevention programs in the public sector. However, a few indicated that social circumstances were the predominant factor. One interviewee stated that another factor contributing to a lack of primary prevention is the education of healthcare workers.

*“Training of healthcare workers in medical schools are aimed primarily to cure disease rather than prevent them.”*

As a result, patients are not treated adequately and there is no primary prevention program to guide healthcare workers. The combination of poor education of the public, inadequate training of healthcare workers and poor social conditions combine to intensify unhealthy lifestyles which increase the risk factors for kidney disease. This should result in a higher number of patients requiring RRT. Healthy lifestyle habits, such as diet and exercise, mitigate these risks.

#### B: Secondary prevention

Three categories of secondary prevention were established: screening, lack of specialist care and early mortality.

##### Screening

Screening of patients is vital for an early diagnosis. This is essential as the earlier a disease is recognized, the higher the chances of a cure. If no cure is available, measures could be implemented

to prevent disease progress or prolong the period before RRT begins. In the public sector there are no screening of at-risk patients to prevent the complications of disease.

*“...it is within the realm and capabilities of the province to do something about it, to make sure that the urine of diabetics is tested. Make sure that patients have access to hypertension medications. Make sure the patients adhere to their therapy. So, we put together a comprehensive plan and presented it to the province and said, well, we need a comprehensive service starting at primary level where we test urine once a year, make sure the patients are compliant with the medication and although they thought it was a very good plan there was no implementation of this kind thing.”*

Screening in general does not occur in the public sector. No formal programs exist to screen the public and diseases are usually diagnosed at a late stage when complications occurred.

### Specialist care

Early detection of hypertension, diabetes and early stages of kidney disease from whatever cause on may support prevention of the need for RRT in future. Once a disease is detected, specialist care could potentially decrease morbidity and mortality. This requires a functional primary healthcare setting with adequate resources such as education, finance, staff and expertise. A good primary healthcare system decreases CKD and the resultant need for RRT. Unfortunately, despite an increase in the budget and the preference of the government for primary health care, a functional system does not exist.

*“There are no systems to provide models of care, managed care, standards of care, monitoring and outcomes in the public sector.”*

In patients in which the disease was detected early, referral to specialist care is suboptimal. This results in a loss of follow-up of many patients and early referral to specialists. When patients are referred, it is often too late. In the Western Cape, there *“were attempts to improve primary health care by providing models of screening for kidney diseases but the lack of communication between primary, secondary and tertiary care due to inadequate systems made it unworkable”*.

A further complication of lack of specialist care is an increase in mortality. The risk factors which caused the kidney disease are also risk factors for other diseases such as strokes and myocardial

infarcts (cardiovascular diseases), infections, and malignancies. The development of renal failure is a late complication and other diseases are more likely to develop earlier. Thus, patients die before they actually reach the stage of ESRD, reducing the prevalence.

*“End stage is an interesting construct. End stage renal failure is made up of people with chronic kidney disease, who don't die of other things. So, they don't die of cardiovascular disease, they don't die of malignancies, they don't die of infectious diseases, and they survived up to end stage, especially in patients with like, multi-organ diseases like diabetes and stuff like that. So, the problem for poorer populations is because the level of general health care is poor for other things, you know, I think a significant number of people with chronic kidney disease don't survive to end stage renal disease, they die of cardiovascular disease, before they reach end stage, we don't actually know the answer to this”*

The lack of specialist referral has two implications. Firstly, patients may die of complications before reaching ESRD requiring RRT or the patients are not presented to the health system for RRT. In both cases, a lower number of patients will receive RRT.

### C: Tertiary prevention

The aim of tertiary prevention is to improve the lives of people who already receive RRT. In kidney failure patients, this requires efficient RRT and preventing other medical complications. Inadequate care will result in increased mortality and mortality. Adequate care consists of a multi-disciplinary team which manages the physiological health as well as psycho-social support. Kidney failure patients develop complications which require multiple expertise. This is not available in the public sector. As a result, the mortality of patients in the public sector may be higher than the private.

*“... as you know, the biggest killer of renal patients is cardiovascular and infection. Patients die of MI's (myocardial infarction or heart attacks) and infection. What is the use of dialyzing a patient who, if he gets a heart attack, won't be able to be stented as no one has the expertise in your hospital? Try getting a renal patient in public into ICU. There just is no beds available.”*

The higher mortality in the public sector should decrease the number of patients on RRT. However, because of the excess demand the “slot” is easily filled by waiting patients. As no new “slots” are created, the number of patients on RRT in the public sector is stagnant.

## Summary of theme

Figure 7: Summary of prevalence theme in public sector

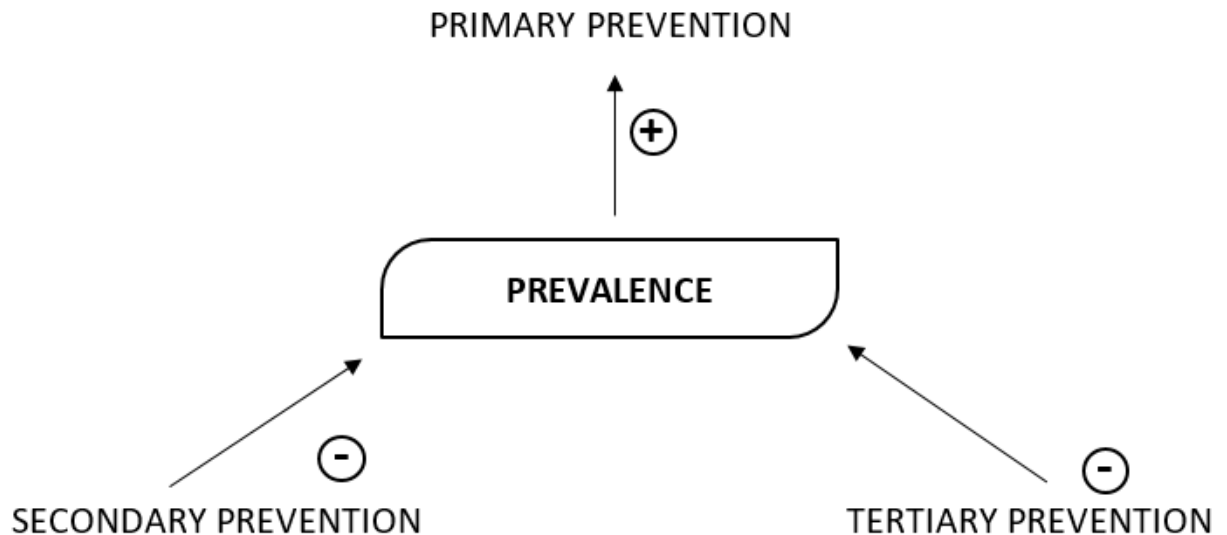


Figure 7 summarizes the prevalence theme. Although there may be a higher prevalence of patients with kidney disease due to a lack of primary prevention, these patients are not diagnosed or have higher mortality because of inadequate secondary and tertiary prevention. This results in a lower prevalence of patients receiving RRT in the public sector.

### **4.4.1.2 Theme 2: Decision-making in the public sector**

Once a patient is clinically eligible for RRT, the next decision is whether he/she would be eligible or not. The decision-making process is quite complex in this sector, which results in rationing RRT and reduces the number of patients receiving RRT. This is seen as a necessary procedure due to a lack of resources.

*“.... basically, I think the only criterion in private for getting dialysis or renal replacement, let’s make it generic, is wanting it. The rest of the restrictions are nonsense. In public, that is not the case. Essentially, it’s determined by other stuff”*

Factors affecting the decision-making process is tabulated In Table 7:

Table 7: Factors affecting the decision-making process

Rationing
Non-standardization of rationing processes
Bureaucracy
Profile of patients
Infrastructure

A: Rationing

*“I think renal patients are very heavily rationed in terms of access”*

*“We follow criteria to ration dialysis. So, we based it around, I’m sure you know, that 2009 DOH guidelines. But we obviously added sub clauses so that at least we can interpret some of what they saying when they see if a patient is transplantable or not.”*

Not all patients requiring RRT will receive it in the public sector. Each patient is subjected to criteria to determine if they are eligible or not. Patients who do not meet the criteria are refused RRT.

Rationing in the public sector is a consequence of the Soobramoney case (wherein the constitutional court made a judgement that RRT should only be provided if the State has the resources) which allowed the State a recourse to actively ration RRT. Thus, there was legal recourse to actively deny someone the right to dialysis. This judgement was detrimental in the long term as it allowed the public sector a sense of apathy and a lack of urgency which resulted in them not intently seeking ways to provide or increase RRT. This was concisely stated in the following quote:

*“The Public sector simply operates as far as I could tell like it is a maverick. There is little accountability, there is no transparency and there is no sort of benchmark like there is in the private sector. There is absolutely no incentive and no challenge, since as far as I am aware, since that*

*famous case, the Soobramoney case. You might have heard of it. There hasn't been a challenge to realisation of dialysis slots since then and that is several decades now."*

Rationing is usually done in a formal manner whereby patients are assessed in terms of viability to receive RRT. This severely restricts the number of patients on RRT. The rationing process depends on the institution providing RRT and differs in each institution. This difference constitutes the second subtheme, non-standardization of rationing process.

#### B: Non-standardization of rationing policies

In the public sector, the decision regarding how to ration dialysis is not standardized and each institution uses its own criteria. Guidelines were initially set by the Department of Health but these were not binding. The last national guidelines were published in 2006 and is now outdated. Attempts to improve and update the guidelines is often met with bureaucracy and inertia, especially from the Department of Health.

*"First of all, Barbara Hogan's initial (guideline), the only published guidelines on dialysis rationing appeared in South Africa over the past 25 years. It took them (Department of Health) 15 years to put it together, and it hasn't been revised in like 12 years. One of the opening lines is that these guidelines should not apply in the same way in the public and private sector."*

Initial guidelines were drawn as a result of frustrations of doctors who felt that rationing was a social and financial problem and not medical, yet doctors were forced to make life and death decisions on who to provide RRT. This decision caused marked emotional turmoil in doctors who essentially had to make life and death decisions daily.

*"In 1993 - 1994 when I was working at ....., I got a message from the medical superintendent in September of one year, saying that because the budget's overspent we must stop dialysing the patients until March, until the next financial year. And so, I did explain to him that you can't stop dialysis in a patient on chronic dialysis, you can't wait till next year when the new budget comes in."*

Early guidelines were broad and open to different interpretations which potentially let it open to abuse. Physicians felt the criteria was not practical and new guidelines were needed.

*“..., and we were summoned to Pretoria, and they said what the heck is going on here and so on. So, the long and short of it was the province said, well look at the time we had some criteria we were using which was not formalized. Some criteria we were using and at that meeting that was a national meeting, they decided well we need to have some sort of guidelines on how to select these patients. But these were not particularly formalized. There was no clear indication of how these guidelines should be used.”*

To improve the rationing process, the Western Cape Department of Health created its own guidelines. It was also felt that kidney failure is treated unfairly as no other chronic condition has a rationing process. Thus, a multidisciplinary team was established, consisting of various stakeholders including psychologists, social workers, medical administrators, ethicists. This team collectively decided on who receives dialysis based on who they consider to be the best candidate. The Western Cape guideline is the only one which is enforced rigorously in the Western Cape. Other public institutions have modified this guideline to suit their purposes. Some institutions have no guidelines.

*“So, we use similar principles although the Western Cape guidelines have not been adopted nationally by the National Department of Health.”*

*“There are no real guidelines we follow. A collective decision is made once a month by our multidisciplinary team.”*

In general, there is no system to implement, monitor or analyze these guidelines and therefore, no accountability. This leads to a haphazard determination of who gets RRT, which ultimately affects the number of patients.

*“No, I have to be honest and say we’ve not audited it. And there’s a few patients who would not be captured, because, for instance, if they call me from outside this hospital, and I realized the 65-year-old, that patient may not necessarily appear as being presented.”*

Non-standardization of the decision-making process essentially means that each institution is allowed to decide on its own who receives RRT and who does not. There is no accountability and number of patients vary considerably depending on the institution, which affects the total number of patients on RRT.

### C: Bureaucracy in public sector

Although the Western Cape guideline attempted to make this process fairer, it may have exacerbated the discrepancy between the number of patients receiving RRT in the public and private sectors. In the private sector, the decision to dialyse is made by the treating doctor alone who has a financial incentive to dialyse the patient. Very rarely do medical insurers deny patients the right to this treatment. As the process is multidisciplinary in the public sector, the decision is made by multiple people, and thus the likelihood of someone objecting to RRT is higher. The process of waiting for the process to occur increases the chance of complications in individual patients, making the likelihood of rejection greater. The decision to provide RRT in the public sector is often made at a single point in time, regardless of whether circumstances may change in the future. In general, no consideration is given to the possibility of a change in a patient's medical or social condition. The net result is patients in the public sector go through an elaborate process to get RRT while those in the private sector are not subjected to any process resulting in the discrepancy.

*“It takes much longer to get a patient on the chronic list in public as there is this whole process we have to go through. Often these patients complicate while awaiting a decision and then they are refused. And there is always that one guy who refuses everybody.”*

*“So, you could argue that there is bias in how we decide (who gets RRT), that someone under 60 (years old would be denied RRT), and the high BMI (body mass index) does not qualify, and also how you interpret, for instance, substance abuse. Should people not be given an opportunity to demonstrate that they can, rehabilitate themselves?”*

In concluding this subtheme, the bureaucratic nature of rationing in the public sector may result in lower number of patients being accepted for RRT. This contributes to the difference in numbers noted between the two sectors.

### D: Profile of patients

The profile of the patients in the public and private sectors is dissimilar. The assumption is that the patients in the public sector tend to be less wealthy and less educated with more social problems, compared to the patients in the private sector being more educated and empowered. More than 50% of the patients in the public sector were denied RRT due to social rather than medical reasons. Thus,

in addition to medical reasons not to receive RRT, patients in the public sector have the added burden of social reasons as a reason for denial of treatment.

Social problems render patients ineligible due to the practicalities inherent in those problems. These include hygiene issues due to poor housing conditions which makes RRT a danger to the patient, inability for a patient to get transport to the hospital for treatment, patients being malnourished and not able to withstand therapy.

*“They majority are turned down because they are unemployed, live too far or are not inherent to medical therapy rather than purely for medical causes. That hasn’t changed which is actually quite sad.”*

Lack of empowerment of patients in the public sector also means that the likelihood of them objecting to being denied RRT is not challenged. The lack of standardized criteria in the public sector also makes it difficult for patients to object. Thus, the most powerless patients are the most vulnerable and have no way of voicing their objection. The outcome of this subtheme is that patients in the public sector are denied RRT because of their social and demographic profile, which affects the total number of patients on RRT in this sector.

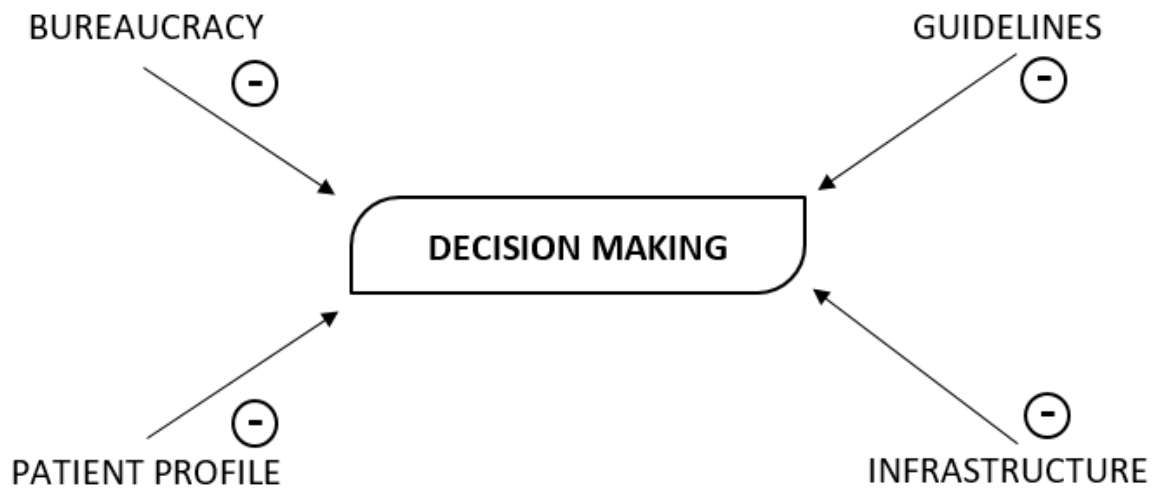
#### E: Infrastructure

There is a lack of infrastructure for RRT in the public sector. This results in patients being denied RRT simply because the infrastructure is not available. For every dialysis machine only 5 patients can be dialysed. Each patients occupies a “slot”. Since there is a finite number of machines, only a limited number of patients can be accommodated. The saturation of “slots” in the public sector denies access to new patients. The availability of infrastructure plays a major role in the decision to provide RRT or not.

*“We would love to dialyze everyone but if the slots are full, they are full”*

The decision-making process involves rationing RRT. This occurs in a non-standardized manner and is highly influenced by the profile of the patient and the available infrastructure. This restricts the number of patients with access to RRT in the public sector. A pictorial representation of the Theme 2 is shown in Figure 8:

*Figure 8: Summary of decision-making theme in public sector*



#### **4.4.1.3 Theme 3: Accessibility to RRT in the public sector**

RRT must be available to patients to receive it. There are many frameworks to assess healthcare access, each with its own advantages and disadvantages (Levesque et al., 2013). Accessibility has been assessed from a provider of healthcare perspective or the actual process of care (Frenk, 1992). As the other themes explored access mainly from a provider perspective, the researcher chose to present this theme from a patient perspective. To do this we used the framework of Levesque in which five dimensions of health access is assessed (Levesque et al., 2013). In this framework, accessibility is investigated from the following perspectives: approachability (identification of health services and ability to access those services), acceptability (conform to patient's needs), availability (size and location of health services) and accommodation, affordability (cost), and appropriateness.

##### A: Approachability

Approachability relates to the fact that people facing health needs can actually identify that some form of services exists, can be reached, and have an impact on the health of the individual. The public generally do not know what kidney services are available until they contract the disease. Advertising of the service through various social or geographical population groups does not occur.

Transparency and information regarding available treatment and services are usually only present in tertiary institutions. Outreach activities are non-existent and do not contribute to making the services more or less approachable. The ability to perceive health needs is determined by factors such as health literacy, knowledge about health and beliefs related to health and sickness. This is generally suboptimal in the public sector.

*“If we look at health literacy as a whole, there is a severe failing. There is no health education in the schools, in the media. How many social influencers do you know that promote health education?”*

The awareness of RRT is even worse.

*“...people are not aware of the services afforded by medicine until they need it. How many lay people are aware what dialysis means let alone whether the service exists.”*

Generally, patients only become aware of RRT services once they get kidney failure. However, as the number of centres in the public sector offering the services is much lower than the private sector, many patients are not offered the service simply because there is no service to offer. Thus, they are unaware of any possible treatment and are often sent home to die.

*“I mean government is going on this whole big thing about diabetes and obesity as a complication of it but they don’t even put renal disease in. Then they are looking at the complications. They are looking at surgical sepsis and cataracts and they’re looking at peripheral neuropathies and I’m thinking like, where is the renal disease?”*

### B: Acceptability

Acceptability relates to cultural and social factors determining the possibility for people to accept the aspects of treatment afforded to them and the judged appropriateness for patients to seek care. Any form of medical therapy needs to be accepted by the patients.

*“RRT has a massive impact on the quality and way of life of patients. HD patients (hemodialysis) spend a minimum of twelve hours a week on a dialysis (machine). Twelve hours!!! This excludes time commuting to and from dialysis, doctor’s appointments, time for procedures, and other interventions. Peritoneal dialysis involves the exchange of bags four times on a daily basis which*

*requires time. The duration of dialysis has a huge impact on the social and occupational life of patients. It decreases the time patients have with their families and in certain instances prevents gainful employment. An enormous “burden of therapy” exists for these patients which is not always acceptable to them.”*

Table 8 summarizes the reasons given by interviewees for reduced acceptability of RRT.

Table 8: Reasons for low acceptability for RRT

Shaming and stigmatisation of patients
Constant fatigue despite therapy
Cosmetic: visible catheters and unsightly veins
Psychological: depression, feelings of unworthiness, burden to family
Religious and cultural beliefs especially with respect to transplantation

Most interviewees thought this was a minor factor and, if given a choice of whether to undergo RRT or not, the overwhelming majority of the patients would have no objection to receiving RRT. Only a negligible number would refuse and this opportunity is easily filled by other patients awaiting therapy.

C: Availability and accommodation

Levesque (2013) defines availability and accommodation as the ability of patients to reach health services both physically and in a timely manner. It is the ability for a health sector to provide health resources and their capacity to produce services. It is the consequence of the characteristics of facilities (e.g., number, concentration, distribution), the contexts in which the facilities function (e.g. urban spread, and transportation system), and of patient characteristics (e.g. social circumstances, duration and flexibility of working hours). It also relates to provider characteristics (e.g. presence of qualified health professionals) and modes of provision of services (e.g. contact procedure, virtual consultations). With respect to RRT, these characteristics are markedly deficient in the public sector.

The number of RRT units in the public sector is restricted to tertiary or academic hospitals which are confined to major cities of major provinces. There are very few RRT centers outside of these institutions in the public sector. Of the nine provinces, only five provinces have RRT units. There are no public healthcare RRT centers in rural areas. This is secondary to multiple reasons including lack of skills and equipment. Healthcare workers are reluctant to move to rural areas mainly for social reasons, for example, their spouses are more likely to have employment in urban areas and access to better schooling for their children.

The decreased number of centers in the public sector is compounded by it being inaccessible to most of the population. Patients usually use public transport which may be unreliable and have higher costs. The time spent in transport as well as on treatment leaves little left for social and occupational activities. In addition, social circumstances may prevent patients from coming to the hospital, for example, nobody to look after children while on treatment. Transport and other social reasons are criteria that is often used to reject patients for RRT.

*“Pretoria has over 30 private dialysis unit scattered throughout the city and only one public center. Private patients are spoilt for choice while the poor public patient is dying to get some service...”*

Peritoneal dialysis (PD) is a form of RRT which can be done at home, thus minimizing some of the issues raised. However, it has been under-utilized. PD requires less equipment and personnel which makes it more amenable for patients for whom ordinarily RRT may not be available. It requires the presence of a hygienic environment at home to prevent infection. This may not be possible for all patients in the public sector because of their home environment. PD also requires monitoring for complications and efficacy of treatment. This is not always possible due to the lack of skilled healthcare workers. Newer modes of monitoring using technology has not been used due to the high start-up cost and user capabilities. Older patients may find it difficult to use technology. Technological infrastructure such as the internet is not readily available in all areas. Devices and data are expensive and contribute to costs. Despite these setbacks, the possibility of benefit to at least some patients have not been explored.

*“.....there is a possibility of PD bridging the gap but that has issues as well...”*

*“We should start looking at novel methods to treat and monitor our patients, but everything has a cost”*

Another aspect of patient accommodation is the ability of patients to have a right in saying what should be afforded or not afforded as treatment on their own bodies. This is known in medical terms as autonomy and it forms one of the cornerstones of medical ethics. It is “the right of competent adults to make informed decisions about their own medical care” (British Medical Association, 2020).

Patients in the public sector lack true autonomy. For autonomy to work, the patient must have sufficient information to decide. This information must then, according to an interviewee, *“be interpreted in conjunction with the patient’s goals, values, family circumstances, experiences, culture and religion. This does not happen in the public sector.”*

The decision to provide RRT is made by individual doctors or a multi-disciplinary panel. This is done independently of the wishes of the patient. Thus, the desires of patients are essentially neglected and the decision to provide RRT made without proper consultation with the patient. Patients are not accommodated. Patients are generally disempowered to fight this injustice.

Another reason for patients needs and desires not being met (accommodation) is a lack of flexibility. In the private sector, due to more resources being available, there is more flexibility for patients. A patient working during the day can be dialysed at night. If no machines are available at night due to saturation, the patient can go to another center where availability is present. Unfortunately, the public sector does not have this capability and popular time slots are filled quickly. A working patient is often unable to dialyse at his preferred time which leaves him vulnerable to being retrenched as it impacts on his hours worked.

The ability of patients to reach RRT physically and in a timely manner is severely hampered due to a lack of resources and the difficulty in accessing the resources. Accommodation is restricted by lack of autonomy, disempowerment and lack of flexibility. The net result is a decrease in the number of patients using RRT in the public sector.

#### D: Affordability

Affordability reflects the economic capacity for people to spend resources and time to use appropriate services. It results from direct prices of services and related expenses in addition to opportunity costs related to loss of income (Levesque et al., 2013).

The cost of RRT is astronomical and prohibitive for many patients. The cost of hemodialysis is approximately R20 000 per month though the average salary for a South African is only R24 000 per month. PD is slightly cheaper with transplantation being the most cost effective in the long term. This makes RRT too expensive for most patients. In the public sector this expense is borne by the State. The public sector patients generally have access to free treatment if they get it. The availability of RRT is restricted by administrators to cut costs. This restricts the number of patients on RRT.

A way to reduce costs internationally has been to prefer PD to hemodialysis (HD). PD is cheaper and many public healthcare centers are now trying to follow a “PD first” policy. Reasons for not offering PD is provided in Table 9. The higher cost of HD and underutilization of PD adds to the increased costs of RRT.

Table 9: Reasons for the lower PD rates

Financial incentive for doctors in private sector to offer HD rather than PD
Lack of hygienic control (thought to be higher in the public sector due to poor social conditions)
Lack of enthusiasm on the part of patients and healthcare workers.
Doubtful patient compliance
Lack of an organized PD program

## E: Appropriateness

Appropriateness explores whether the services provided fulfil the need of the patient. It includes factors such as timing, the amount of care spent in assessing health problems, determining the appropriate treatment and the technical and interpersonal quality of the services provided (Levesque et al., 2013). Measures include adequacy (what services are provided) and quality (the way in which they are provided) of treatment. This in turn has an effect on the quality and duration of the life of the patients.

In the public sector, data measuring appropriateness does not exist. The medical interventions are not always monitored and the response to treatment not always noted.

*“...it would be nice to move to those other measures but doing those evaluations does take time and we don't yet have a dedicated facility for that. So, in the UK where we know that they have the NHS, they have another institute that just does exactly what you're describing, they just do all the evaluations for all interventions whether it's medicines or surgical procedures, whether it's radiological interventions. So that institute is the NICE the National Institute of Clinical Excellence. So they have entire teams of economists and other specialists whose main role is to churn out the most up to date economic and health evaluations for all the interventions that are allowed and that's funded by the NHS, and they then take that and then translate that into clinical guidelines that institutions can use. So, we don't yet have something like that cohesively in SA especially the public sector.”*

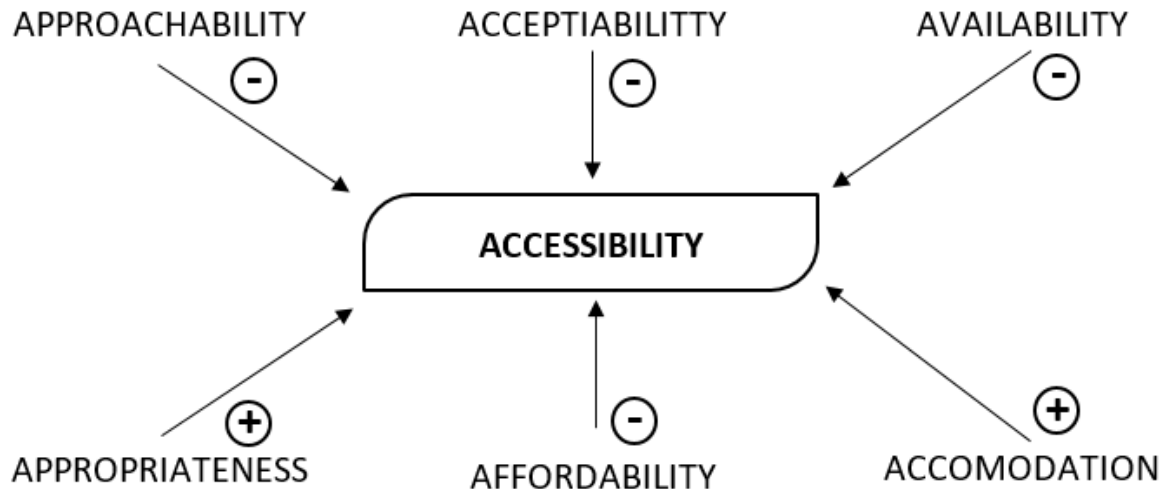
As a result, the outcomes of RRT and the quality of services are not known. There appears to be a differing approach in various parts of the country. Due to a shortage of resources, some institutions choose to service a smaller number of patients but provide good quality care. Other services tend to service more patients but provide lesser quality.

*“I'm just talking about \*\*\*\* (name of institution) There are other people who decided to take on more numbers, more PD numbers. In my own opinion, there are a lot of numbers but they don't do well because they are not followed up as well as they should be because there are not resources to do that. But that is the choices people make and you could make that choice..... Here we dialyse lesser numbers but ensure they get adequate dialysis.”*

Inadequate or inappropriate treatment affects mortality. Whether this has an impact on the number of patients on RRT is still unknown, but theoretically higher mortality should result in lesser numbers. The caveat is, in the public sector, there is always a patient to fill the “slot” of the deceased.

Figure 9 summarizes the accessibility theme. Though approachability, availability/accommodation and appropriateness may decrease the number of patients on RRT, acceptability does not. Affordability has an indirect negative influence on the RRT numbers.

*Figure 9: Summary of accessibility theme in the public sector*



#### **44.1.4 Theme I: Resources in the public sector**

*“It all boils down to one reason. We just don’t have any more resources!!”*

*“Well, I think the reality is the resources are actually reducing. So, the health budget, as I understand it, in at least the last five years is growing, although it grew less than inflation.”*

The most consistent, empathetic and unambiguous cause for the discrepancy is a lack of resources. Interviewees were unanimous that government was not meeting its obligation as set out by the Soobramoney constitutional court judgement which mandated that there must be a “progressive

realization of increasing resources.” For this theme, resources were divided into three main categories or subthemes, namely, financial, equipment and human resources.

#### A: Financial

*“I would like to believe that a lot of the officials and administrators are good people who would like to do better. We just don’t have the money.”*

A lack of finance was assumed to be the single main contributor for rationing dialysis. For ease of understanding, the researcher divided this aspect into funding (provision of funds) and the expenses incurred.

*“So that’s obviously a perfect storm, less total government revenue, but then what little we have buys less.”*

#### Funding in the public healthcare sector

The public health sector receives money from the national treasury. At some hospitals a negligible amount is sometimes received from private donations but this almost never influences RRT. The government has historically reached out to local and international non-governmental organizations but this comes with prescribed conditions which they are opposed to. Extra governmental funding through loans and partnerships is difficult, complex and usually has long term commitments. There is therefore a resistance to go that route. No other significant income is received.

The amount of money allocated to health is determined by the Minister of Finance. This declined annually in real terms and has largely been attributed to a decline in the national economy. Amongst interviewees, there was a lack of knowledge of how this determination occurs. However, there was strong consensus that the amount of money has declined in real terms.

*“I think mainly, our economy is in bad straits. So that simply means there’s less revenue coming to government. We do know that some government revenue and government funds never reaches its intended target, it ends up in certain pockets. So that’s a really big part of it.”*

Money from the treasury is allocated to provincial health departments. A separate allocation for tertiary hospitals is made based on the number of beds available. Since most RRT centers are based

in tertiary hospitals, the budget for RRT in the public sector is dependent on tertiary allocation. A minority of provincial hospitals have RRT, so in practice negligible funding occurs from provincial allocation. Since RRT therapy is expensive, it is not in the interest for provinces to initiate dialysis units as this would deplete their budget.

The money from the treasury is budgeted by either the provincial government or tertiary hospital. Budget allocation should be highly specialised but is not. In contrast to some international countries, there is no separate department within the public health sector to assess economic evaluations. For example, in the United Kingdom, the National Health Service has a dedicated sub-department called the National Institute for Healthcare and Excellence (NICE) which evaluates all medical interventions, decides what is cost-effective, draws up guidelines and then implements recommendations for the costs and allocation of services. In South Africa, there is a dependency on academics to draw up guidelines. The process followed is some advocacy is made by interested groups of a particular disease, followed by epidemiological studies by academics who develop clinical guidelines. These are appraised by administrators and policy makers who allocate funding.

As mentioned previously, most RRT in the public sector occurs in tertiary centers. In tertiary hospitals, allocation of funds differs in each center. In some institutions, there is a central pool of funding and each clinical department submits their requirements, which is analysed and processed by higher structures. In other institutions, each department is given a set budget and they must prioritize how they spend it. Multiple medical disciplines compete for funds and channeling of funds to one discipline means less funding available to others. As HIV has a huge advocacy platform, is more dramatic and has the potential to assist more people at a lower cost, it has historically been allocated a substantial proportion of funds to the detriment of other disciplines.

*“But unfortunately, the roll out of the HIV program came at a huge cost and I think part of the reason that renal services and I’m sure many other services have suffered is because all the money has actually been channeled into HIV. So, the TAC was good for HIV it was actually very bad for the rest of us.”*

In general, the budget allocation within these institutions depends on historical spending to determine future allocation. Historically, huge spending on HIV occurred thus guaranteeing a substantial amount in future. Recently, this has changed to a model in which the availability of

money for each department is dependent on clinical managers motivating for more funds. Competition for funding is fierce and most motivations are centered on urgent repairs needed for an ailing infrastructure. Long-term planning and the creation of new infrastructure is difficult and nonexistent. It is also thought by some doctors interviewed that clinical managers “*lack insight, is far removed from the impact and lack understanding of clinical conditions to make informed decisions.*”

There are no formal processes to evaluate the cost to benefit ratio of health interventions, based on which funding can be determined. They are done haphazardly and fair comparisons between conditions cannot be made. Since RRT is less dramatic in presentation to other diseases and patients lack expertise in advocating for their rights, no advocacy occurs and hence no funding comes forth.

In conclusion, RRT funding in the public sector is dependent on a diminishing source from treasury. It is also subject to competition from other departments, inefficiency and complex bureaucratic procedures. Less funding implies less money available to provide RRT. This would diminish the number of RRT patients.

### Expenses

The second component contributing to the financial resources available for RRT is the costs involved. The major costs for RRT are salaries, equipment and consumables.

### *Salaries*

By far, the highest cost is salaries. RRT is highly specialised and requires multiple expertise such as surgeons, nephrologists, psychologists, and nurses. The Health Professional Council of South Africa (HPCSA) requires that for every dialysis patient treated via HD, three nurses are required. For PD, the ratio is much lower with a team of four nurses can care for 40 patients. The higher the expertise, the higher the cost. Some interviewees questioned whether such a high level of specialisation is really required as there is a trend internationally to offer dialysis in community centres where patients are trained to dialyse each other, thus reducing the cost. No such initiative exists in South Africa.

*“We should be following the Australian model whereby patients dialyse each other at local clinics.”*

Despite the higher number of personnel required for HD and increased costs, the most frequent form of dialysis is HD. The reason for the higher number of HD patients is multifaceted. Doctors are generally more familiar with HD. Training occurs in both modalities but patients on HD attend hospital more frequently and are seen more regularly by training doctors (an HD patient will be seen weekly whereas a PD clinic will be seen once in two or three months). Some patients prefer HD as the procedure is less demanding than PD. Finally, it is more common for patients on PD to move to HD due to medical complications than the reverse. The preference of HD over PD, implies a higher staff complement is required for a given number of patients with a concomitant increase in cost.

The increased cost of salaries occurs in both sectors. There is often a seasonal movement of staff between the two sectors depending on where remuneration is higher at the time. This creates competition between the sectors resulting in increased costs.

#### *Cost of equipment and consumables*

The cost of equipment will be discussed under the subtheme of equipment.

#### Consumables

For both HD and PD, another major expense is the consumables. It was felt that the price of consumables was determined by multinational companies (Big Pharma) whose main aim is to make a profit.

*“If you want an example of local substitution, you should probably go to India, and then you will see how low prices can go for many of these so-called advanced products. If someone could go to the Georgia Institute, and spend time and when they come back and try and provide cheaper products, it may help the State to care for its people.”*

Big Pharma tend to have an oligopoly on RRT consumables through sophisticated mechanisms. Table 10 displays the reasons for this oligopoly.

Table 10: Reasons for oligopoly for the supply of consumables

Inefficiencies of South African Health Products Regulatory Association (SAHPRA) lead to long delays which prevents newer drugs from coming to market.
Large start-up capital needed to produce these consumables.
Complexity in production of consumables such as need for sterility and quality control.
Access to distribution channels is difficult and complex. For example, logistical support for transportation of PD solutions, which is the bulk of the expense for PD.
Brand familiarity of doctors.
Difficulty and cost of marketing new brands.
Lack of advancement of newer products.

In addition to the oligopoly, other facets also contribute to increased cost. Big Pharma does not manufacture the consumables locally and importing these products attract additional costs such as custom duties, transport costs and taxes. The depreciation of the rand over the years has added to the costs. Consumables are also bought individually by each public sector RRT unit. There is no collaboration between different units to purchase in bulk and thus benefit from huge discounts from higher volumes (economies of scale).

*“...is whether we should investigate bulk buying by the state. For instance, why is dialysis, effectively each province and even each hospital competing out there for resources, not necessarily competing but they are each buying individually. There might be a case where we can ask why isn't dialysis products bought centrally which might translated into discounts, I think that is the one thing that could be done, potentially there is a role for local manufacturers because a lot that we use is imported.”*

Newer therapies have increased costs but lowers the costs of previous modes of treatment. In RRT, there has been no significant advances in the type of therapies available and therefore the cost of

treatment has remained consistently high. The few advancements that were made is only available for private sector patients as the public sector is unable to afford these costs. Thus, costs remain high.

The cost of treatment is also controlled by multinational pharmaceutical companies (Big Pharma). Big Pharma has an oligopoly on the consumables needed for RRT and therefore the prices remain high. Any new pharmaceutical treatment must be approved by the South African Health Products Regulatory Authority (SAHPRA). This body is notoriously inefficient and takes a long time to approve new medication. According to one interviewee, *“the average time for approval is two years which is the second longest time in the world.”* The long approval rate means older drugs monopolize the market at higher costs which is borne by the State.

All these reasons essentially add to the costs of RRT. In an environment with limited funding, this would decrease the number of people who would be able to receive RRT.

#### B: Equipment and infrastructure

*“I think what is really striking is that if you look at the number of dialysis units which gives you an idea of the investment that has been made in renal service and perhaps in curative medicine over the past. Since 1994, which is about 25, 30 years, the number of new dialysis units in the country has increased by like 5 or 6 units.”*

The infrastructure of the public sector is old, stagnant and in a state of disrepair. This is affirmed by the fact that over the last three decades only two new RRT centres have been built. The lack of infrastructure is extended to other disciplines curtailing services. As patients often have multiple comorbidities, mortality is high. This may decrease the number of patients on RRT either by these patients dying before they reach ESRD, dying from not receiving RRT or dying from other complications.

Existing equipment in the public sector tends to be more archaic and is used to a greater extent than those in the private sector. This leads to more frequent breakdowns which diminishes their usage. Older and dysfunctional equipment is often not replaced, reducing capacity and increasing costs.

It was felt by interviewees that the process of acquiring equipment such as HD machines in the public sector was filled with bureaucracy to the point where people felt despondent and developed burnout. Some interviewees were of the opinion that the process of acquiring equipment was so complex and exhausting with few successes that the effort required was not justified.

Purchasing of equipment in the public sector is limited to certain providers. This is because of the finite number of vendors available as a result of the tender process. This results in a type of oligopoly wherein vetted providers can charge higher prices. Increased bureaucracy and limited vendors cause inflexibility in the purchasing of equipment. Purchase of these consumables is often laden with an additional mark-up cost which increases the overall cost. A further increase to costs is thought to be corruption with costs inflated to benefit some individuals. Contracts are thought to be drawn with increased costs that includes kickbacks.

There is often duplication of the use of resources which results in wastage. Monitoring the use of resources does not occur. The use of newer equipment or newer technology such as electrical health records does not exist in the public sector. Patients often undergo repetition of the same tests as a result of loss of former records. The optimal usage of resources and equipment is lacking and often there is wastage and repetition.

To summarize, the public sector lacks money to purchase equipment, has increased bureaucracy to acquire new equipment, has increased breakdown with no replacement and often duplication of services with decreased efficiency. This leads to dysfunctional RRT centres with a diminished capacity to provide a service, resulting in a lower number of patients receiving RRT in the public sector.

### C: Human Resources

*“Yeah, definitely more staff because the renal unit consists of myself, and as I say the MD, the ... MD, and one registrar only. Just because I’ve got so few medical officers and, and registrars, so I can only accommodate so much, even though we have these 240 patients.”*

There is a dire shortage of personnel in the public sector. There are multiple reasons why people leave the public sector for multiple reasons.

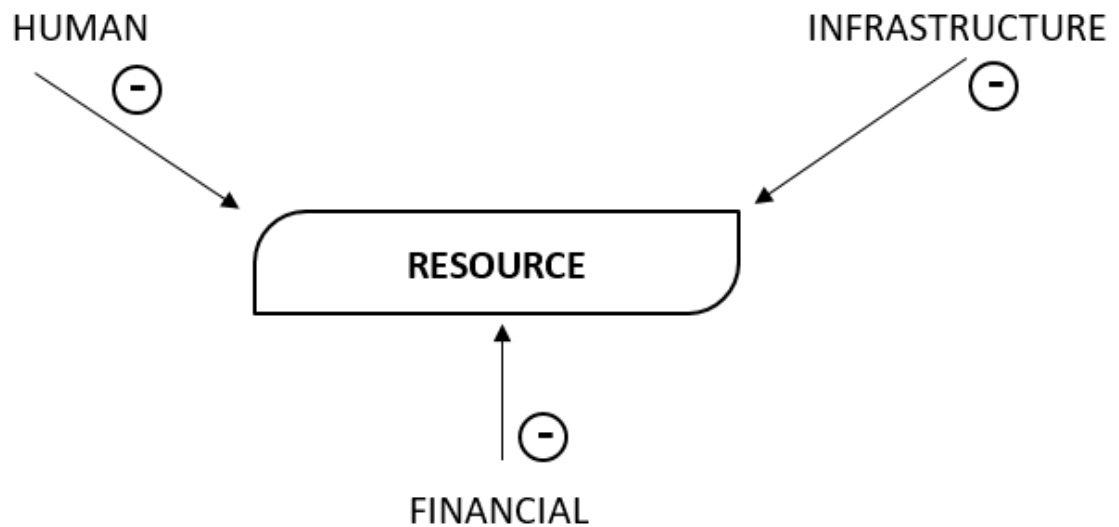
- To lower expenses, the government put a moratorium on the number of people hired. No new hiring of staff occurs and vacancies created by people retiring or leaving are not replaced.
- People leave for the private sector as it is financially more rewarding.
- The working environment is less conducive in the public sector where people are thought to be overwhelmed and exhausted.
- Training of healthcare workers in some public centers are thought to be inadequate as it occurs in tertiary centers and tend to concentrate on tertiary prevention (curing or palliation of disease) rather than primary prevention. Thus, healthcare workers lack the capacity to provide care in other settings. As the government has shifted its emphasis to primary healthcare, skilled workers move to the private sector whose main priority is tertiary care. This makes healthcare workers more comfortable working in the private sector as compared to public sector.
- A proportion of interviewees felt “*management have no clue what is happening on the ground*”. Despite calls for more staff, it was felt their pleas were disregarded.
- Lack of prospects for progression due to affirmative action policies also leads to people leaving the public sector. The net result is a flux of people moving from the public to the private sector creating a shortage which then exacerbates the working environment.

As personnel is the greatest contributor to expenses, various ideas were tried to reduce this cost. This included cutting of salaries, reducing staff components and hiring of cheaper lower skilled workers. This was met with resistance especially by the unions of medical workers. It was felt by some interviewees that key positions within the union were held by highly skilled individuals who “*protected their turf*” preventing retrenchment and hiring of lower skilled workers.

As RRT occurs in mainly tertiary centres, training of new individuals is an incentive for attracting new staff. However, this increases staff turnover as most individuals leave for the private sector once the training is complete. The high turnover of staff impacts on the quality of service provided. As people became more aware they are most likely to leave, as little of the conditions within the public sector will change. The result is a low number of staff who are disillusioned within the sector. Since morale is low, no change occurs to provide improved services both in quantity as well as quality.

In concluding this theme, financial, equipment and infrastructure, and human resources are all suboptimal within the public sector while the public sector has access to more of these resources. This inequality results in a diminished capability of the public sector to increase their number of patients on RRT or provide a quality service. Figure 10 illustrates this theme graphically.

Figure 10: Summary of the resource theme in the public sector



## **4.4.2 ANALYSIS OF OBJECTIVE 2: TO UNDERSTAND HOW RRT OCCURS IN THE PRIVATE SECTOR AND WHAT ARE THE FACTORS THAT DETERMINE THE NUMBERS OF PATIENTS RECEIVING RRT IN THIS SECTOR**

For ease of comparison, the patients in the private sector undergo the same journey as public sector patients, we can conveniently use the same themes.

### **4.4.2.1 Prevalence of kidney disease in the private sector**

Similar to the public sector, the true prevalence of kidney disease in the private sector is not known. However, the degree of prevention differs.

#### **A: Primary Prevention**

Primary prevention in this sector is marginally better than the public sector. Some medical insurers, like the Discovery Vitality program, have wellness programs that promote healthy living with various incentives. The social class of people is thought to be higher in the private sector and information is more readily available through the media and internet. As a result,

*“...they are more likely to lead healthier lifestyles through being more aware of their own risk factors”*

Access to healthier food, exercise options and health literacy may be higher in the private sector and this may reduce the risk profile of this population to kidney disease.

#### **B: Secondary prevention**

The same three categories of secondary prevention discussed under the public sector will be used for this sector, namely, screening and lack of specialist care.

#### **Screening**

In the private sector, *“a financial incentive exists for increased surveillance of patients. It is in the interests of people working in the private sector to conduct screening tests as this makes money for them.”*

The primary care practitioners in the private sector are the general practitioners (GP). They often see their patients on multiple occasions and screening occurs regularly to control their risk factors. Each time a patient is seen, the GP charges a fee and gains financially. Any screening test conducted could be potentially billed and any abnormality found would increase the chances of subsequent visits. The patient's benefit due to the chance of an early diagnosis of kidney failure and commencement of RRT.

In addition to GPs, educational programs regarding health screening are often conducted by pharmaceutical companies and laboratory services as there is a financial incentive to increase the numbers of patients. In addition, the referral to specialist care is easier as there are more specialists in the private sector for fewer patients compared to the public sector.

Screening of patients is more likely to detect kidney diseases. This has the effect of either ameliorating the disease or starting RRT should it be necessary, subsequently, the influence on the number of patients receiving RRT is unknown.

#### Specialist care

Referral to specialist care is much easier in the private sector. Again, a financial benefit for specialist care exists in the private sector. A fear of litigation may also result in more patients being referred. The increase in early referral could potentially increase the number of patients requiring RRT as more sophisticated diagnostic techniques are used. At the same time, optimal treatment of risk factors may delay or ameliorate the need for RRT. This affects the number of patients on RRT. Referral to specialists may also increase the likelihood of commencement of RRT in a subgroup of patients.

Treatment of risk factors and specialist care may prevent the onset and debilitation of other disease conditions. Patients are less likely to die from infection and other cardiovascular complications and therefore live longer. Aging with risk factors increases the likelihood of eventually developing kidney failure. Theoretically, this may increase the number of patients on RRT.

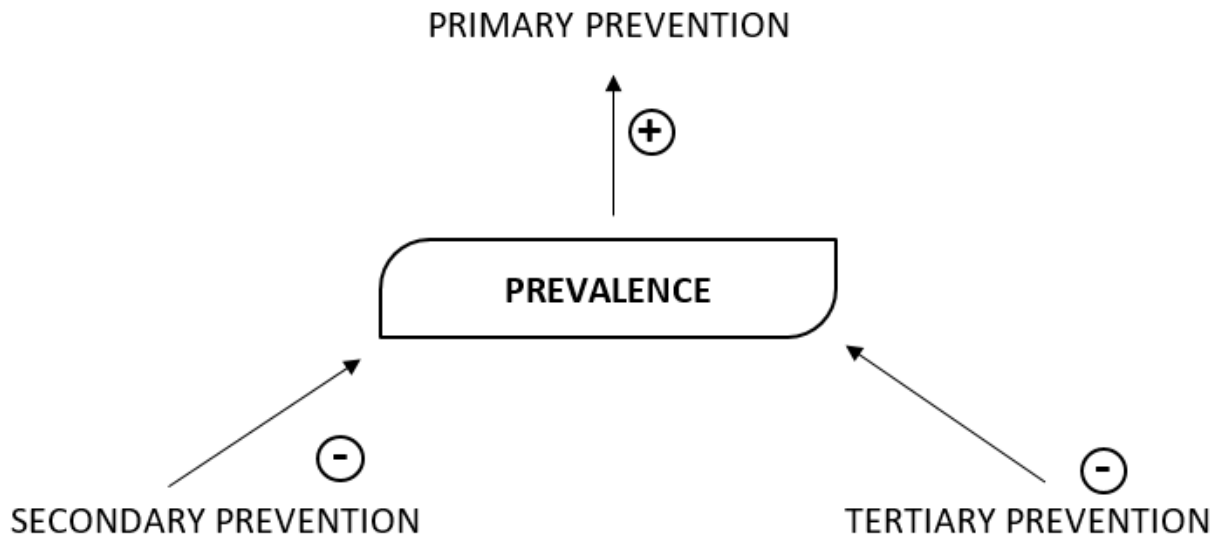
#### C: Tertiary prevention

Once patients are on dialysis, private sector patients have more access to complementary services, such as surgeons and other specialists as well as access to facilities such as intensive care units should they need it. This translates into better prognosis and patients are dialysed longer in the private sector. This may increase the number of patients on RRT.

*“I have a feeling that mortality rates are better in private. It is so much easier to treat complications in private.”*

A summary of the factors affecting prevalence of kidney disease is given in the Figure 11. There is a possibility that risk factors may be lower. The role of secondary prevention is equivocal in raising numbers. Finally, tertiary prevention may increase the number of patients on RRT.

Figure 11: Summary of prevalence theme in the private sector



#### 4.4.2.2 Theme 2: Decision-making in the private sector

Rationing does not occur in the private sector. Everyone who needs RRT in this sector has access. Rationing does not occur due to several reasons. The first is that kidney failure is a prescribed minimum benefit (PMB), a list of medical conditions for which medical insurers are compelled to provide. As a result, no rationing occurs.

*“... it is legislated in the private sector. It is a prescribed minimum benefit, so any medical aid that doesn't adhere to that may face a legal challenge or something like that. So they adhere to that and the patients accessing that service are financially more empowered to follow that through”*

The definition of a PMB condition is open to interpretation. Some medical insurers use the definition that a PMB is a condition for which the state provides. Others use the definition that a PMB is any condition that a state can provide for if they had the resources. This leads to a dilemma of how to ration dialysis in the private sector. Legally, using the definition that a PMB is a condition provided by the public sector compels the insurer to pay for RRT as dialysis is provided by the public sector albeit in a limited capacity. The use of the second definition is also problematic. There are no set criteria which is used universally in the public sector. Therefore, the application of criteria used by the public sector is impossible. To date, there are no medical insurers who have denied dialysis based on criteria used by the State.

*“We definitely anchor like 90% of our PMB definitions to what the state can offer. We are definitely anchored to that. We definitely anchored to what is covered in the state and that is what we will cover in the private sector. Then we starting to deviate around where we have like stuff, where it is obvious clinically. We must cover this as a minimum benefit even if the state is not covering it because of affordability and resource issues and not clinical issues.”*

Another reason for not rationing, is that by their very nature, insurers are companies who provide a guarantee of payment for specified loss, damage or illness in return for a premium. In the case of medical insurers these premiums are paid by healthy individuals for health-related issues. Members who have been paying their premiums would therefore expect the company to pay for RRT should they get kidney failure. Insurers are thus wary of litigation should they refuse. The publicity this may

cause may affect their membership numbers and hence profitability. Therefore, all patients who require RRT in the private sector usually get it unless there are exceptional circumstances.

*“... medical aids may be afraid of getting sued as their members pay a premium for a possible eventuality. The eventuality is the possibility of getting ill. If this eventuality occurs, they have a contractual obligation to pay.”*

A third reason is there is less bureaucracy in determining who gets RRT. The decision to provide RRT is made by the treating physician. As he stands to gain financially, the probability that he would deny RRT is low. The fourth reason is the availability of resources in this sector for dialysis. As resources are available, it is easier for the physician to prescribe RRT. Finally, there are no guidelines to which the treating physician needs to adhere to ration RRT.

The lack of rationing in the private sector means everyone who needs dialysis essentially receives it. This increases the number of patients on RRT.

#### **4.4.2.3 Theme 3: Accessibility to RRT in the private sector**

The same Lévesque (2013) framework was used to describe accessibility in the private sector.

##### A: Approachability

The ability of people to recognize that services exist, can be achieved and have an impact on their health appears more pronounced in this sector. However, similar to the public sector kidney services are generally not known unless the patient is diagnosed with the condition. Advertising of medical services is not allowed by law in South Africa. However, medical services are present throughout the major private hospitals and their visibility and network throughout the country makes the services more accessible. General practitioners are aware of services and communication between them, specialists and the patients make the RRT service more approachable. Health literacy, while still not optimal, may be better compared to the public sector.

*“.... The likelihood of someone getting diagnosed and treated via a renal service is greater in private because of networking of GPs, nephrologists and dialysis units”*

## B: Acceptability

This acceptance of patients to undergo therapy in the private sector was similar to those in the public sector. Most patients would accept the treatment and of the minority who would not accept, the reasons were similar to that of the public sector (See Table 8).

## C: Availability and accommodation

The number and distribution of RRT centers in the private healthcare sector is much greater and therefore private-funded patients have more accessibility to RRT. Most private patients are concentrated within urban areas because of their employment. RRT centers are often in residential areas close to people's homes. Transport is easier and more affordable. Patients generally have access to their own vehicles and are not reliant on public transport facilities. The spread of multiple dialysis units also means patients have a choice to choose which unit is more accessible with shorter distances and lower transport costs. As multiple service providers exist in the private sector, patients have a choice to choose whom they are more comfortable with and competition between these providers increases the quality of service.

## D: Affordability

The cost of RRT is borne by medical insurers as kidney failure in a PMB condition. Therefore, if a member continues to pay his premium, he should be able to afford RRT. The average medical insurance premium is approximately R12 000 for a family of three. The average RRT cost is about R20 000 per month. Hence, paying for medical insurance is in the interest of a member.

*“...that is what they were doing, and we have proof of this, they were colluding with public sector the guys in the nephrology department. Basically, they were getting patients who require dialysis in the public sector, they then took that list of patients – they went door to door to those patients and offered to pay their medical aid premiums for them.”*

While the above is an extreme case of fraudulent activity, public sector patients who are denied RRT in that sector often come for therapy in the private sector. They either pay for the service or join a medical insurance where there is normally a waiting period for a year in which the member continues

to pay premiums but the insurer is exempt from paying for RRT. After the waiting period the insurer starts to pay for RRT. This has led to some of the increase in numbers noted in the private sector.

#### E: Appropriateness

In the private sector, the adequacy of treatment is also not always known. However, it is slightly better than the public sector. Medical insurers are able to determine adequacy of treatment by sophisticated mechanisms using data gathered from claims from patients and doctors. This data is analysed by actuarial scientists in conjunction with clinicians to produce reports on treating doctors thus ensuring a degree of quality control. It is thus in the interest of private doctors to ensure that patients are being treated optimally.

*“I think the dialysis set up run by NRC and Discovery are about the most developed outcome systems, you know, which we have in the country. Obviously, they are based on the experience of providers overseas and Discovery has done it obviously, because dialysis is a major cost driver. But they haven’t been punitive about it. They’ve been sort of educational about it. They send you a report and this is what your patient’s figures are looking like. These are the numbers of patients who are out of target. And so, I think that’s a good start. But I think that needs to be implemented across the board.”*

Thus, the quality of care may be better in the private sector because of enhanced monitoring. This improves the survival rate which may increase the prevalence of patients on RRT.

#### **4.4.2.4 Theme 4: Resources in the private sector**

This theme was analyzed in the same format as public sector resources and is divided into financial, equipment and consumables, and human resources.

#### A: Financial

The source of the funds and expenses will be described.

#### Funding in private sector

In the private sector, the funding model is based on subscriptions paid by members on a monthly basis. Medical insurance companies have actuaries who determine subscription rates. This is

determined by considering past medical expenses, projecting future expenses and predicting medical inflation. Data is collated and premiums calculated by dividing the amount needed by the number of members. Members have an option to pay higher premiums to access more services. Lower premium members would have to pay for some services from their own finances.

*“... we charge members more. In other words, we say to them, the whole pool goes up. Say we are R50 million over or whatever that number is on dialysis. Next year, we need to recover R50 million in total across our 3 million lives. And so, we will charge them each R3 more in the premium for it. Yeah, and it won't only be dialysis that are going up...”*

The allocation of funds is dependent on need. All funds go to a central pool and as members access services, these are billed by providers who pay get paid from this pool. There seems to be more transparency and accountability in the private sector as the costs and number of medical interventions are easily recorded via claims from members and computerized. This data is then amenable to analysis. No such system exists in the public sector. There is no separation of funds within each individual health insurance agency and claims are paid on an on-need basis.

### Expenses

The major costs for RRT in the private sector are the same as the public sector. Salaries is the main contributor followed by consumables and equipment.

### *Salaries*

Salary costs in this sector is similar to the public sector. The costs are market driven and any increase in salary by one sector is followed by migration of workers into that sector. Thus, it is in the interest of each sector to keep salaries marginally close to each other. It therefore has negligible effect on the disparity.

### *Equipment costs*

This will be discussed under the subtheme of equipment.

## *Consumables*

The costs of consumables are should be similar as the public sector except for the following reasons. The first is that a substantial proportion of consumables are manufactured by companies who are direct providers of RRT. This vertical integration is a major cost-saver. Furthermore, these companies are multi-nationals who can derive benefit from economies of scale reducing costs further. The third difference is the competition between these multi-nationals. Independent vendors are not obliged to purchase from vetted vendors in the public sector and this competition may reduce cost. Finally, newer therapies are more amenable to get onto the private healthcare market as opposed to the State. These newer therapies are expensive but reduce the costs of older treatments.

The impact of these cost saving measures on the number of patients on RRT is not known. It is not known whether these cost savings are passed down to the consumer or the increased demand for services keeps costing high. What is certain is that the lower cost increases profitability of these companies and this is an incentive for them to provide more services, resulting in higher numbers in the private sector.

## B: Equipment and infrastructure

In the private sector, equipment is readily available as it is sold by multiple medical equipment companies who ensure sufficient stocks to make a profit. Competition between these companies and the provision of financial loans by the companies itself ensure that the purchase of equipment in private healthcare sector is available and affordable. Manufacturers of dialysis machines have their own RRT centres in the private sector with vertical integration maximizing their profits. Therefore, the cost of equipment is discounted to them. The equipment tends to be newer as there is an incentive to retain patients in each unit. Older equipment would result in patients moving to other centres with a loss of income and profitability. The result is a more efficient service with the latest available equipment with sufficient resources available to service all those who need it. Increased demand in the private sector is readily met by easily available equipment which has to be acquired to derive a profit.

## C: Human Resources

The quality, quantity and spread and multitude of skills in the private sector is greater compared to the public sector. Practitioners are usually self-employed and have an incentive to improve quality. Access to skills is determined by need and practitioners move practice according to market dictates. This provides a spread of skills over the country. Financially, it is more lucrative in the private sector. Working conditions and access to ancillary services is better. Most private companies offering RRT are multinationals with access to skills internationally. Collaboration between centres is easier. All these factors make human resources replete in the private sector.

The disparity between skills in the two sectors contributes to the number of patients treated. Even though the public sector may want to increase the number of centres offering RRT, this may not be possible as the skills required may not be available. This is one of the main reasons given for the paucity of RRT in some provinces as they simply lack the capacity to provide it.

The end result is more patients treated in the private sector with a possible higher quality of service. The higher quality of service could potentially mean patients treated in the private sector live longer and in this way, contribute to the disparity.

#### **4.4.2.5 Theme 5: Transplantation**

The final theme of transplantation will be discussed together as it is usually done as a joint program between the two sectors. Transplant programs are run regionally and affiliated to an academic institution. As not all provinces have an academic institution, not all provinces have a transplant program. Donated organs are shared between the two sectors.

There is a shortage of organs. Reasons for the shortage are listed below:

- Lack of education of the public with respect to transplantation.
- Social, cultural and religious beliefs often prevent donation of organs.
- Previous experiences of dubious practices in the medical fraternity, such as selling of organs, has also led to the public being wary of transplantation.
- The law in South Africa is not fully consistent to increase the number of organs available. Internationally, countries such as Spain have an “opt out” system in which each citizen is

deemed to have given consent for his/her organ unless they specifically declined (opted-out). South Africa does not have such a system.

- South Africa relies solely on altruistic donations which severely restricts the numbers available.
- Healthcare workers are not trained to recognise and counsel potential donors and there is a resultant hesitancy to refer potential organs for the program.

*“I think that government hasn’t bought into transplantation per se and without a very good transplant program you can’t move state patients out of the slots. I think that’s a huge stumbling block and I think there’s been a very deliberate non-engagement at government level around that.”*

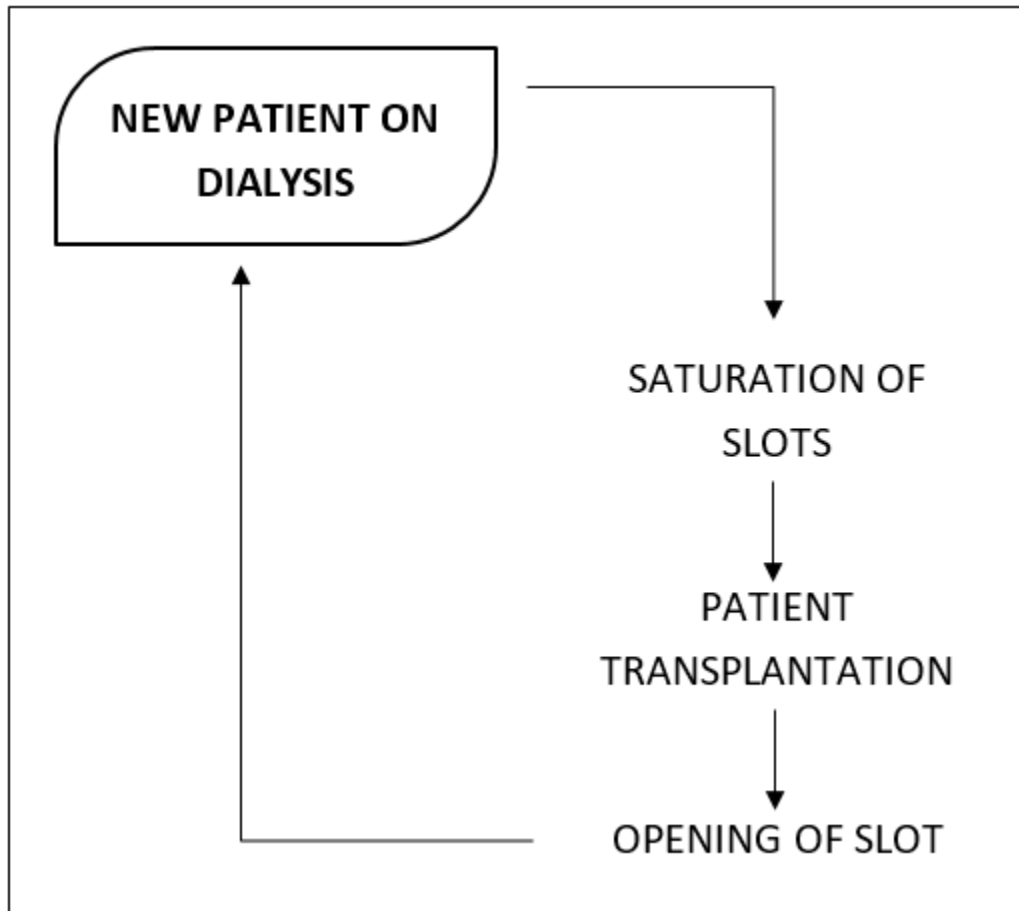
The public sector is more dependent on transplantation to increase RRT numbers. Only patients who are transplantable are offered RRT in the public sector. As there is a fixed number of machines available for RRT, only a limited number of patients are able to receive it (5 per machine). New patients cannot access therapy if someone is already using the machine. Those occupying a machine are said to be occupying a “slot” and the only way to “free up slots” is either transplantation or death of the patient. If transplantation does not occur, these patients “clog up the system” preventing further patients from receiving RRT. Often, public sector patients remain on dialysis for years developing complications which renders them non-transplantable.

*“As patients remain longer on dialysis they become, a certain proportion and I don’t know what that proportion is at the moment, become un-transplantable for whatever reason. For example, say you get a very bad heart and then you are unable to be fit for anesthetic. There are certain number of patients that are already on our program that are not transplantable, they already clogging up a slot, they are holding a slot. We have a proportion of those and in our setting, we don’t actively remove those patients. But the reality is they prevent other patients from accessing dialysis.”*

It is not ethically correct to stop their RRT once they have started and they remain on RRT until their demise preventing others from accessing it. Such patients exist in the private sector. However, as there is always access to new machines, any new patient can be easily accommodated. There is no “saturation of slots” and the impact of transplantation is negligible.

The end result is the shortage of organs prevents new patients from accessing dialysis in the public sector, but it has no effect in private healthcare. The outcome of this may have an effect on the disparity in the two sectors.

Figure 12: Impact of transplantation on RRT in the public sector



**4.4.3: OBJECTIVE 3: COMPARISON OF PUBLIC AND PRIVATE SECTORS TO TRY AND ASCERTAIN REASONS FOR DISPARITY NUMBERS OF PATIENTS ON RRT IN EACH SECTOR**

As the patient in both sectors followed the same journey with kidney failure, the themes are the same, supporting easier comparison. Each theme is discussed by tabulating the comparison, followed by comments.

**A: Theme 1: Prevalence of RRT**

*Table 11: Summary of prevalence in the two sectors*

<b>Subtheme</b>	<b>Component of subtheme</b>	<b>Public sector</b>	<b>Private sector</b>
Primary prevention	Risk factors	++	+
Secondary prevention	Screening and referral	--	+
	Specialist care	-	++
Tertiary Prevention	Prevention of complications	--	++

Note: + denotes the sector has that particular component affecting the sector. - denotes that particular component is absent in the sector. The degree of presence or absence is denoted by the number of + or -.

The risk factors are probably increased in both groups but detection and referral to specialist care is worse in the public sector, and a patient is likely to be diagnosed with kidney failure. Patients receiving RRT are more likely to die in the public sector. The last two factors offset the risk factors thus causing a decrease in the number of patients on RRT in the public sector and an increase in the private sector.

## **B: Theme 2: Decision-making**

*Table 12: Summary of decision-making in the two sectors*

<b>Subtheme</b>	<b>Public Sector</b>	<b>Private Sector</b>
Rationing	+++	--
Guidelines	++	--
Bureaucracy	+	--
Patient profile	++	--
Infrastructure	--	++

The public sector severely rations RRT following guidelines that are old, non-standardized and subject to interpretation. This is a highly bureaucratic process. In addition, the profile of the patients in this sector makes them vulnerable to being rejected in this rationing process. A lack of infrastructure also influences decision-making.

In contrast, rationing does not occur in the public sector. There are no guidelines and bureaucracy in the decision-making process. All patients who need dialysis gets it and infrastructure does not play a role in decision-making.

The net result is a low number of patients in the public sector and higher number in public sector.

### C: Theme 3: Accessibility

*Table 13: Summary of accessibility in the two sectors*

<b>Subtheme</b>	<b>Public Sector</b>	<b>Private Sector</b>
Approachability	--	+
Acceptability	+/-	+/-
Availability and accommodation	--	+
Affordability	(--)	+
Appropriateness	--	++

From Table 13, the public sector has less accessibility than the public sector. In each of the components mentioned, except acceptability, the sector was wanting. Affordability is affected indirectly in this sector as patients do not pay directly for RRT. The high cost of RRT causes administrators to cut services and the number of patients on RRT. Lower accessibility in the public sector translates to lower numbers, while greater accessibility in the private sector allows for a greater number of patients. This drives the disparity further.

### D: Theme 14: Resources

*Table 14: Comparison of resources in the two sectors*

<b>Subtheme</b>	<b>Public Sector</b>	<b>Private Sector</b>
Financial	--	+
Equipment and infrastructure	--	++
Human Resources	---	+++

The private sector has better resources in all three subthemes. This makes it easier to provide RRT. The public sector has severely restricted resources, which limits the number of patients it can accommodate. This further drives the disparity.

**E: Theme 5: Transplantation**

Although described above, for completeness, the role of transplantation is reiterated. Transplanted organs are generally shared between the two sectors in various ways. However, the impact of transplantation on the number of patients on RRT is greater in the public sector. The shortage of organs means that it would affect the public sector more than the private sector. Again, this would drive the disparity.

**4.3.5 Overarching theory:**

The analysis using grounded theory, illustrates that there exist multiple complex causes which disenfranchises the public sector patient. These range from the aetiology of the disease to diagnosing and ultimately treating the condition. Figure 13 illustrates this phenomenon.

*Figure 13: Overarching theory to explain discrepancy of RRT between the two sectors.*

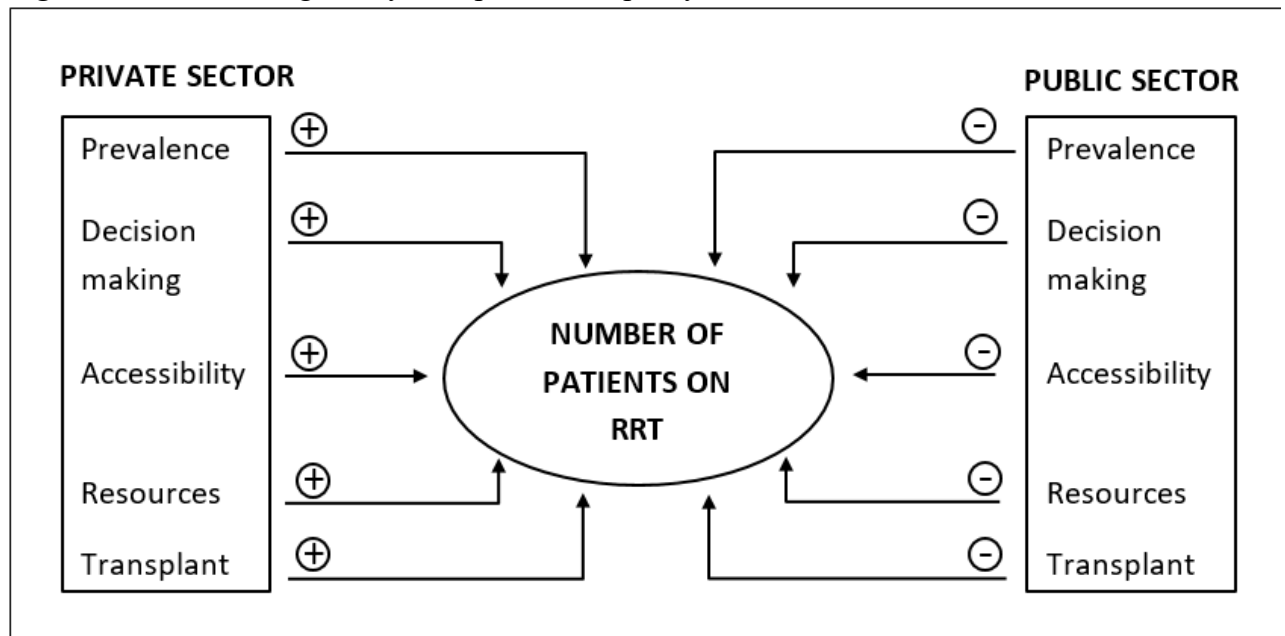


Figure 13 shows that in the private sector, the prevalence of the disease may be higher. The decision-making process does not hinder and may contribute to the increased numbers. There is more accessibility for these patients to treatment and more resources are available. Transplantation does not negatively impact the number of patients on RRT. All these factors contribute to larger numbers of patients in this sector. In contrast, all of these themes negatively impact the private sector resulting in lower number of patients.

#### **4.3.4 CONCLUSION OF ANALYSIS**

The analysis proves that the causative factors for the disparity in RRT between the public and private sectors is not only due to a lack of resources or unfair legislation as stated in literature. The disparity is in effect driven by every step in the journey of patients with kidney disease from the causative factors until they receive RRT. Patients in the public sector are disadvantaged at each step and it has a cumulative effect that not only maintains the disparity, but most likely increases it. Correction of multiple variables are required before there would be an improvement in the imbalance.

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## 12 DISCUSSION

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### **5.1 Introduction**

The objective of this chapter is to discuss the research findings related to understanding the reasons underpinning the disparity seen between the number of patients being treated with RRT in the public and private health sectors. The report considered the current perspectives in literature to explain this disparity and the aim is to expand our understanding of this complicated topic. To accomplish this, grounded theory from a “constructivist” perspective was used to analyse the data collected from interviewing stakeholders in the industry. From this data, themes were deduced which could explain the number of patients being treated in each sector. These themes were compared to identify the reasons for the disparity.

### **5.2. Brief contextual background**

As stated in the literature review, the number of patients with CKD is likely to increase as a result of an increase in risk factors associated with the disease. This outcome would mean more patients would require RRT in future. South Africa has a two-tiered healthcare system, comprising of a private and a public or public sector. The increase in kidney disease should result in an increase in the number of patients requiring RRT. Though this trend has been observed in the private sector, the converse occurred in the public sector where the number have remained static and actually declined in real terms.

The causative factors for this disparity have not been fully investigated. Lack of resources in the public sector has often been quoted as the sole cause although there are no definitive studies proving this. The only other possible causative factor proposed by Eldredge, et al. (2017) is unfair legislation which allows withholding RRT treatment in the public sector but not the private sector. This led to market forces increasing resources within the private but not the public sector with resultant increasing in numbers of patients in the private sector.

Health disparity in general is complex and there are usually complex mechanisms at play that either initiate or perpetuate the problem. The researcher proposed that similar complex mechanisms exist with respect to RRT in the two sectors. By interviewing stakeholders in the industry and using

grounded theory for analysis, the researcher attempted to elucidate these mechanisms. By doing so, these mechanisms could be dealt with, contributing to a more equitable distribution of therapy across the two sectors.

### **5.3. Comparison to other similar studies**

This study is unique in that no other studies have been conducted to specifically elucidate the causes for the disparity in RRT between the two healthcare sectors in South Africa. It is also the first study to use grounded theory to ascertain differences in healthcare in the private and public sectors. It is hoped that this study may form the basis for other studies in the future to confirm or refute the perceptions of healthcare stakeholders in South Africa. Though some of the factors mentioned have been noted by other researchers, none of these have been attributed to cause a disparity. No studies have been done to look at the disparity in a holistic manner.

RRT in the public sector occurs almost exclusively in an academic environment. There are some research investigating RRT in this sector. In contrast, almost no academic activity occurs in the private sector. Hence, minimal research is available for this sector. Therefore, in the empirical interrogation, more comparison to previous studies can be made in the former while little to no data is available for the latter.

### **5.4 Empirical Interrogation**

In this section, the researcher aimed to effectively and efficiently conduct an empirical interrogation of the data. The research findings are discussed in the context of each of the research objectives. Our research objectives were:

- To understand RRT in the public sector and what contributes to the number of patients treated.
- To understand RRT in the private sector and what contributes to the number of patients treated.
- To understand transplantation and its impact on RRT

### **5.4.1 Research objective 1: RRT in the public sector**

In describing this objective, the researcher provided a framework of five themes which mimics the pathway an individual undertakes from acquiring the disease, being diagnosed and finally receiving RRT. The themes are prevalence, decision making, accessibility, resources and transplantation. The last theme will be discussed under the third objective.

#### Theme 1: Prevalence of RRT in the public sector

All respondents were in agreement with past literature that there is a rise in patients with CKD. This is a result of an increase in risk factors for CKD. Though previous literature confirmed the increase in risk factors, few studies investigated the reason for the increase. Our study indicated that participants thought the increase in risk factors was due to social circumstances, lifestyle changes as well as a lack of education. Social circumstances include poor social infrastructure, lack of access to healthy foods and increased social anxiety. Lifestyle changes were difficult to elucidate but increased urbanization in a setting of genetically predisposed individuals may contribute. Finally, lack of education as well as the means to acquire such education may help in increasing numbers.

The increase in risk factors should increase the number of patients with ESRD and the number of patients on RRT. However, patients have to be diagnosed and treated via screening and referral systems. There were practically no screening programs and although attempts were made to initiate some, the logistics and lack of systems proved a stumbling block. This finding is in keeping with other studies (Peer, et al., 2018; Voig, 2021). Referral systems are also inadequate and inefficient. This has been corroborated by Mojaki et al., (2011). The lack of screening and referral has led to a gross underreporting of patients with CKD. This sentiment is supported by Naicker (2019). What this translates to practically is that although there may be a high prevalence of ESRD, many patients are not diagnosed and are therefore not treated. Whether lack of screening and suboptimal referral systems lead to the increased patients with ESRD has not been studied.

This study indicated that the prevalence of ESRD may be lower in the public sector. This is due to the high mortality of these patients. It is well known that the risk factors for CKD is the same as those for cardiovascular diseases, such as strokes and myocardial infarctions. Due to suboptimal treatment, it is possible that patients may die of these complications before actually reaching ESRD.

It is also thought that patients already on RRT may have a poorer prognosis due to complications that are more difficult to treat when compared to the private sector. No studies have investigated this and this is purely observational. More studies need to be done to confirm this possibility.

In concluding this theme, this study suggests that the lower number of patients on RRT seen in the public sector may be possible because of a decreased prevalence and increased mortality. This lower prevalence is not as a result of lower number of patients but rather the suboptimal diagnosis and treatment of patients. Comparison of the actual prevalence of ESRD contributing to numbers of patients being treated has not been reported in literature. This hypothesis has not been proven and should be interrogated with additional studies. Addressing this may facilitate redressing the disparity.

## Theme 2: Decision-making

Once a patient is in need of RRT, a decision is made whether he will receive the therapy or not. This is because of a rationing process in an attempt to use the limited resources effectively. It is well known that rationing occurs in the public sector. However, rationing as a causative factor in actively contributing to the RRT disparity has not been considered. Our study showed that this process may be one of the main contributors for the lower numbers.

As the rationing process is not standardised there exists marked variabilities, not only inter-provincially but also intra-provincially. The rationing process occurs through institutions following certain guidelines which limit the number of patients on RRT. In general, these guidelines consider medical and social factors in determining who receives RRT. Moosa (2016) showed that social factors contributed more to declining RRT than medical factors. Moosa (2014) found that more than 50% of the patients are denied RRT in the public sector, are based on criteria in these guidelines. Though the most frequently used guideline is that of the Western Cape Province, many centres have adapted their own or follow no guideline at all. Reason for the adaptation is not entirely clear as a thorough guideline should be comprehensive and adequate. The transparency of such adaptation is not always known. The guidelines are outdated and the process of instituting new guidelines is difficult. There is no standardisation of the guidelines and doing so may allow for more fairness and insight. No studies have compared the different rationing processes and their possible contribution

in limiting the number of patients on RRT. Though these guidelines are necessary as resources are limited, the actual factors within these guidelines which contribute to increasing or decreasing numbers have not been fully studied.

The decision-making process is filled with bureaucracy in an attempt to be fair and transparent. However, this has led to delays in treatment with many patients dying while waiting for the process to play out. The huge number of people involved in the decision-making also make it more probable that someone will have a reason for denying therapy. The contribution of following bureaucratic channels in limiting numbers of people on RRT have not been studied. The time, logistical process, regulatory framework and administration for such procedures have not been defined and each centre has its own bureaucratic channels. The process of implementation, monitoring and modifying such processes have not been done.

The profile of the patients in the public sector may contribute towards the decision-making process. The type of patients accessing healthcare in the public sector has not been defined. It is assumed that these patients are less wealthy, less educated and less empowered and are therefore not subjected to the same degree of scrutiny. In addition, they may have more co-morbid conditions which would prevent them from accessing RRT. The social conditions of the patients may prevent accessibility. All of these factors play a role in the decision-making process. No study has been done to show the differences in the demographic profile of the patients accessing healthcare in the public sector. Again, our study is more observational and more research should investigate this aspect.

The final subtheme for decision-making was the presence or absence of infrastructure. The lack of infrastructure makes the decision not to dialyse easier. The South African Renal Registry (Davids, et al., 2011-2019) has consistently showed a relationship between the number of patients on RRT and the number of centres available. Having more infrastructure would make the decision to provide RRT easier.

This theme indicated that the number of patients on RRT is highly restricted because of the decision-making process of who is eligible for RRT. This theme was not considered in other studies dealing with disparity. The guidelines guiding such decisions are problematic and may contribute to the disparity. The rationing process itself is bureaucratic and limited by the infrastructure availability.

More studies need to be done to explore the impact of these guidelines and the processes required to implement them.

### Theme 3: Accessibility

Although many frameworks exist to test accessibility, the researcher chose that of Levesque (2013). The reason for this choice is it combines accessibility from both the provider and patient aspect and included a qualitative point of view. Most other frameworks tend to favour one aspect at the expense of others. In this framework, six facets are analysed, namely, approachability, acceptability, availability, accommodation, affordability and appropriateness.

Approachability indicates the ability of a patient to identify that a service exists and has the capability of reaching it. Acceptability points to the aspect of accepting the treatment offered. Availability analyses the resources available to provide treatment. Accommodation ensures that the treatment satisfies the patients' needs. Affordability highlights the cost implication of therapy. Finally, appropriateness focus on whether the treatment is appropriate for the condition of the patient.

Each of these facets were found to be lacking in the public sector. The access to healthcare is a basic human right enshrined within the constitution (South African National Constitutional Assembly, 1996). Interviewees were unanimous that accessibility to healthcare in the public sector was not adequate for various reasons including political, social, financial and environmental. The prospect of universal health coverage (called National Health Insurance – NHI), part of the World Health Organization's Millennium Development Goal of which South Africa is a signatory, polarized participants as to whether it would help increase accessibility or not. Many felt that that the infrastructure was simply not available while others felt this was a first step to achieving health equality.

Reasons given for poor access complied with most previous studies. Poor implementation of policies and lack of accountability was accepted as a reason by the National Planning Commission of the Presidency (South African Department of the Presidency: National Planning Commission, 2012). Govender et al., (2021) found that convenience, affordability and quality of care were the primary determinants of health seeking behaviour. In their study, the majority of patients in the public sector were of the opinion that these aspects could be improved upon. A recent study by Davis et al., (2022)

showed that the majority of patients in the public sector were unaware of therapeutic options available to them for RRT impacting the approachability of patients. Only after multiple interventions, mainly from healthcare professionals, did they agree to a particular therapy. Culture and language continue to detract some of the population from accessing services thus reducing acceptability (Van den berg, 2016), (Wagner & Roda, 2017). Malakoane et al., (2020) showed that the availability of health services in the Free State public sector was severely restricted by staff shortages, financial shortages, staff deficits and fragmentation of services. All these studies were done on general patients and were not confined to kidney patients. However, they agree with our results that approachability, acceptability, availability and appropriateness of care were hindering accessibility to health care and may be a reason for low number of patients in this sector.

Our participants also hinted at a possibility of decreased accommodation and affordability. Surprisingly, this has not been shown in other studies. Redda & Suriylal (2020) showed that the majority of patients in the public sector were very satisfied with the care they received. These findings were also found by Maseko & Harris (2018) and Jacobsen & Tahumi (2014). However, these studies were conducted on a generalized patient group and were not specific to kidney patients. Whether this specifically applies to kidney patients will require more studies. Affordability is difficult to assess in the public sector as the service is usually free. The restrictions which affordability places on accessibility is made by management structures. Patients as well as direct healthcare givers are not usually aware of the costs involved and therefore, in the public sector, it may be difficult to obtain an opinion.

This theme shows that accessibility to RRT is a major contributor to the low number of patients in the public sector. Though previous studies explored the individual aspects of accessibility of healthcare in South Africa, there were no studies that investigated it holistically or studied it from a recognized framework. The reasons for decreased accessibility are complex and need to be addressed to ensure future health equity. There is a possibility that kidney patients have unique issues which renders them dissatisfied with the health service they receive compared to other services in the public sector, which also requires further investigation.

#### Theme 4: Resources

Lack of resources within the public sector was the most frequent theme mentioned by participants. Most interviewees were aware of the Soobramoney judgement in the constitutional court and were of the view that there is no attempt of “progressive realisation” of resources by the State. This is in keeping with views expressed by Elderidge et al. (2016).

Surprisingly, not many articles focussed on the current funding model of the State and its efficacy. The public sector currently functions according to the Beveridge model with tax funds used by the State to fund healthcare (Vera, 2020). The healthcare provider is in institutions owned by the State. This has the advantage of providing health services to all who need it. However, there are two main disadvantages. Firstly, the State is dependent on taxes for its revenue and in a country with dwindling taxpayers this could be problematic. The second is overutilization of services. Since the service is free, there may be a potential for wastage. The only way of reducing costs is to reduce the number of services provided and one of the first service to reduce is RRT. Whether this is truly the case has not been studied.

Funding in other countries uses different models such as the Bismark model, National Health Insurance and the out-of-pocket model (Vera, 2020). South Africa is currently undergoing changes to the health insurance model with the government acting as a single payer for health services, but the providers of that service may not necessarily be employed by the State. Participants in this study were divided whether this is an adequate solution as the country is unique, with its own health issues.

The perception of the participants that government health expenditure has decreased is not in keeping with the statistics. Government health expenditure has increased consistently since 1995 (Blecher, et al., 2021). Nominal expenditure increased from R18.7 billion to R227.7 billion in 2020. This is equivalent to an average of 4.15 % increase in real terms. The per capita health expenditure increased from R2200 to R3700 (68% increase over 25 years). This increase is obviously not perceived by workers on the ground. The question of where the money is spent becomes quite pertinent. The roll out of the HIV program has contributed substantially. Currently it consumes about 10% of the total health budget. This has led to the diversion of funds from other health services including RRT, which was acknowledged by some interviewees.

Salaries were the biggest contributor to costs. The reason for this, as mentioned by interviewees, was the high remuneration required for highly skilled personnel. This is supported by the treasury report when a specific increase in salaries, the occupational specific dispensation (OSD), was introduced in 2012 to try and keep skilled workers. Personnel numbers grew from 228 729 in 2005 to 309 367 (3.5%) in 2015. The average salary increased from R201 285 in 2005 to R312 598 in 2016 (55%), an increase above the consumer price index (Blecher et al., 2021). The increase in number and cost was thought to put a strain on the health finance. As a result, measures were put in place to curb spending on health personnel. This resulted in the “freezing” of posts, non-hiring of new personnel and the possible perception of an increased workload experienced by our participants.

Consumables and medications also contribute significantly. The public sector has managed to control this remarkably and it only contributes 8% of the total health expenditure. This is in comparison to 20% of other Organization for Economic Cooperation and Development countries (OECD – group of 37 countries with democracies and market-based economies that collaborate to develop policies) and 15.5% of the private sector (Council of Medical Schemes, 2016). Reasons given for such success is the central procurement of medication, treatment protocols, improved international price benchmarking and price negotiation strategies (Blecher et al., 2021). Interestingly, these strategies have never been used in the renal industry as borne out by the stakeholders interviewed and the reasons given to curb costs are the exact reasons why the costs are so high. This has resulted in the oligopoly seen today. It appears that priority is given to some conditions at the expense of others and no formal policies and implementation processes are at hand to ensure uniform standards. Application of these policies to the renal sector may reduce cost and increase the number of patients on RRT. The reasons given for the oligopoly in this study has never been fully interrogated. Globally, oligopoly is assumed as a result of the high cost of research and development, patents as well as mergers and acquisition (Spitz & Wickham, 2012). The reluctance of pharmaceutical companies to enter certain markets decreases competition and may play a role in the formation of oligopolies by other pharmaceutical companies operating within those regions. Again, this has not been tested within the RRT market in South Africa.

The reduction in the infrastructure noted in this study has also been shown in other reports (National Treasury Report, 2016). This reduction may be a result of shifting priorities with a shift of policies from tertiary care to primary healthcare. Primary healthcare expenditure in local services increased

from 35.1% in 1994 of the total budget to 47.1% in 2020 (Blecher, 2021). Despite the budget increase, the success of this has never been studied. The participants in this study did not know of any primary health care program attributable to non-communicable diseases. Most of the funding shift to primary healthcare is a result of the HIV program (Blecher, 2021) and it may be worthwhile leveraging the systems from this program to include other conditions as well. The reduction in infrastructure has notably been felt with the static number of RRT centres in the public sector over the last three decades. The possible deficiencies in the primary health program together with a lack of infrastructure to take on new patients may be a contributor to lesser numbers. An important subtheme mentioned by participants was the bureaucracy burden to acquire new equipment. No other studies have shown this and proving this may be difficult due to multiple different processes in the different provincial health systems.

The final component of resources coded was human capital. The underlying intimation was that there is a lack of skilled personnel with a flux into the private sector and to other countries. This is in keeping with Van Ryneveld et al. (2020) who studied human resources in this sector for the last 25 years. She noted that the *“country continues to face major problems of affordability, availability, distribution and management of its health workforce.”* As noted earlier, the government grappled with high costs related to salaries with both an increase in the number of people hired as well as the cost to hire them. To address this, the government cut down posts. From a peak of 314 636 in 2013 the number has since declined by 0.5% each year (National Treasury, 2016). Though the number of generalized healthcare workers have increased, highly skilled specialized workers have decreased. Furthermore, there has been a decline in the number of filled post of 0.5% per year since 2013 (Blecher, 2021). This is evidenced by this study’s finding that there is a lack of skilled workers in the public sector. This study noted several possible reasons for the migration of workers from the public to private sectors. No studies have been done to ascertain the causes and it would be interesting to know if these are true. Working conditions in the public sector are poor with high levels of dissatisfaction, burnout and psychological stress (Manyisa, 2016). A comparison with the private sector has not been done. The perception that training of healthcare workers is geared toward tertiary care and therefore health personnel may be more comfortable working in this setting has not been confirmed. Similarly, the effect of affirmative action and unions on human health resources have not been studied.

This was the most empathetic theme discussed by participants. Many of the subthemes were confirmed by other studies and some require substantial investigations to verify its authenticity. The perception of lack of resources may be a problem especially with the distribution and administration of resources. Health quality indicators are non-existent and therefore it is difficult to ascertain the best use of our resources. However, it is clearly evident that this theme contributes greatly to the disparity seen in RRT in the public and private sectors.

#### **5.4.2 Research Objective 2: RRT in private sector**

In researching this sector, the researcher found that factors leading to RRT, conducive to and adverse to RRT, were similar to that in the public sector and was able to provide the same themes. In other words, the journey to getting RRT is the same in both the public and private sector and hence the themes are the same. This made comparison of the factors much easier. The following section discusses the themes related to RRT in the private sector.

##### Theme 1: Prevalence of RRT in private healthcare sector

The prevalence of a disease is related to the risk factors associated with the disease, the likelihood of detecting the disease, the effectiveness of its treatment and the mortality associated with the disease. Similar to the public sector, the true prevalence of CKD is unknown. Dennison et al., (2007) showed a differential in the risk factors of non-communicable diseases, including those related to kidney failure. The study compared similar demographic data of patients receiving health care in the public and private sectors in Cape Town. They indicated that there was a higher prevalence of hypertension and diabetes with poorer control in the public sector, compared with a genetic disposition towards non-communicable disease and obesity in the private sector. There were no differences in the two groups in terms of lipid abnormalities and smoking. Physical activity was more pronounced in the private healthcare group and excessive alcohol use greater in the public sector group. The current study highlighted that the general risk profile may be similar or even lower in the private healthcare group. The participants did not categorize the different risk factors. The relative role of each factor in causing kidney failure is unknown and needs to be investigated.

Treatment of these risk factors are greater in the private healthcare group. This was shown in the same study by Dennison et al., (2007) and was the predominant opinion in our study. The

effectiveness of treatment is also greater. El-Sayed et al., (2015) in a study done in the Netherlands showed that medical insurance was associated with higher treatment likelihood and hence lesser complications of diseases. Whether this is true in South Africa would require further investigations. Discovery Insurance (South African Insurance company) runs a health promotion program called Vitality Health which encourages members to undergo primary health care tests and healthy living. Patel et al., (2010) showed that compliance with the program resulted in fewer health problems and lower healthcare costs.

The interviewees in the current study indicated that screening for kidney disease and referral to specialist care was better in the private sector. This is purely observational and no data supports this. The bureaucracy associated with referral in both sectors was not explored in this study.

The mortality rate of patients receiving RRT in South Africa are comparable to first world countries (Jardine et al., 2020), which is higher than patients not receiving therapy at all. Our participants were of the opinion that mortality may be lower in the private sector due to the ability and resources to treat complications in these patients. No study has done this comparison and the validity of this argument remains to be proven.

In concluding this theme's discussion, our participants were of the opinion that in the private sector, the risk factors leading to kidney disease may be lower, treatment of these risk factors and the detection of kidney disease may be better and the mortality of patients may be lower. This may lead to the higher number noted. Literature supports this statement showing that although risk factors are not homogenous, treatment and detection of kidney diseases may result in lower mortalities.

## Theme 2: Decision-making

All patients who require RRT and are not on the lowest option of medical insurance will receive RRT. Thus, the decision-making process to deny a person RRT does not exist in the private sector, and no rationing occurs. The reason given for this non-rationing process is that kidney failure is a component of the prescribed minimum benefits (PMB) - a set of conditions which necessitates treatment by law. This non-rationing process has increased the numbers of patients on RRT according to this study. This was the principal reason given by Etheridge et al., (2016) for the disparity.

The impact of PMB in the treatment of different disease entities is difficult to quantify. Apart from the Etheridge article regarding PMB and kidney disease, no other disease entity as a PMB or the impact of PMB on any disease has been studied. It should be noted that the payments for PMB conditions is priced into the premium members of a medical insurance pay. Anecdotally, it has been claimed by some interviewees that RRT has the highest individual cost compared to any other conditions and medical insurers may be looking for an opportunity to reduce these costs. The researcher could not find any evidence of this. What is known is that the greatest proportion of PMB claims by value is consumed by obstetrics-neonatal, conditions followed by cardiac and gastrointestinal conditions (Fish et al., 2002). This is probably due to the large volumes of patients seen in these specialities. It appears that by total value, the medical insurers are still able to afford RRT and hence the reason for not restricting this service.

Rationing of services can occur at four levels, namely, health care policy makers, health managers, health care providers and patients (Kellidar, 2017). None of these levels threaten access to RRT resources in the private sector and the decision to ration treatment is unlikely in the foreseeable future.

### Theme 3: Accessibility

The researcher investigated accessibility of healthcare services using the same framework as that used to analyse the public sector, the Lévesque framework. However, data in the private sector is lacking and more investigations is required.

The first subtheme of accessibility is approachability or health literacy. The participants indicated that this subtheme would be better in the private sector. Only a few studies have been done to compare the health literacy rate in this sector and none to compare the two sectors. Internationally, health literacy and the ability to seek assistance is limited by low income, immigration, ethnicity and level of education (Greenhalgh, 2015). Gordon et al., (2020) found that the wealthy have a greater desire for healthcare compared to the poor, who tend to postpone care for various reasons. It is probable that these factors are less likely to play a role in the private sector and as a result patients are able to identify when they need help and have the means to seek it. Again, this needs to be proven by more studies.

The second subtheme is acceptability. In general, South Africans have a high level of acceptability of treatment. In a study by Burger & Christian (2018), general acceptability was 10%. However, they point out that this is highly dependent on the availability and affordability of providers. Studies of acceptability of treatment in the private sector has not been done. Whether this subtheme has contributed to the disparity cannot be accurately assessed.

The third category of the Lévesque framework is availability or resources that are available. This will be discussed more fully in the next theme.

The fourth subtheme is affordability. South Africa's two-tiered health system divides the population into those who can afford healthcare and those who cannot. The former tends to have medical insurance who pay for RRT, and affordability is usually not an issue provided a patient has medical insurance. It is conceivable that cost is not an issue for individuals with medical insurance. The affordability of health insurance was beyond the scope of this study.

The last subtheme is appropriateness. The measure of appropriateness of RRT is difficult as there are multiple variables involved. Quality of life measures, mortality rates, degree of morbidity, clinical effectiveness of the treatment all have shortcomings in determining the appropriateness of treatment. Few studies have been done, especially in the private sector. The notion of over-servicing of health services in the private sector has not been proven. Contrary to popular belief, in international studies, the disadvantaged social classes actually have higher rates of usage of health services (Brameld & Holman, 2015). The reasons are complex, including poorer state of health, later detection rates of disease, greater complication rates, multiple admissions and lack of oversight by funders. Whether over-servicing occurs with RRT in the private sector is unknown. If it does occur, the extent of over-servicing would not wholly account for the discrepancy in numbers and it is more likely that multiple factors contribute to this.

#### Theme 4: Resources

There is no doubt that the private sector has more resources available. In terms of financial resources, the budget for both sectors is about the same, though the private sector only services a quarter of the population. The funding model of the private sector ensures that money will always be available. Any shortfall of funds is easily met by increasing premiums. This has been proven by the fact that

since the inception of medical insurance in the country, the premiums have increased consistently above the consumer price index. This is in keeping with the findings of this study.

This study also found that human resources are more prevalent in this sector, especially skilled labour, as supported by multiple studies. Kumashie et al., (2021) found that the number of nephrologists in South Africa is 2.5 per million people which is substantially less than developed countries with 20 to 25 per million. Africa has 3.64 per million. The study showed that nephrologists in the private sector is 8.1 per million and in the public 1.3 per million. Similar studies with other healthcare workers indicated the same trend of a higher density in the private sector (Dell et al., 2018), (Heunis et al., 2019), (Scribane & Bhagwanjee, 2007). Multiple reasons have been provided for this. Some of these reasons for example greater job satisfaction (Pillay, 2009), financial advancement and working conditions (George, et al., 2013) are supported in literature. Other reasons for the migration to the private sector, such as lack of career development, affirmative action policies still need to be studied. The number of healthcare workers may improve the quality of healthcare resulting in lower mortality which may increase the prevalence of patients receiving RRT.

The infrastructure for RRT is superior in this sector. There are more RRT centres and the distribution of these centres occurs over a wider area. This has been consistently been shown by data in the South African Renal Registry (Davids, et al., 2019). The process of providing infrastructure and equipment is market driven. The number, quality, technological advancement and maintenance of RRT equipment is also superior in the private sector. There are no studies to confirm this. However, intensive care units between the two sectors are designed better with more advanced equipment in this sector (Mahomed, et al., 2017). Whether this is confined to the intensive care units or can be extrapolated to equipment generally needs to be further interrogated. The cost of consumables and the savings due to vertical integration has not been explored. Whether this is true needs to be fully investigated.

#### Theme 5: Transplantation

Transplantation was considered as a separate theme as the program is often run jointly between the two sectors. There is a sharing of resources not only from an organ perspective, but often human resources as well. Legally, unlike other forms of RRT, both sectors are subjected to the same rules.

Both sectors struggle in terms of the number of transplants and the main obstacle is a shortage of organs for transplantation.

In the current study, a number of reasons have been highlighted for this shortage. Most of these reasons have been corroborated by others. Etheredge (2019) stated in an opinion piece that the shortage of organs was multifactorial and included religious and cultural hesitation, legal inadequacies and public suspicion of the donor process. Thomson (2017) stated that the main reason for a lack of organs is a lack of education. Du Toit et al., (2020) showed that the rate of consent by the families of deceased patients to allow deceased organs to be donated had declined over the last 10 years. Reasons for this decline has not been investigated.

However, some opinions in this study were contrary to selected literature findings. The role of legislation has not been shown to impact transplantation. Some of this study's participants were of the view that legislation should be changed that all citizens' organs are available for donation unless a person specifically declines and states this intention. This is the so-called "opt-out" approach, which is practiced in some countries. South Africa practices an "opt-in" approach whereby an organ is only used if explicit permission is given to use it. Etheredge, et al. (2017) showed in her paper that a hard "opt-out" approach may not be the most practical or ethical and a compromise of a soft-in approach and mandatory physician referral may be more beneficial. Another reason in this study was hesitancy for the referral of potential transplantable organs to transplant programs. This was also not supported by the literature. Crymble et al., (2017) showed that contrary to perception, there is a willingness in healthcare workers to refer organs when requested to do so.

Transplantation plays a major role in the number of patients on RRT in the public sector. Patients are only accepted for RRT in this sector if they are eligible for transplantation. In other words, patients who are not eligible to transplantation are not offered RRT. The ability to receive a transplant is not a criterion for acceptance in the private sector. This difference has contributed significantly to the disparity. Etheredge & Paget (2014) argued that this principle was ethically acceptable and is required to improved management of resources in this sector. Patients who are not suitable for transplantation are included in the number of patients receiving RRT in the private but not in the public sector.

The sharing of organs by the two sectors necessarily means that there is an uneven distribution of resources as the public sector is much larger. Although there were slightly more patients receiving transplants in the public sector, Moosa (2019) showed that the number of transplants in the public sector averaged 4.8 per million people between 1991 and 2015. In the same period the private sector averaged 15.5 per million people. These numbers may be influenced by the number of live versus cadaveric donations as it is only the latter that is shared between the sectors. Of the total number of transplants that occur in South Africa, 75% occurs in two main centres. In the one centre, cadaveric donations dominate, and in the other living donations. A direct comparison of the two types of donation is difficult. Overall, there has been a slight preponderance of cadaveric donations over the last 25 years but this trend may be reversing (Moosa, 2019). Muller et al., (2015) state that living donations are not actively pursued in the public sector due to a lack of resources. The influence of the type of donation in each sector remains to be identified.

The impact of transplantation on the two sectors was never studied. A key subtheme in this study was the reliance of the public sector on transplantation to increase their numbers. This reliance needs to be further interrogated, as does the mortality rate related to transplantation in the two sectors.

In summarising this theme, the main barrier to transplantation is a lack of organs. The reasons for this are multiple and generally apply to both sectors. The number of organs is not shared equally in the two sectors, when corrected for the population. More studies are needed to fully understand the impact of transplantation on RRT.

### **5.4.3 Research Objective 3: Comparison of Public and Private sectors**

Few studies focussed on a direct comparison between the two sectors. The prevalence of CKD and the contributing factors in each sector has never been studied. This is possibly the first study proposing that there may be a disparity in the number of people reaching ESRD in each sector and this needs to be verified. The effect of prevalence as a cause for the disparity has never been considered and needs to be investigated more fully.

The variables affecting the decision-making of who receives RRT has never been considered. The rationing process and its impact on the numbers has been documented by Moosa et al., (2016). The impact of the guidelines used for rationing, the degree to which it is utilised and the monitoring of its effectiveness is not known. A comparison of the decision-making process and the related variables between the two sectors has not been done. This study gives some indication of the variables that may be involved, but this needs to be investigated more fully.

A major finding in this study is the role of accessibility to healthcare as a potential contributor to the disparity. No study using the Lévesque framework has been done to ascertain what impact accessibility has in providing a comprehensive health service. Each subtheme has the potential to be studied to confirm whether the observational data noted in this study is true or not. Though some of these components have been studied in the public health system, more needs to be done in the private sector. A comparison of accessibility between the two sectors would also facilitate defining the conditions that predispose to healthcare delivery.

The lack of resources has been mentioned in literature as a causative factor for the disparity. The main variable has been a lack of financial resources. An actual comparison of the funding models and costs of RRT for the two sectors has not been done. This study added a lack of human resources as well infrastructure and equipment as further contributors. A differential in human health resources between the two health sectors as a collective entity has been found (van Reinefeld et al., 2020). However, a specific comparison in the renal sector has not been done. Measurement of infrastructural and equipment resources can be gained from the South African Renal Registry (Davids et al., 2022). The question of this being a causative factor in the disparity or as a result of the disparity is not known. The quality of resources in terms of all three subthemes needs further evaluation. A direct comparison between all three components must be done to truly appreciate the impact on RRT delivery.

Finally, the role of transplantation on the number of patients treated in the public healthcare sector has been mentioned (Fabian & Etheredge, 2017). Reasons for the shortage of organs has not been fully probed. The role of sharing of organs and the numbers contributed by each sector needs to be fully considered as it has an impact on RRT.

To conclude, this was a qualitative study that investigated the causes for the disparity between the two healthcare sectors in South Africa. The study found that the causes are multiple and layered and the disparity is most likely cumulative. More studies are required to confirm or refute some of the data presented. Corrective measures to decrease the disparity would imply interventions at multiple levels. However, these interventions would save lives, thus providing a fairer and more just healthcare system.

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## 6 SUMMARY, CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

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### **6.1 Summary and conclusion**

There is an increase in the number of people with kidney disease in South Africa and this is likely to continue into the future. This escalation is due to the rise in number of people with risk factors associated with kidney disease. The increase in kidney disease will result in an increasing number of people requiring RRT.

Presently, South Africa has a two-tiered healthcare system consisting of a public and private sector. The number of people receiving RRT differs markedly between the two sectors, with more patients in the private sector. Currently, the reasons given for this disparity is a lack of financial resources in the public sector and an unjust legislation mandating therapy in the private sector but allowing the public sector to deny treatment. The researcher was of the opinion that the reason for this disparity is much more complex and multiple other reasons may exist. This was informed by a review of health disparity in general. This research investigated the reasons using grounded theory. The researcher posed three research questions. What contributes to the number of patients receiving RRT in the public sector? What contributes to the number of patients receiving RRT in the private sector? How does transplantation affect these numbers? By answering these questions and understanding these reasons, it is hoped that a more equitable playing field may be achieved.

The study generated five main themes to account for this disparity, each with several subthemes. The first theme may be a difference in the prevalence of kidney disease in the two sectors. This theme was not considered previously as a possible cause for the disparity. Though it was assumed that the number of people requiring RRT in the two sectors may be similar, there may actually be a difference with a larger prevalence in the private sector. This difference may partially explain the disparity. However, more studies need to be done to prove this.

The second theme is related to decision-making. This is the process of deciding whether a patient would receive RRT, which has not been considered previously. The decision-making process is markedly different between the two sectors, with the public sector using a highly bureaucratic, non-

standardized process to ration dialysis. This does not occur in the public sector. This process may contribute to the disparity, but requires additional investigation.

The third theme was the accessibility of RRT. This had never been considered previously. This research used the Lévesque framework to better understand the accessibility issues RRT patients may have. There were deficiencies in each of the subcategories consisting of approachability, acceptability, affordability and appropriateness in the public sector, however, there appeared to be more accessibility in the private sector. This may further contribute to the disparity.

The fourth theme was resources. Literature concentrates on financial resources, however, this research showed that there is a broader deficiency involving not only financial but also human, infrastructure and equipment in the public sector. A comparison of the number of resources in the above categories in each sector has never been done. The lack of resources may explain the difference in the numbers in the two sectors.

The final theme focussed transplantation. This theme showed that the lack of organs available for transplantation was acutely felt in both sectors. Reasons for this shortage was similar in both sectors. However, there was more reliance of transplantation to increase the number in the public sector. This may also impact the number of patients receiving RRT in each sector.

In conclusion, the disparity that exists between the number of people receiving RRT in the public and private sector is not only confined to a lack of resources and legislation. There are much more complex issues at play and resolving the disparity would need addressing of all of the components to achieve a more just and equitable distribution.

## **6.2 Limitation of the study**

This study has several limitations:

- The study is highly subjective and is dependent on the views of its participants. These views, although informed by experience within the industry, may be biased. The analysis and conclusions require further investigation to confirm the veracity of the findings.
- As the study used grounded theory, purposeful sampling was done to attain participants. Although every attempt was made to interview a wide variety of stakeholders an element of self-selective bias may be present.
- The sample size was relatively small. This may be due to the limited number of stakeholders in the industry, as well as the COVID-19 pandemic.
- The COVID-19 pandemic also posed a challenge. Many possible interviewees were not available and the interview process had to be done remotely using video conferencing platforms. This may have affected nuances which could have been obtained with more personal interviews.
- The COVID-19 pandemic may also have affected people's views and mindset. As all interviewees are related to the healthcare profession, the stress and workload of the pandemic may have affected their views.
- The time limit to complete the dissertation may also have limited the study. Although theoretical saturation was reached, there may be a possibility that other factors may have been missed.
- The results and conclusions of this study is restricted to RRT in South Africa. Extrapolation of this study cannot be made to other areas.

### **6.3 Recommendations**

This study recognizes that a disparity exists in RRT between the two health sectors in South Africa. The increased prevalence of kidney disease and the potential for further increases in the number of people who may require RRT in future necessitates that we focus critically at the cause of the disparity to prevent the gap from widening.

The study confirms that a lack of financial resources and current legislation contributes to the disparity, which should be addressed. However, correcting the two aspects would not eradicate the disparity as there are much more complex issues at play. This study showed that the patients in the public sector are disadvantaged at every step of their journey from the reason of developing renal disease, to seeking help for their condition, being diagnosed and ultimately treated.

The control of risk factors such as hypertension and diabetes mellitus will support prevention of the disease. Health education and lifestyle modifications may prevent these risks from occurring. Early detection may ameliorate or prolong the development of ESRD. Multi-disciplinary involvement of various specialities may prevent early mortality. For all of the above to occur, a good primary health care system with adequate resources for the detection and referral systems is needed. In addition, implementing the World Health Organization's Social Determinants of Health may decrease the probability of patients developing the disease in the first instance.

The decision-making process should be addressed. Rationing of RRT is inevitable due to a lack of resources. However, the process should be standardised, involve a multi-disciplinary team and be less bureaucratic. The eligibility criteria should be reconsidered, especially since the main criterion at present, the ability to be transplanted, does not appear to be a workable solution.

Accessibility of patients to RRT centres should be priority. It appears that accessibility may play a prominent role in refusing RRT. Use of PD as opposed to HD may improve accessibility. The population needs to be more aware of their health status and where to access assistance should they need it. Health literacy needs to be improved on not only in terms of healthy living, but also the freedom and rights that every citizen is entitled to as per the constitution. Empowerment of patients may prevent the authorities from abusing resources. The proposed National Health Insurance may

alleviate some of these issues but needs to be addressed in the greater context of what is expected, needed and the resources available.

Resources should be investigated more holistically. The funding model at present is clearly inadequate. Other means of funding, such as donations and investments need to be considered. The use of funds has to be more transparent and a scientific evaluation of the most cost-effective needs to be done. Cost-saving measures need to be investigated and implemented. Infrastructure and equipment must be assessed and improved to gain maximal benefit. Payment for consumables need to be optimized. The flux of human resources to other health sectors needs to be stemmed. To do this, reasons for the migration requires investigation and corrective measures put in place. The use of human resources must be optimised to gain maximal benefit of skills over a wider sector.

Transplantation rates should to be increased. Organ procurement and utilization policies need to be reviewed. These include improved legislation, education of the public and healthcare workers and improving resources. The distribution of organs for transplantation in patients has to be reconsidered. The reliance of transplantation to increase numbers in the public sector has to be reassessed.

In conclusion, to reduce the disparity of RRT between the two healthcare sectors, the healthcare system needs to be improved on holistically. Measures need to be implemented at every stage of the disease process to ensure optimal treatment. Through doing this, the survival of patients will be improved and access to life saving treatment for future generations guaranteed.

#### **6.4 Recommendation for future research**

This study used grounded theory and can be considered as a pilot study to ascertain the reasons for the disparity in RRT between the two healthcare sectors. To the knowledge of the researcher, no other similar study has been done in this field. The study was a deductive process in an attempt to form a theory. The theory is that multiple factors are involved in the disparity and can be traced back to the journey a kidney patient undergoes to ultimately receive RRT. Some of these factors have been reported individually in other studies, specifically related to kidney disease. Some factors are true in other disease conditions, but have not been tested in kidney disease. Some factors have been proposed as reasons, but have not been studied. No studies have proposed a unified theory to explain the disparity, and multiple aspects still require in-depth research.

A list of unanswered questions and possible future topics is provided. It is hoped that these topics will be investigated in future to provide an in-depth understanding of this pertinent topic.

- What are the reasons for the rise in risk factors in kidney disease?
- Does screening decrease ESRD?
- Screening of kidney diseases in public versus private health sectors in South Africa.
- What is the prevalence of kidney disease in the private sector?
- What is the role of different risk factors in the development of kidney disease?
- Does mortality secondary to cardiovascular disease decrease ESRD?
- What is the mortality rate in patients with CKD in the private versus public sector?
- Comparison of RRT rationing policies in the different public healthcare institutions in South Africa.
- Does bureaucracy in the public sector delay treatment?
- Comparison of demographic profiles of patients in the public and private sectors.
- What are the factors that determine acceptability of RRT treatment?
- Comparison of health literacy in the public and private sector patients.
- Is healthcare funding in South Africa inadequate or inappropriate?
- What are the factors that contribute to higher costs of RRT in South Africa?
- What is the role of pharmaceutical oligopoly in determining prices?
- An audit of the healthcare equipment in the public sector.
- What are the reasons for the low human resources in the public healthcare sector?
- Why do healthcare workers migrate from the public to other sectors?
- Comparison of public versus private healthcare resources.
- What are the reasons for the shortage of organs for transplantation?
- Comparison of live versus cadaveric donations in the public and private sectors.
- What is the role of social factors in transplantation?

It is clear that this research generated a huge number of unanswered questions due to the observations of stakeholders in this industry. As explained in the discussion, some of these opinions have been found to be true, but others have not. Most opinions remain just opinions and an significant amount

of work should be done to fully explain the differences in the well-being between the two healthcare sectors in South Africa.

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## 8 APPENDICES

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### Appendix 1: Informed Consent

#### PARTICIPANT INFORMATION & INFORMED CONSENT DOCUMENT

**STUDY TITLE:** Investigating the reasons for the differences in accessibility to renal replacement therapy in the public and private healthcare sectors in South Africa

**Supervisor:** Leeford Ameyibor

**Principal Investigator/s:** Zubair Mahomed Asmal

**Institution:** Wits Business School: University of Witwatersrand:

**Daytime telephone numbers:** 0825183994

**Email:** zubair2asmal@gmail.com

#### DATE AND TIME OF INFORMED CONSENT DISCUSSION:

<b>Dd</b>	<b>Mm</b>	<b>Yr</b>

:
<b>Time</b>

## **Dear Prospective Participant**

Dear Prof/Dr/Mr/Ms \_\_\_\_\_

### **1) INTRODUCTION**

You are invited to volunteer for a research study. I am doing this research for an MBA (wits) degree at the University of Witwatersrand. The information in this document is provided to help you to decide if you would like to participate. Before you agree to take part in this study, you should fully understand what is involved. If you have any questions, which are not fully explained in this document, do not hesitate to ask the researcher. You should not agree to take part unless you are completely happy with the kind of questions that will be asked.

### **2) THE NATURE AND PURPOSE OF THIS STUDY**

You are invited to take part in a research study. The aim of this study is to investigate reasons for the differences in accessibility to renal replacement therapy in the public and private healthcare sectors in South Africa by doing so we wish to learn more about your experience of renal replacement therapy and what affects access to it.

### **3) EXPLANATION OF PROCEDURES TO BE FOLLOWED**

This study involves answering some questions regarding your experience with patients accessing renal replacement therapy in South Africa. We would like you to answer some questions. It will take approximately 60 minutes. The researcher will keep records of the interview in a safe place to make sure that only people working on the study will have access to it. This will ensure that your answers are kept confidential (so nobody will know what you have answered).

### **4) RISK AND DISCOMFORT INVOLVED**

There is no foreseeable physical discomfort or risk involved. If there are questions that are too sensitive for you to answer, you do not need to answer them.

### **5) POSSIBLE BENEFITS OF THIS STUDY**

This study may help to determine what factors affect patients getting access to renal replacement therapy in South Africa. Once these factors are known, we can look at solutions

to these problems which may help many patients accessing renal therapy and thereby saving many lives.

**6) I understand that if I do not want to participate in this study, I may decline.**

**7) I may at any time withdraw from this study.**

**8) HAS THE STUDY RECEIVED ETHICS APPROVAL?**

The study has received ethics approval from the University of Witwatersrand. The ethics approval number is: WBS/BA9202460R/767.

**9) INFORMATION**

If you have any questions concerning this study, you should contact:

ZUBAIR ASMAL on 0825183994 or email: [zubair2asmal@gmail.com](mailto:zubair2asmal@gmail.com)

**10) CONFIDENTIALITY**

All records from this study will be regarded as confidential. All results will be published or presented in such a way that it is not possible to identify the participants.

**11) CONSENT TO PARTICIPATE IN THIS STUDY**

I confirm that the person requesting my consent to take part in this study has told me about the nature and process, any risks or discomforts, and the benefits of the study. I have also received, read and understood the above written information about the study. I have had adequate time to ask questions and I have no objections to participate in this study. I am aware that the information obtained in the study, including personal details, will be anonymously processed and presented in the reporting of results. I understand that I will not be penalised in any way should I wish to discontinue with the study.

I am participating willingly. I have received a signed copy of this informed consent agreement.

\_\_\_\_\_

\_\_\_\_\_

Participant's name (Please print)

Date

\_\_\_\_\_

\_\_\_\_\_

Participant's signature

Date

\_\_\_\_\_

\_\_\_\_\_

Researcher's name (Please print).

Date

\_\_\_\_\_

\_\_\_\_\_

Researcher's signature

Date

**INFORMED CONSENT FOR RECORDING THE INTERVIEW**

I, the undersigned, \_\_\_\_\_ (participant name) consent to the recording of this interview. I understand that my interview will be anonymised and that I may withdraw consent at any time.

\_\_\_\_\_

\_\_\_\_\_

Participant's name (Please print)

Date

\_\_\_\_\_

\_\_\_\_\_

Participant's signature

Date

\_\_\_\_\_

\_\_\_\_\_

Investigator's name (Please print)

Date

\_\_\_\_\_

\_\_\_\_\_

Investigator's signature

Date

## **Appendix 2: Sample of Interview Questions**

The interview was open-ended and often dictated by the content of what the interviewee responses. However, the following questions were used as a guide to ask questions.

### **INTERVIEW GUIDE**

This is a sample of questions which would be asked. These questions are a guide and not meant to be comprehensive. Some questions may not be asked and others added depending on the progression of the interview.

#### **Demographics:**

Could you please give me some background in what you do for a living?

Where do you practice?

How long have you been involved in RRT?

What are your experiences with respect to access to RRT?

What do you think about the state of renal care in South Africa? Do you think it is improving or getting worse?

What guidelines or policy do you follow in accepting or rejecting patients for the RRT program?

#### **Drawing up of policies**

Have you any experience in drawing guidelines for RRT?

Do you know who drew up the policies and how they were drawn up?

Do you think the way in which the policies were drawn up is fair?

Do you know the evolution of policies relating to RRT?

Do you know of any other policies with respect to RRT in South Africa?

Were there previous policies your institution followed?

### **Content of the policies**

Do you know the main contents of your policy?

Do members of your staff know about the policy or its contents?

How does it relate to acceptance or rejection of patients to the program?

Are there any other reasons, not include which may lead to acceptance or rejection?

Do you know how many patients in your institution are accepted or rejected for the RRT program?

What is the main reason for accepting or rejecting a patient?

Do you think the policy is adequate or needs improvement?

What would you take out? What would you include?

What do you think of the department guidelines? What works, what does not work?

Are there any ways of determining whether the policies are fair?

Do you think the policies are ethically fair? Is there any way of making the policies ethically and legally more fair?

### **Implementation**

Do you know if the policy is being implemented?

How are you implementing the policy?

Are there mechanisms to ensure that the policies are implemented?

### **Adherence**

Are you obligated to adhere to the policy?

Are there any ramifications should the policy not be adhered to?

Do you know how the policies are implemented?

Do you feel safe from litigation? Are there any safeguards to ensure you are safe from litigation?

### **Monitoring**

Are the policies being monitored for adherence?

Are the policies being monitored for effectiveness?

Do you know if access to RRT is monitored in your institution? Does it conform to the policies you are following?

### **Improvement**

How can we improve the care of patients on RRT?

How can we improve access to RRT?

Are the models available now sustainable?

Is there any way we can improve our policies?

### **Appendix 3: Brief biography of researcher**

I am a nephrologist, practicing in Pretoria for the last 15 years. I am currently in full private practice in the Pretoria area. I was previously the Head of Nephrology at Dr George Mukhari Academic Hospital, which is affiliated with Sefako Mokgathi University, both of which are state entities

I am a qualified doctor by profession and graduated with my undergraduate degree from the University of Witwatersrand. My post graduate degrees in becoming a physician and sub-specializing in kidney disease was obtained from the College of Medicine, South Africa. My training for these degrees occurred in a hospital affiliated with the Wits Medical school.

My interest in this topic stems from my experience working in this industry and noting the differences between the two health sectors.

I am currently enrolled for the MBA degree at Wits Business School and as my studies are fully paid for by myself, I have no pecuniary interest.