

**HEALTH LITERACY OF SESOTHO-SPEAKING PATIENTS
WITH END-STAGE RENAL DISEASE IN THE FREE STATE
PROVINCE**

by

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DECLARATION

I, Elsabet van Rensburg, hereby declare that the dissertation, HEALTH LITERACY OF SESOTHO-SPEAKING PATIENTS WITH END-STAGE RENAL DISEASE IN THE FREE STATE PROVINCE, submitted for the Master of Nursing at the University of the Free State, is my own independent work and has not previously been submitted by me at another university/faculty. I, furthermore, cede copyright of the dissertation in favour of the University of the Free State.



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30 November 2020

DATE

DEDICATION

To all the patients living with end-stage renal disease, their families and friends – together, we will endure.

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- My husband and three daughters, who supported me from day one.

SUMMARY

Background: End-stage renal disease is a global health concern, and health literacy is essential for managing this complex disease. In South Africa, the health literacy status of Sesotho-speaking patients is unknown. Meaningful data will only be generated if health literacy is tested and local context, and cultural and dialectal diversity is taken into consideration.

Aim: This study aimed to assess the health literacy of Sesotho-speaking patients with end-stage renal disease in the Free State province of South Africa.

Objectives: The objectives were to establish the health literacy association between Sesotho-speaking patients with end-stage renal disease in the Free State province who received haemodialysis and peritoneal dialysis at private and public dialysis centres in this province.

Methodology: The researcher followed a quantitative, descriptive, cross-sectional design. The research technique used was the culture- and context-sensitive Sesotho Health Literacy Test (SHLT). Patients receiving haemodialysis and peritoneal dialysis in the private and public healthcare sectors in four towns of the Free State province were included in the study (N=420). Convenience sampling (n=263) was used to collect data. Frequencies and percentages for categorical data and medians and percentiles for numerical data were calculated per group. Associations were calculated utilising the Chi-square or Fisher's exact tests for categorical data and the Kruskal-Wallis test for numerical data.

Results: The researcher studied 263 respondents: 57.4% (n=151) were from the public sector, 74.9% (n=197) received haemodialysis, and 25.1% (n=66) were on peritoneal dialysis. Male gender predominated, with 60.3% (n=158) men, and the median age of respondents was 49 years. The majority (58.4%) of respondents had an education level between Grade 9 and 12. Hypertension (91.3%) and diabetes mellitus (27%) were the highest reported comorbidities. Respondents had been on renal replacement therapy for a median of four years, and 46.8% reported having problems reading due to inadequate eyesight. Low health literacy levels were identified in 12.9% (n=34), moderate health literacy levels in 49.4% (n=130), and high health literacy levels in 37.6% (n=99) of the respondents. Low health literacy levels

were significantly associated ($p<0.01$) with lower education levels. Lower health literacy levels were not associated with healthcare sector groups ($p=0.58$), treatment modalities ($p=0.80$), gender ($p=0.20$), age ($p=0.06$), years on dialysis ($p=0.50$) or with a higher number of comorbidities ($p=0.81$). However, a significant association ($p<0.01$) was reported between lower health literacy levels and the scores obtained in appraisal and understanding questions.

Recommendations: The South African Renal Society could possibly implement context- and culture-related health literacy assessment for end-stage renal disease patients when they are diagnosed. Training institutions could integrate health literacy training into the education of healthcare workers in the dialysis field. End-stage renal disease patients could benefit if they received education and training from dialysis role players in their home language. End-stage renal disease patients' health outcomes could improve if the staff-to-patient ratio was 1:4. Health literacy levels of end-stage renal disease patients should be considered when selection for renal replacement therapy in the public sector, and selection for transplant in both sectors take place. Education and training of end-stage renal disease patients should be related to the language, cultural and environmental context of living of the patient, education level and age of the patient, whether the patient has inadequate eyesight, and the patients' health literacy level. Knowledge about emergencies, the influence of lifestyle, understanding of prescriptions, volume measurement, tuberculosis and hepatitis B, and the impact of nephrotoxic medications have to be reinforced during patient training.

Conclusion: The health literacy of Sesotho-speaking end-stage renal disease patients was unknown. The SHLT was applicable for assessing the health literacy of these patients. Almost 50% of Sesotho-speaking end-stage renal disease patients have difficulties with measurement, possess inadequate knowledge about health, nutrition and exercise, and experience problems following medication prescriptions. This study suggests that end-stage renal disease patients' health literacy status should be known, to improve self-management and health outcomes.

Key terms: end-stage renal disease; general health literacy; Sesotho-speaking; Free State; context; culture; self-management; health outcomes

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LIST OF ABBREVIATIONS

ESRD	End-stage renal disease
HIV	Human immunodeficiency virus
HSREC	Health Sciences Research Ethics Committee
NVS	Newest Vital Sign
REALM	Rapid Estimate of Adult Literacy in Medicine
SHLT	Sesotho Health Literacy Test
TB	Tuberculosis
TOFHLA	Test of Functional Health Literacy in Adults
WHO	World Health Organization

CONCEPTUAL AND OPERATIONAL DEFINITION OF TERMS

End-stage renal disease: The South African Renal Registry defines end-stage renal disease (ESRD) as follows: “ESRD refers to advanced chronic kidney disease, which is considered to be irreversible and requires the initiation of renal replacement therapy in the form of dialysis or transplantation” (Davids, Marais & Jacobs, 2017:202). For the purposes of this study, this definition of ESRD will apply.

Health literacy: Health literacy encompasses the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health. Health literacy includes the capacity to communicate, assert and enact these decisions (Dodson, Good & Osborne, 2015:Online). In this study, health literacy will also include the characteristics listed by Dodson *et al.* (2015:Online) and will be measured using the Sesotho Health Literacy Test (SHLT).

Health literacy test: The most commonly used health literacy tests originated in developed countries and focus on assessing vocabulary, reading skills and numeracy (Hunt, Dowse & La Rose, 2008:268). The SHLT was developed in South Africa for patients with ESRD who speak Sesotho as their first language; it assesses general health literacy, without a singular focus on either vocabulary, reading or numeracy skills.

Patient with ESRD: A patient with ESRD is defined as a patient who has advanced chronic kidney disease, and chronic renal replacement therapy has started to sustain life (Davids *et al.*, 2017:202). In the context of this study, patients with ESRD will be either male or female Sesotho first-language patients, 18 years and older, who are receiving renal replacement therapy in the form of haemodialysis or peritoneal dialysis, from either a private or public dialysis centre in the Free State province of South Africa.

Sesotho-speaking patients: A patient is an individual who receives medical care (Smeltzer, Bare, Hinkle *et al.*, 2010:5). Sesotho is the home language of the Basotho ethnic group (Statistics South Africa, 2016a:1). In this study, Sesotho-speaking patients are Sesotho first-language speaking patients with ESRD, treated in private and public dialysis centres in the Free State province of South Africa.

CHAPTER 1: OVERVIEW OF STUDY

1.1. INTRODUCTION AND BACKGROUND

Time is considered to be more valuable than money. You can get more money, but you cannot get more time (Rohn, 2018:Online). For an end-stage renal disease (ESRD) patient, neither of these options is possible, because of the expensive nature of renal replacement therapy (White, Chadban, Jan *et al.*, 2008:229), and because life expectancy of patients on dialysis is only five to ten years (National Kidney Foundation, 2019:Online).

ESRD is a major health concern globally. This debilitating illness is ranked the ninth leading cause of death in the United States, and without treatment, patients die of uraemia within a matter of weeks (Neil, Walker, Sesso *et al.*, 2009:73; Wells, 2011:155). It is one of the most critical and life-threatening diseases, and imposes huge mental and economic burdens on societies. The major causes of ESRD in both developed and developing countries are diabetes and hypertension (Nasri & Rafieian-Kopaei, 2015:1112).

The American Kidney Foundation reported in 2014 that diabetes and hypertension are accountable for more than 70% of all cases of ESRD (Rivera, 2017:211). In South Africa, where the Renal Registry is still relatively new, the South African renal registry's annual report for 2016 reveals that the most common causes of ESRD are hypertensive renal disease (34.7%), unknown causes (32.4%) and diabetic nephropathy (15.2%) (Davids, Jardine, Marais *et al.*, 2018:66). This health problem is increasing in prevalence and incidence worldwide (Tannor, Archer, Kapembwa *et al.*, 2017:1).

Globally, 223 per million population are treated for ESRD, compared to 20 per million population in Africa (Tannor *et al.*, 2017:1). In South Africa, 10 257 patients were treated for ESRD in 2016, which calculates to 183 per million population (Davids *et al.*, 2018:66). The number of patients treated in the public sector in 2015 was low, compared to the 7 042 patients treated in the private sector (Davids *et al.*, 2017:201–213). The costs of treating ESRD are increasing, and this is creating financial challenges globally (Neil *et al.*, 2009:77). In developing countries, where government is responsible for funding of ESRD treatment, affordability remains a challenge (White *et al.*, 2008:229). The treatment of ESRD, leading to renal replacement therapy, is an expensive and technically advanced type of treatment. Rationing of renal replacement therapy is the norm in low and middle-

income countries, and also in the public sector of South Africa. Over the 15 years from 1988 to 2003, only 47% of patients diagnosed with ESRD in South Africa were accepted for treatment of their ESRD, in the form of renal replacement therapy. “The majority of patients with ESRD fail to qualify for treatment for poverty-related problems such as illiteracy, lack of funds to travel to the treatment centre, and poor record of compliance” (Moosa & Kidd, 2006:1107-1108; Moosa, Maree, Chirehwa *et al.*, 2016:1-16). Renal replacement therapy, which includes *haemodialysis*, *peritoneal dialysis* or *kidney transplantation*, is the only treatment options available for ESRD.

Haemodialysis is the most commonly prescribed method of renal replacement therapy. A semipermeable membrane is used to remove wastes, extra chemicals and fluid from a patient’s blood. Patients have to attend dialysis two to three times per week at a clinic, and sessions last three to four hours. *Peritoneal dialysis* is a home-based method of treatment. The patient administers dialysis fluid into the abdominal cavity by using a Tenckhoff catheter. The removal of uremic toxins and excess fluids is achieved by the principle of osmosis and diffusion between the peritoneum’s blood vessels and the dialysis fluid. *Kidney transplantation* usually is considered to be the best and most cost-efficient clinical treatment option. However, not all patients are suitable candidates for transplantation, and the demand far exceeds the supply of kidneys (Neil *et al.*, 2009:73). Renal replacement therapy gives patients a reasonable quality of life and prevents them dying (Vanholder, Annemans, Brown *et al.*, 2017:393), but positive outcomes require more than just attending dialysis. The treatment regimens can be complicated and require life-changing and sustained health behaviour to stay healthy, and adherence to these prescriptions are crucial to survival (Wells, 2011:155).

ESRD is a complex illness and requires patients to participate actively in their care and to adhere to their treatment (Rivera, 2017:213). Patients’ health outcomes are influenced by interaction of physical and psychological distress, and their capacity to utilise health information effectively. They have to manage renal replacement therapy constraints, comorbid conditions, dietary and fluid restrictions and taking of multiple medications. The degree to which patients participate in self-management and their treatment determines their quality of life and health outcomes (Dodson, Osicka, Huang *et al.*, 2016:91). In a recent study by the National Kidney Foundation in America, more than 50% of Americans were found to be “kidney clueless”, because they do not understand what their kidneys do, nor what the signs and symptoms of kidney disease are (Rivera, 2017:213). Limited

health literacy is common amongst people receiving haemodialysis, and patients with lower health literacy have a higher mortality risk than those with higher health literacy levels (Dodson *et al.*, 2016:91).

1.2. PROBLEM STATEMENT

Four decades ago, the concept of health literacy was introduced and researchers are still continuously attempting to operationalise it (Marimwe & Dowse, 2017:2). The World Health Organization (WHO) defines health literacy as encompassing the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health. Health literacy includes the capacity to communicate, assert and enact these decisions (Dodson *et al.*, 2015:Online). Health literacy in individuals is shaped by social factors and structures, which emphasise the difficulty of measuring the health literacy of individuals and in communities (Marimwe & Dowse, 2017:2). Various health literacy tests focus on different aspects of health literacy, such as vocabulary, reading level and numeracy (Hunt *et al.*, 2008:268).

There are more than 100 health literacy tests worldwide, but none of them can be used as a “golden standard”, because of the diversity of populations (Marimwe & Dowse, 2017:2). The Test of Functional Health Literacy in Adults (TOFHLA) (Parker, Baker, Williams *et al.*, 1995:538) or Short Test of Functional Health Literacy in Adults (S-TOFHLA) (Baker, Williams, Parker *et al.*, 1999:33-42), which test reading fluency and numeracy, and Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis, Crouch, Long *et al.*, 1991:433-435) which tests vocabulary, are three of the most commonly used tests in the healthcare setting (Baker, 2006:880). The Newest Vital Sign (NVS) (Weiss, Mays, Martz *et al.*, 2005:514-515), is another quick screening test for literacy, and consists of a nutrition label with six questions, which correlates with the TOFHLA. All these tests were developed in the United States and are not suitable for use in South Africa, with its diversity of populations, of which 84% live under poor economic conditions and have low educational levels (Marimwe & Dowse, 2017:2).

Internationally, most educational health material is written at Grade 10 level, which means that the reader must have completed at least ten years of schooling to understand the material (Aleligay, Worrall & Rose, 2008:383-407). The South African Census of 2011 (Statistics South Africa, 2012:33) indicates that 8.6% of the population has had no

schooling and 12.3% has a primary school education of Grade 7 or lower. In the Free State province, the comparative percentage is 21% (Statistics South Africa, 2012:39). In a study done in Australia, Aleligay *et al.* (2008:383-407) recommend that health material is prepared at a fifth or sixth-grade level, which is still too advanced for the South African context. Furthermore, evidence of limited health literacy is linked to higher mortality rates, suboptimal adherence to taking medication, poorly managed chronic diseases, failing to frequently use preventive services, and higher hospitalisation rates (Hunt *et al.*, 2008:1; Marimwe & Dowse, 2017:1). Dowse, Lecoko and Ehlers (2010:470) found that applying the REALM Health Literacy test for English second-language patients was inappropriate; they suggest that health literacy is tested in the first language of a patient. Dowse (2016:5) states that the understanding of health literacy skills in developing countries needs urgent attention. Meaningful data will only be generated by taking local context, cultures and dialectal diversity, and the full range of literacy and intellectual skills into consideration and by including all parts of the population (Vinhas, Gardete-Coreiha, Bohavida *et al.*, 2011:c36-c39).

In a diverse country like South Africa, only 8% of the population is Sesotho-speaking. In the Free State, Sesotho-speaking people comprise almost three quarters (71.9%) of the province's population (Statistics South Africa, 2016a:19). The health literacy status of these citizens is unknown. The Sesotho Health Literacy Test (SHLT) (Reid, Krige & Janse van Rensburg-Bonthuyzen, 2019:1–13) was, therefore, developed to assess the health literacy status of the Basotho ethnic group. The test is contextually and culturally appropriate. The SHLT has, however, not been applied with Sesotho first-language ESRD patients. Currently, there is no evidence of the health literacy status of ESRD patients in South Africa, specifically of Sesotho first-language speaking patients with ESRD.

By gaining insight into the health literacy status of Sesotho first-language speaking ESRD patients, patient outcomes and overall health of this population may be improved. This study's focus will be on gaining an understanding of the health literacy status of Sesotho first-language speaking ESRD patients in the Free State province, to assess whether health literacy is another challenge these patients have to face.

1.3. RESEARCH QUESTION

What is the health literacy status of Sesotho-speaking patients with end-stage renal disease in the Free State province?

1.4. AIM

This study aimed to assess the health literacy status of Sesotho-speaking patients with end-stage renal disease in the Free State province.

1.5. OBJECTIVES

The objectives of this study were to establish the health literacy association between Sesotho-speaking patients with end-stage renal disease in the Free State province,

- Who were receiving haemodialysis and those receiving peritoneal dialysis
- At private or public dialysis centres in the Free State province.

1.6. PHASED RESEARCH PROCESS

Within a positivistic paradigm, this study followed a quantitative, descriptive, cross-sectional design. In quantitative studies, researchers move from formulating a question to obtaining an answer by following a typical, general flow of activities (Polit & Beck, 2017:54). Figure 1.1 describes the phased research process of this study.

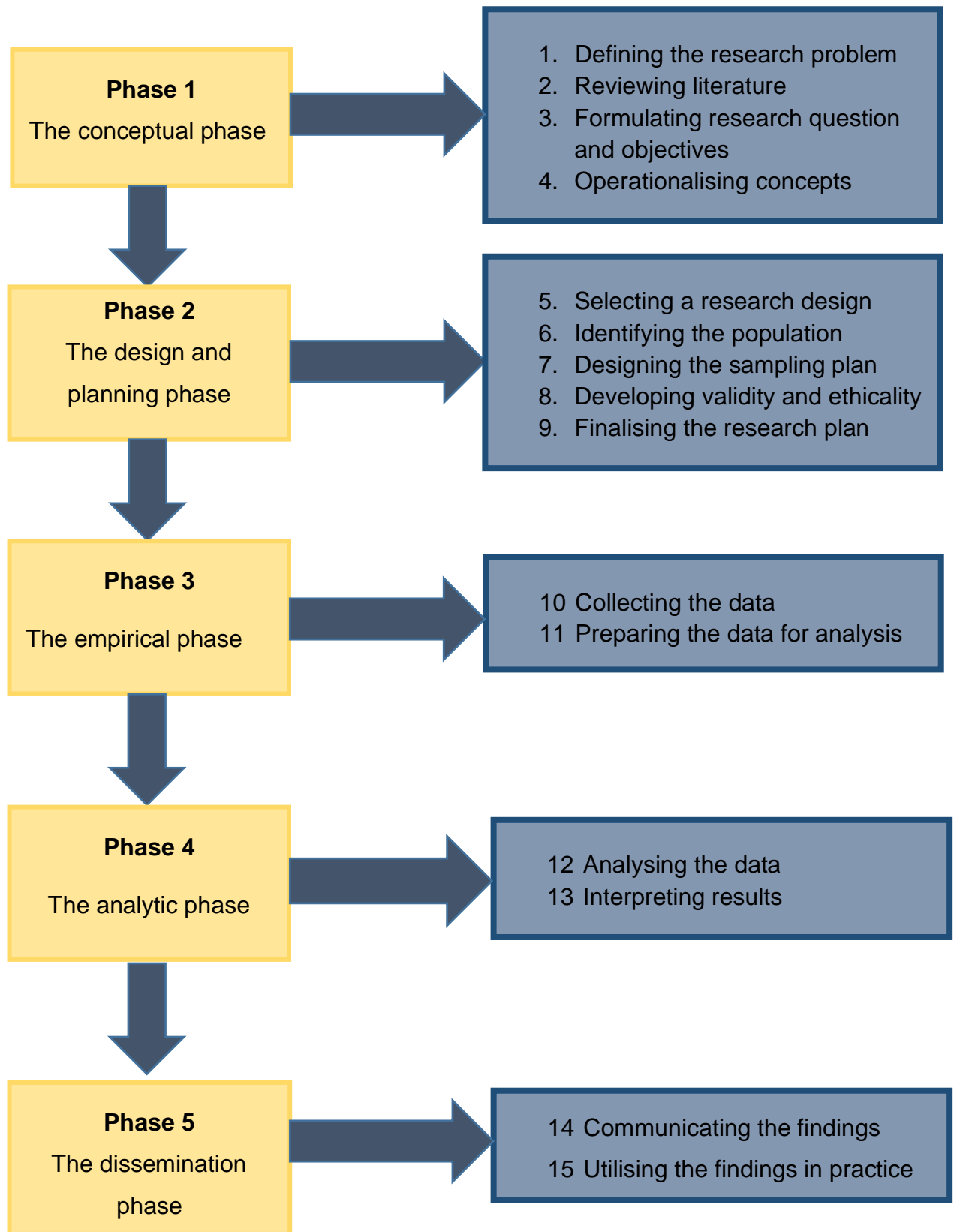


Figure 1.1: Phased research process with relevant steps followed by study
 (Adapted from Botma, Greeff, Mulaudzi *et al.*, 2010:38-30; Polit & Beck, 2017:55)

1.7. CONCEPTUAL FRAMEWORK

A conceptual framework is an organisation of the key concepts, defined for the proposed research, organised systematically to provide a focus and interconnection of ideas, describing the relationship between the concepts (Botma *et al.*, 2010:217; Polit & Beck, 2017:723). This study was guided by the conceptual framework depicted in Figure 1.2.

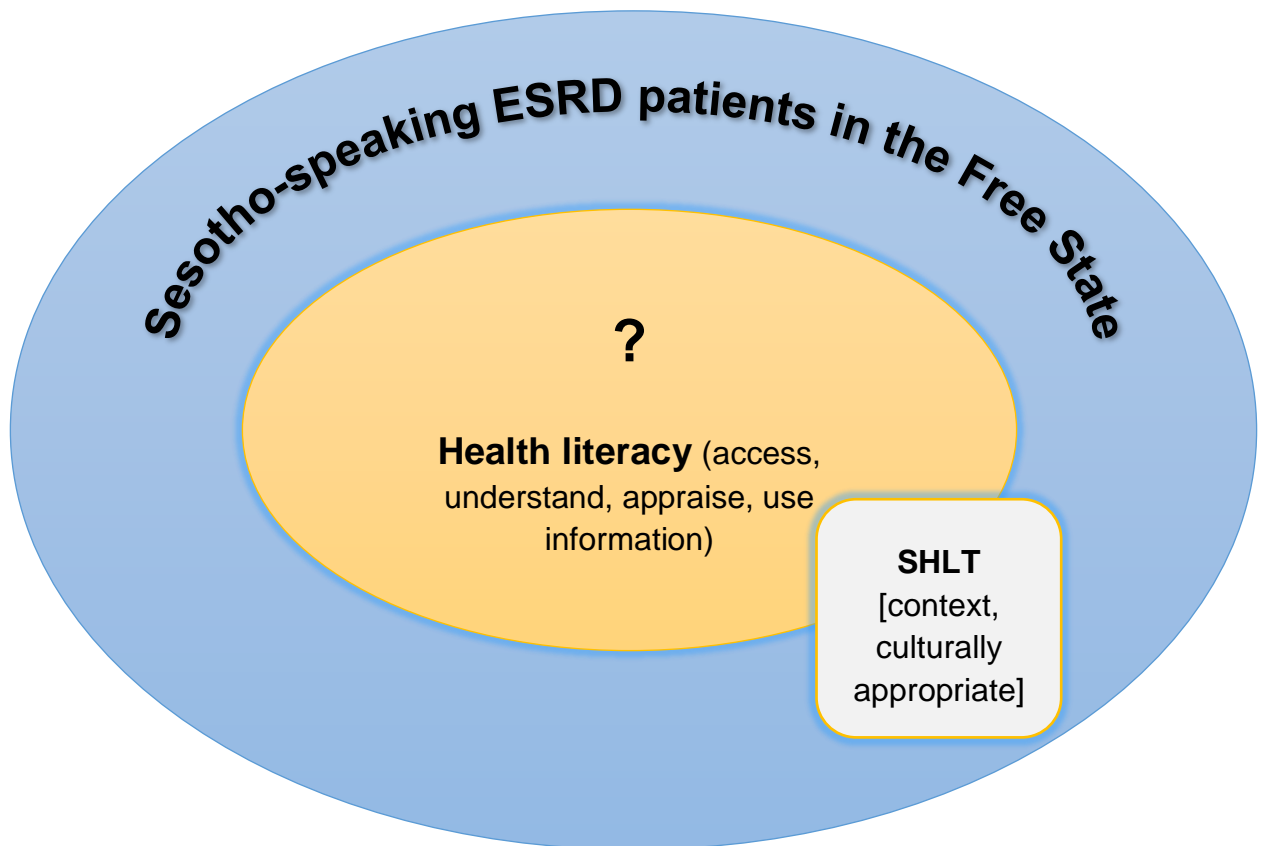


Figure 1.2: Proposed conceptual framework of health literacy of Sesotho-speaking ESRD patients in the Free State province

Figure 1.2 depicts that health literacy encompasses the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health. Health literacy includes the capacity to communicate, assert and enact these decisions (Dodson *et al.*, 2015:Online). The health literacy status of ESRD patients in South Africa, and specifically that of Sesotho-speaking ESRD patients receiving haemodialysis and peritoneal dialysis treatment, is unknown.

The SHLT is contextually and culturally appropriate for the Basotho ethnic group. By applying the SHLT for Sesotho first-language ESRD patients, insight will be gained into their health literacy status, and patient-specific health outcomes can possibly be improved.

1.8. RESEARCH DESIGN

A research design is an outline for increasing control over influences that could change a study's desired result. The design chosen by the researcher guides the selection of a population, the methods of sampling and measurement and the plan for data collection and analysis. The knowledge of the researcher, the problem and purpose of the study and the preferred overview of the findings, influence the researcher in choosing a specific research design (Burns & Grove, 2009:41).

This study utilised a quantitative, descriptive, cross-sectional design, as it aimed to assess the health literacy status of Sesotho first-language speaking patients with ESRD receiving treatment at private and public dialysis centres in the Free State province.

Quantitative research is a formal, detached, accurate and logical process for generating numerical information to describe events and examine relationships amongst variables (Burns & Grove, 2009:33). In this study, a quantitative design was applied to assess what the health literacy status of Sesotho first-language speaking patients with ESRD are by using a structured questionnaire, the SHLT (Addendum A).

A *descriptive* study wishes to portray what already exists in a population and seeks to describe these characteristics accurately, discover new meanings and organise information (Burns & Grove, 2009:429). The health literacy status of Sesotho first-language speaking patients with ESRD receiving treatment in private and public dialysis centres in the Free State province will be described in this study.

Cross-sectional studies involve looking at different characteristics of a population at a single point in time. They can indicate what is going on in the population at present (Brink, Van der Walt & Van Rensburg, 2012:101). Data were collected according to the treatment schedules of the patients at the different dialysis centres in the private and public sector of the Free State province.

1.9. RESEARCH TECHNIQUE

Research methods reflect the techniques that researchers use to structure a study and to gather and analyse information relevant to the research question (Polit & Beck, 2017:56). The study utilised a structured questionnaire, the SHLT (Addendum A). The SHLT (Reid *et al.*, 2019:1–13) was developed locally and the language, culture, education, and health system context of the Basotho ethnic group were taken into consideration, making this test appropriate for use with Sesotho first-language speakers.

Structured methods of data collection give respondents limited options of explaining what they mean by an answer. A structured questionnaire usually is a fixed set of questions that are to be answered in a specific order. Structured data can be analysed without difficulty and quantified easily (Polit & Beck, 2017:174). The SHLT is a validated, structured questionnaire, with ten fixed, structured questions with closed-ended options, that was administered by fieldworkers. This technique enabled numerical data to be analysed using statistical procedures.

1.10. POPULATION

The study population comprised Sesotho first-language speaking patients with ESRD receiving treatment at private and public dialysis centres in the Free State province.

1.11. SAMPLING

Convenience sampling (n=263) was used to collect data from the respective dialysis centres, and detail will be provided in Chapter 3.

1.12. PILOT STUDY

A pilot study was conducted at one of the dialysis centres, about which more detail will be provided in Chapter 3.

1.13. DATA COLLECTION

Data collection is the process of gathering data according to a pre-established plan (Botma *et al.*, 2010:131). Data were collected during the pilot study and main data collection, as indicated in Figure 1.3.

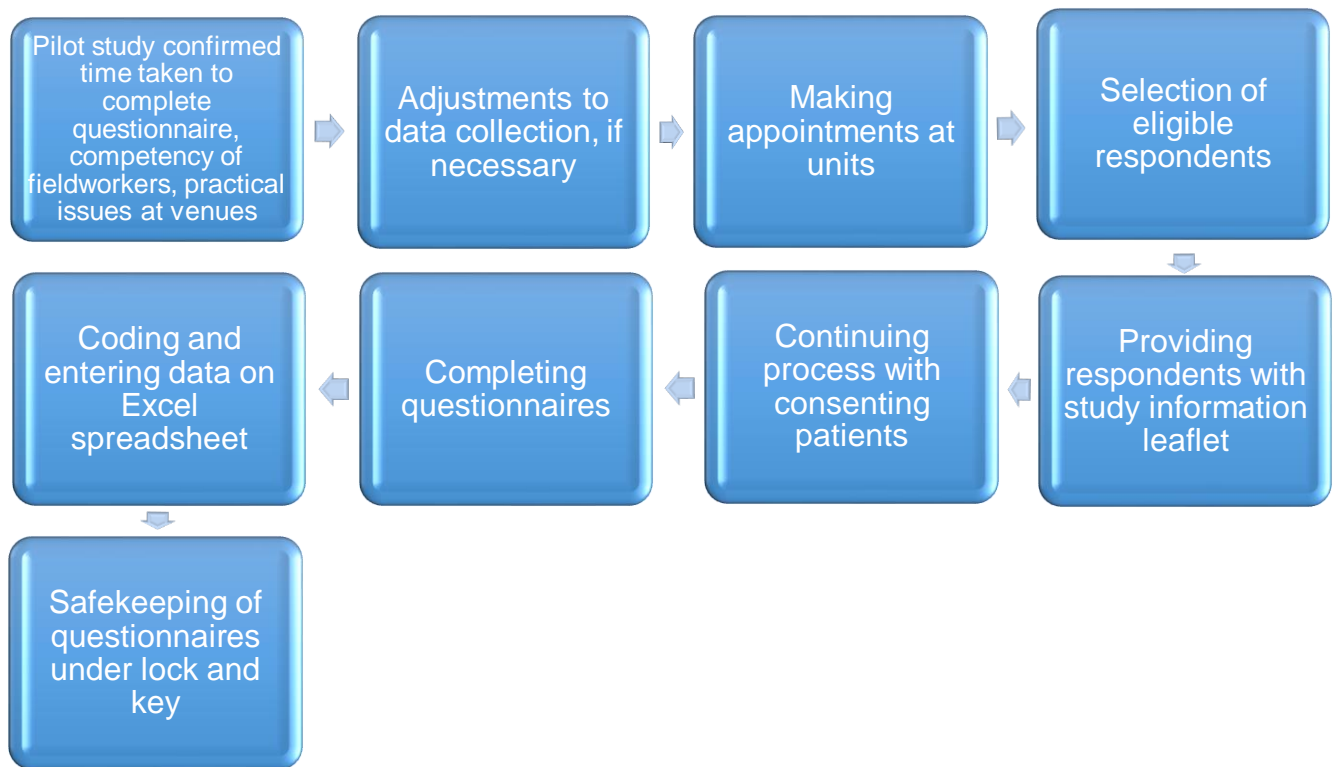


Figure 1.3: Data collection plan

The detail of the data collection process will be discussed in Chapter 3.

1.14. VALIDITY AND RELIABILITY

Rigour in quantitative research is defined as “the striving for excellence, and it involves discipline, scrupulous adherence to detail and strict accuracy” (Burns & Grove, 2009:33).

1.14.1 Validity

Face and content validity were enhanced in this study, and these measures will be discussed in Chapter 3.

1.14.2 Reliability

Reliability is defined as the consistency of the measurement that is used, and whether it will give the same results if repeated in different situations with different people (Botma *et al.*, 2010:17; Polit & Beck, 2017:742). De Vos, Strydom, Fouché *et al.* (2011:163) believe that reliability is not concerned with what needs to be measured, but rather with

the effective measurement of the construct. Reliability was enhanced by the researcher and fieldworkers in this study, and the detail will be discussed in Chapter 3.

1.15. MEASUREMENT AND METHODOLOGICAL ERRORS

The possible methodological and measurement errors and the plan to limit the effect of these possible errors are described in Table 1.3.

Table 1.1: Possible methodological and measurement errors and the plan to limit the effect of these possible errors

POSSIBLE METHODOLOGICAL AND MEASUREMENT ERRORS	PLAN TO LIMIT THE EFFECT OF THE ERRORS
Management members of different dialysis providers may be concerned that personal information of respondents may not be kept confidential, which may affect their willingness to give consent to conduct the study in the units	The researcher will make it clear that confidentiality is an essential factor of the study and that there are measures in place to ensure that the data is kept confidential. Each dialysis centre and respondents from such centres will only be identified numerically and not by name. All completed questionnaires will be placed in the same sealed box after completion.
Respondents may be unwilling to participate in the study, which may result in failing to recruit a sufficient number of respondents from the sample selected.	When obtaining consent, the researcher will emphasise the value of the study to the respondents. The questionnaire only has ten closed-ended questions, and the fieldworkers will assist the respondents to complete it. It should only take 10 to 15 minutes to complete the questionnaire.
Coding errors	The researcher will check the completeness of the questionnaires directly after data collection. The researcher will capture data on an Excel spreadsheet, with a co-data capturer repeating the data capturing on a separate Excel spreadsheet.
The patient might want to impress the fieldworker by providing only yes/no answers to questions and not making use of the "I don't know" option.	Fieldworkers will be trained according to the guideline (Addendum B). They will emphasise the value of the "I don't know" option as an answer.

1.16. ETHICAL CONSIDERATIONS

Protecting the rights of human study participants is of primary concern to a researcher (Polit & Beck, 2017:137). Ethical conduct applies to all the phases of the research process (Botma *et al.*, 2010:4). The principles of the Belmont Report guided the study. These principles include beneficence, respect for persons and the principle of justice (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979:1-10) and will be discussed further in Chapter 3.

1.17. DATA ANALYSIS

Statistical analysis enables researchers to organise, interpret and communicate numeric information (Polit & Beck, 2017:356).

Descriptive statistics, namely frequencies and percentages for categorical data and medians and percentiles for numerical data, were calculated per group. The groups were compared utilising the Chi-square test or Fisher's exact test for categorical data, and the Kruskal-Wallis test for numerical data. The Department of Biostatistics, School of Medicine, Faculty of Health Sciences at the University of the Free State assisted with the analysis of the data.

1.18. CONCLUSION

This chapter provided the reader with an overview regarding the purpose, the aim and objectives, and the research question – *What is the health literacy status of Sesotho-speaking patients with end-stage renal disease in the Free State province?* – of this study. The researcher emphasised why the study was done, and elaborated on the research design and technique applied to undertake this study to answer the research question. The concepts of validity and reliability were introduced, followed by the essential ethical aspects that were maintained throughout this study. At the end of this chapter, a short description of what the data analysis entailed was included.

The second chapter will provide a review of the literature relating to the study, and Chapter 3 will discuss the methodology that was used in detail. The results of the study will be provided in Chapter 4. In conclusion, Chapter 5 will give a summary of the research findings, recommendations based on the findings of the study, the limitations, value of the study and a final conclusion.

CHAPTER 2: REVIEW OF LITERATURE

2.1. INTRODUCTION

Chapter 1 provided an overview of the study. The researcher briefly introduced the methodology used in the study, the concepts of validity and reliability, as well as the ethical aspects that were maintained. Chapter 2 will present a review of the literature on the development of health literacy, measuring health literacy, and the influence health literacy has on health outcomes. A summary will be provided on ESRD and the relationship between ESRD, self-management and health literacy. The assessment of health literacy in ESRD, the determinants of limited health literacy in ESRD patients, and the role of culture and language in measuring health literacy, will be discussed. Lastly, a brief overview will be given of Sesotho-speaking patients with ESRD.

2.2. DEVELOPMENT OF HEALTH LITERACY

Health literacy was introduced in 1974 as a matter relating to policymaking, and which affects health systems (Muhanga & Malungo, 2017:108; Peerson & Saunders, 2009:285). Since the mid-nineties, health literacy has become an exciting and evolving area of research (Baker, 2006:878; Rudd, 2015:7), and has created awareness of *literacy* concerns in the context of *health* (Institute of Medicine, 2004:Online).

Although health literacy is related to general literacy and patient activation, there is a distinction between health literacy and general literacy (Taylor, Fraser, Dudley *et al.*, 2018:1545). Literacy is more than the ability to read and write, and more than understanding and speaking a language. It enables a person to "identify, understand, interpret, create, communicate, compute and use printed and written materials associated with varying contexts" (UNESCO, 2004:13). People's literacy skills enable them to function to their full potential, in their community and broader society. UNESCO (2004:12) considers a person as literate if the permanent skill of reading and writing has been acquired. In South Africa, adults are identified as literate if a formal level of education of Grade 6 or 7 has been obtained, or, alternatively whether a person indicates the ability to read and write in a language (Posel, 2011:39–40).

Health literacy, however, is a more complex construct, and includes content and context specifications (Okan, Bauer, Levin-Zamir *et al.*, 2019:11), and its diversity is reflected by

the variety of health literacy definitions (Berkman, Davis & McCormack, 2010:17; Peerson & Saunders, 2009:286). There are multiple health literacy definitions available, and still researchers in this field, "grapple with what health literacy really is" (Mackert, Champlin, Su *et al.*, 2015:1161).

2.2.1 Conceptualisation of health literacy

In the early stages of health literacy research, Nutbeam (2000:259–267) proposed a health literacy framework. He promoted the idea that health literacy involved more than reading and writing, and emphasised what health literacy enabled a person to do. He identified three levels of health literacy: level one – functional health literacy, level two – communicative health literacy and level three – critical health literacy (Nutbeam, 2000:263–264).

- *Functional health literacy* is the ability to understand and interpret health information, written or spoken, to be applied in daily life (Bezerra, Lessa, Do Ó *et al.*, 2019:3). Functional health literacy poses a barrier to the way patients must use the health system and how they access health information resources to manage their health conditions (Marimwe, 2018:12).
- *Communicative health literacy* focuses on more advanced cognitive skills in combination with personal skills, that are used to apply the information derived from healthcare providers to actively change and participate in circumstances (Marimwe, 2018:13; Nutbeam, 2000:263–264).
- *Critical health literacy* refers to superior cognitive skills, in combination with social skills, which enable a patient to think abstractly and use the information to bring change to life events and situations (Marimwe, 2018:13; Shih, Chang, Jensen *et al.*, 2016:7).

Nutbeam's conceptual framework of health literacy emphasises the dynamic process of health literacy (2000:259–267). A patient can progress from one level to the next, not only by increasing cognitive abilities, but by exposure to health information, including communication with healthcare providers and how patients respond to the information they receive (Marimwe, 2018:13; Nutbeam, 2000:264).

The WHO has adopted Dodson's definition, which describes health literacy as "the ability to *engage* with health information and services" (Dodson, Good & Osborne, 2015:Online). Skills, such as accessing, understanding, evaluating and applying health information and

agreeing with the core of the construct of health literacy definition and conceptual frameworks could strengthen this ability to engage with health information (Dodson *et al.*, 2016:95; Pleasant, 2014:1483). Thus, the responsibility for health literacy is placed on the patient him- or herself (Dageforde & Cavanaugh, 2013:311).

Although these individualised skills are acknowledged as necessary for the development of health literacy, health literacy is only acquired when those skills are aligned with the demand and complexity of healthcare services and social structures (Aldoory, 2017:212; Parker & Ratzan, 2010:28). Rudd (2015:8) indicates that the narrow definition of health literacy has to be revisited; Rudd motivates researchers to look closer than merely the skills and capacity of the individual.

Health literacy, therefore, has to be acknowledged as a multidimensional concept, which includes individual, as well as health system factors. These features influence a person's health literacy and, furthermore, provide a link to health outcomes (Sørensen, Van Den Broucke, Fullam *et al.*, 2012:3). Rudd (2015:8) suggests that "both sides of the coin" have to be included in studies linking health literacy and health outcomes: individual literacy skills as well as the communication skills of the professionals; the communication skills of healthcare professionals and the policies within the practice where they are operational.

Initially, health literacy focused on the mathematical and reading capabilities of individuals in a health context (Aldoory, 2017:212; Mackert *et al.*, 2015:1162), which did not necessarily indicate the ability of an individual to apply these skills (Pleasant, 2014:1483). The application of health literacy skills is certainly a top priority in health literacy (Parker & Ratzan, 2010:29).

Pleasant (2014:1483) states, furthermore, that "the definition of health literacy has to be written in a way that can be measured". This is not the case for all health literacy definitions (Pleasant, 2014:1483), and health literacy, being such a diverse concept without a specific definition, creates a challenge relating to what should be accepted as a health literacy measurement tool (Haun, Valerio, McCormack *et al.*, 2014:326).

2.2.2 Measuring health literacy

Measuring health literacy is complicated, and a tool that measures all aspects of health literacy has not been developed (Dickens, Lambert, Cromwell *et al.*, 2013:67).

Measurement of health literacy should be based on the definition of health literacy and, in the same way, measurement should continuously inform definition (Okan *et al.*, 2019:67). Accurate measurement of health literacy is critical for identifying topics and populations that need support, to adapt providers' involvement, and to develop systems to measure improvement (McCormack, Haun, Sørensen *et al.*, 2013:11).

A plethora of health literacy measurement tools have been developed in different contexts in the past 20 years (Haun *et al.*, 2014:303); most were designed in developed countries, for use in populations with socio-economic, cultural, and health systems environments that differ from that in South Africa (Reid *et al.*, 2019:1). Most health literacy tools are available in English, and translation, especially into local phonetic languages, can influence the validity of the instrument (Marimwe & Dowse, 2017:2). Measuring health literacy, therefore, has to be multidimensional, and must take the context and objective of the activity into account (Dodson *et al.*, 2015:Online).

Health literacy tools are divided mainly into screening and more comprehensive measurement tools (Haun *et al.*, 2014:303; Okan *et al.*, 2019:68). Screening tools for health literacy are quick, easy to use, short tools, while measuring health literacy investigates the structure and functions of objects of interest (Marimwe, 2018:23). Haun *et al.* (2014:302–333) classify validated health literacy tools into three categories: general health literacy tools, disease-specific tools, and population-specific tools. The most commonly used general health literacy tests, the REALM and the TOFHLA, are used to compare other measures against (Haun *et al.*, 2014:326; Paasche-Orlow & McCormack, 2020:Online).

The **REALM** is based on word recognition and pronunciation of 66 increasingly complex medical terms. It measures reading ability in a medical setting in two to three minutes (Davis *et al.*, 1991:433–435). The Rapid Estimate of Adult Literacy in Medicine Revised (**REALM-R**) (Bass, Wilson & Griffith, 2003:1036–1038) is the shortened version of the REALM, and consists of eight to 11 medical words; it is administered in an average time of two minutes. Neither the REALM nor the REALM-R version measure understanding or interpretation – only pronunciation of the words is measured, which is one of the shortfalls of this test (Institute of Medicine, 2004:51; Wasserman, Wright & Maja, 2010:1). To the researcher's knowledge, the REALM and revised versions of the REALM have been translated into Arabic, Spanish, Lebanese, Turkish and Persian (Paasche-Orlow & McCormack, 2020:Online).

Disease-specific health literacy tools have been promoted as more effective for assessing specific health literacy needs. Content validity of the **REALM-T** was enhanced by the input of four transplant physicians (Gordon & Wolf, 2009:27). The REALM-T (Gordon & Wolf, 2009:25–34) is a modified, validated version of the REALM that measures knowledge of 69 terms that kidney transplant patients might have been exposed to.

The **TOFHLA** was developed to assess reading comprehension and numeracy skills in about 22 minutes. Three passages are used to measure the ability to read and understand: a hospital informed consent form; a section of a Medicaid application; and preparation instructions for a medical procedure. This test is based on the "Cloze-method", which requires blank spaces to be filled in from words selected from a multiple-choice list (Parker *et al.*, 1995:537–541). An abbreviated version of this test, the **STOFHLA**, an 8–12 minute test, is reduced to two reading passages: the first passage at a 4th-grade reading level, and the second at a 10th-grade reading level (Baker *et al.*, 1999:33–42). The TOFHLA is also available in Spanish (Parker *et al.*, 1995:537–541) and other languages, such as Lebanese, Mandarin, French, German and Italian (Paasche-Orlow & McCormack, 2020:Online).

Both tools are commonly used, and measure basic print literacy using health-related terminology. However, the tools fail to measure other skills and knowledge associated with the comprehensive definition of health literacy (Institute of Medicine, 2004:71). Another concern with tests like the REALM and TOFHLA, is that patients with limited literacy may be ashamed of their health literacy status (Parikh, Parker, Nurss *et al.*, 1996:33–39). Furthermore, the lengthy TOFHLA may be impractical for the clinical setting (Parker *et al.*, 1995:540). Weiss *et al.* (2005:514–522) developed the NVS specifically for use in the clinical setting.

The **NVS** is structured around a six-item ice-cream label, and measures reading and understanding of the information on the label (Osborn, Weiss, Davis *et al.*, 2007:S37). This tool takes about three minutes to administer and is available in English and Spanish. Osborn *et al.* (2007:S37–S46) found that the NVS had a high correlation with both the REALM and S-TOFHLA, and was an accurate health literacy measuring tool. A study by Taylor, Fraser, Bradley *et al.* (2017:1082) found the NVS was the only health literacy tool that measured numeracy, which is one of the functional tasks that a dialysis patient has to perform (Mazarova, Hiremath, Sood *et al.*, 2017:e139–e140). The NVS is recommended by Mazarova *et al.* (2017:e136–e144) for assessing health literacy in

haemodialysis patients, because the ability to read and understand a nutrition label is a critical self-management skill needed by dialysis patients. However, by categorising literacy into either low (0–4 correct), or adequate health literacy (5–6 correct), this test does not differentiate between adequate and marginal literacy, which could possibly overestimate patients with low literacy due to its oversensitivity for low literacy (Weiss *et al.*, 2005:514–522). A further limitation of the NVS is that the NVS is not a predictor of adverse health outcomes (Osborn *et al.*, 2007:S44). Nevertheless, the NVS measures low literacy accurately (Kazley, Hund, Simpson *et al.*, 2015:86) and does not invoke shame or embarrassment for patients (VanGeest, Welch & Weiner, 2010:409–410).

Single-item screening tools, which are also categorised amongst general health literacy tools (Paasche-Orlow & McCormack, 2020:Online), have been developed to identify patients with low literacy in the clinical environment: The **Brief Health Literacy Screener** uses a total of three items to assess confidence in filling out forms (Chew, Bradley & Boyko, 2004:588–594). This subjective tool is completed by self-administration or an oral interview, takes one to two minutes to complete, and has shown validity across diverse populations, including haemodialysis patients in the United States (Cavanaugh, Osborn, Tentori *et al.*, 2015:463).

The **Single Item Literacy Screener** consists of a single question, "How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?", which measures reading ability only (Morris, MacLean, Chew *et al.*, 2006:1–7). This fast, effective test is used in clinical settings as a self-administration health literacy tool, but has the potential for self-report bias (Haun *et al.*, 2014:320). Single screening tools, including the NVS, only identify those at risk of low health literacy, and do not provide a full assessment of health literacy (Cutilli, 2015:28).

The Institute of Medicine (2004:6) states that current health literacy tools are indicators of reading skills, and do not measure the full range of skills needed for health literacy, which include "cultural and conceptual knowledge, listening, speaking, numeracy, writing and reading". The **Health Literacy Questionnaire** (Osborne, Batterham, Elsworth *et al.*, 2013:1–17) is a comprehensive, general health literacy tool, and the **Decision-Making Capacity Assessment Tool** (Kazley, Jordan, Simpson *et al.*, 2014:263–270), is a transplant-specific test.

The **Health Literacy Questionnaire** is a comprehensive measurement tool that measures nine domains of health literacy, and is available in several languages (Osborne *et al.*, 2013:1–17). The tool is verbally or self-administered, takes an average of seven and a half minutes to complete, and consists of 44 items (Paasche-Orlow & McCormack, 2020:Online). Self-administration of this tool compromises its objectivity (Haun *et al.*, 2014: 321).

The **Health Literacy Questionnaire** was used in two studies of haemodialysis patients (Dodson *et al.*, 2016:91–98; Skoumalova, Kolarcik, Geckova *et al.*, 2019:1–10). Dodson *et al.* (2016:91–98) used this tool to explain why patients with ESRD struggle to face the challenges they experience. The authors found that ESRD patients had a better ability to find and utilise useful health information than other health consumers, which could have been influenced by their contact with the healthcare system pre-dialysis (Dodson *et al.*, 2016:95). However, on the health literacy domain of actively managing health, lower scores were reported, which could possibly be explained by the psychological distress and fatigue experienced by dialysis patients (Dodson *et al.*, 2016:96).

The Slovak version of the **Health Literacy Questionnaire** (Kolarcik, Cepova, Madarasova Geckova *et al.*, 2017:591–604) was used in the study by Skoumalova *et al.* (2019:1–10) of 452 patients on dialysis in Slovakia, to determine whether health literacy was related to dietary and fluid adherence. An association of lower health literacy was identified with non-adherence to both diet and fluid intake (Skoumalova *et al.*, 2019:6). By using this multidimensional tool to capture the contextual nature of health literacy, the influence of health literacy on dietary and fluid intake adherence was identified (Skoumalova *et al.*, 2019:7), while the use of one-dimensional tools was considered insufficient (Baker, 2006:882).

The **Decision-Making Capacity Assessment Tool** (Kazley *et al.*, 2014:263–270) was developed specifically for measuring health literacy levels of ESRD patients navigating the healthcare process, and, more specifically, the transplant process. Kazley *et al.* (2014:263) illustrate that patients' health literacy and decision-making capacity vary significantly in relation to their stage of care. The importance of decision-making as part of a patient's health literacy and access to care is illustrated by using this tool (Kazley *et al.*, 2015:87).

In the South African context, two contextual and culturally applicable health literacy tests were identified. **The Health Literacy Test for Limited Literacy** (Marimwe & Dowse, 2017:1–12) was developed in South Africa for use with the isiXhosa speaking population in the Eastern Cape. The **SHLT** (Reid *et al.*, 2019:1–13) is a general health literacy tool that was developed for use with the Sesotho-speaking population.

The **Health Literacy Test for Limited Literacy** (Marimwe & Dowse, 2017:1–12) was developed for use with public healthcare sector isiXhosa speakers in the Eastern Cape province of South Africa. The item bank of health literacy questions investigates factual and procedural knowledge about the national disease burden, and focuses on the social environment (Marimwe & Dowse, 2017:10), which reflects the multidimensional character of health literacy. The authors acknowledge that the questions in the test still need refinement to suit the isiXhosa population (Marimwe & Dowse, 2017:11).

The **SHLT** is a comprehensive, general health literacy tool, which was developed and conceptualised to measure the health literacy of the Sesotho-speaking population in the Free State province of South Africa (Reid *et al.*, 2019:1–13). The authors of this health literacy tool chose to use an expansive health literacy definition endorsed by the WHO (Dodson *et al.*, 2015:Online). Educational and intellectual characteristics of the target population, as well as other characteristics, such as socio-economic and cultural characteristics, morbidity and mortality, and the healthcare setting of the Sesotho population (Reid *et al.*, 2019:5), were included when the test was developed.

Reid *et al.* (2019:1–13) used a combination of traditional and modern approaches to develop this tool – similar to the Health Literacy Questionnaire (Osborne *et al.*, 2013:1–13). Traditionally, previously developed tests and literature are consulted and used as examples; in this case, a modern approach was followed instead, by ensuring that the cultural, language, education and health system contexts of the Sesotho-speaking population were studied and incorporated in the test items (Reid *et al.*, 2019:5). The ten-item multiple-choice test measures appraisal (questions 1–6), and understanding (questions 7–10) of health information, and is administered by a trained, Sesotho first-language fieldworker (Reid *et al.*, 2019:4). A score of <6 is considered low health literacy, ≥6 moderate health literacy, and ≥8 is regarded as a high health literacy level (Reid & Nel, 2021)

Measuring health literacy depends, ultimately, on the objective of the study (Dodson *et al.*, 2015:Online) and, in low- and middle- income countries, individual and community contexts have to be considered (Dodson *et al.*, 2015:Online). In this study, the aim was to assess the health literacy status of Sesotho-speaking ESRD patients in the Free State province. The SHLT is contextualised for the Sesotho-speaking population (Reid *et al.*, 2019:5), and was used in this study as the most appropriate health literacy tool that was available.

Fraser, Roderick, Casey *et al.* (2013:2) state that inadequate health literacy in patients with chronic diseases can be modified, and one of the main objectives of measuring health literacy accurately (Dodson *et al.*, 2015:Online) is improving health outcomes.

2.2.3 Influence of health literacy on health outcomes

Limited health literacy has been recognised as a determinant of poor health outcomes and a driver of unnecessary costs (Mackert *et al.*, 2015:1161). Health outcomes are negatively affected by limited health literacy (Levine, Javalkar, Nazareth *et al.*, 2018: 33; Taylor *et al.*, 2018:1546), which consequently leads to four times more medical resources, compared to patients with adequate health literacy, being used (Chisholm-Burns, Spivey & Pickett, 2018:2326; Mazarova *et al.*, 2017:e136; Shih *et al.*, 2016:2). Limited health literacy is associated with less knowledge of chronic diseases, higher rates of hospitalisation, poorer self-management, failure to do preventive healthcare, and increased morbidity and mortality (Cavanaugh *et al.*, 2015:463; Mazarova *et al.*, 2017:e136; Moore, Smith & Reilly, 2013:35). Furthermore, literature globally confirms the association between limited health literacy and lifestyle diseases, such as diabetes and hypertension (Shaw, Huebner, Armin *et al.*, 2008:460–467; Shih *et al.*, 2016:1).

The management of lifestyle behaviours has a crucial influence on the progression of chronic kidney disease to ESRD (Lambert, Mullan, Mansfield *et al.*, 2015:16). Consequently, the increasing prevalence of diabetes and hypertension have a direct relationship with the rapid rise in the numbers of patients developing ESRD (Liyanage, Ninomiya, Jha *et al.*, 2015:1975).

According to Fraser and colleagues (2013:132), an average of 23% of ESRD patients in the United States, has inadequate health literacy levels. Understanding ESRD is an

essential part of self-management and shared decision-making for this condition, and is required to improve outcomes (Fraser *et al.*, 2013:130).

2.3. TREATMENT OF END-STAGE RENAL DISEASE

The most severe form of chronic kidney disease, stage 5, or ESRD (Etheredge & Fabian, 2017:1), is diagnosed when the glomerular filtration rate is less than 15 ml/min and the patient has one or more of the following symptoms:

- symptoms or signs of uraemia;
- diuretic-resistant fluid overload;
- uncontrolled blood pressure;
- evidence of malnutrition; and
- refractory metabolic acidosis (South African Renal Society, 2015:2).

At this stage, treatment has to be commenced to sustain life. Renal replacement therapy replaces part of the kidney function that has been lost, either with dialysis therapy or through transplantation (Etheredge & Fabian, 2017:1; Liyanage *et al.*, 2015:1975; Skoumalova *et al.*, 2019:2).

2.3.1 Renal replacement therapy

Despite transplantation being the therapy of choice, the vast majority of ESRD patients are treated with either in-centre haemodialysis or at-home peritoneal dialysis. Both haemodialysis and peritoneal dialysis are characterised by the filtration and purification of protein-based wastes, such as urea and creatinine, from the blood (Bezerra *et al.*, 2019:3).

2.3.1.1 Peritoneal dialysis

Peritoneal dialysis is recommended as the first line of treatment for ESRD. A permanent abdominal catheter, the Tenckhoff catheter, is inserted in the peritoneal cavity, through which dialysis fluid fills the peritoneal cavity. One type of peritoneal dialysis is continuous ambulatory peritoneal dialysis, during which a patient performs four to five dialysis exchanges per day in order to manage the intake and output of water and electrolytes from the body. The patient has to choose a dialysis bag of a specific concentration to

infuse into the peritoneal cavity. Uremic toxins and excess water are removed through osmosis (Baillie, Gill & Courtenay, 2018:203; Sarian, Brault & Perreault, 2012:18).

Peritoneal dialysis gives rural patients access to renal replacement therapy, as they can treat themselves at home, and patients can continue with employment (Baillie *et al.*, 2018:203). In South Africa, 27.8% of the ESRD patients receiving healthcare from the public sector are treated with peritoneal dialysis, compared to 6% of patients being treated by the private sector (Wearne, Okpechi & Swanepoel, 2019:193). "PD-first" has been successfully practiced in some provinces in South-Africa, with survival rates equal to those in developing countries (Wearne *et al.*, 2019:193).

However, peritoneal dialysis is contraindicated in patients with severe obesity, previous abdominal scarring, illnesses of the abdomen, such as diverticulitis, polycystic kidneys, psychotic disorder, and when a patient's residence is not suitable for doing peritoneal dialysis (Oliver, Garg, Blake *et al.*, 2010:2740). Haemodialysis is initiated when patients are not suitable for peritoneal dialysis treatment or when peritoneal dialysis fails (Brown, Bargman, Van Biesen *et al.*, 2017:362).

2.3.1.2 Haemodialysis

Haemodialysis is based on two main processes, diffusion and ultrafiltration. Diffusion refers to the passage of solutes through a semipermeable membrane, which is made possible by the membrane concentration gradient between the blood and the dialysis solution. Uremic toxins are removed, electrolytes are balanced, and acidosis is restored. Ultrafiltration removes the excess fluid from the patient's blood as a result of the pressure difference between the positive pressure on the blood side and the negative pressure on the dialysate side of the dialyzer (Breuch & Servos, 2010:116; Levy, Brown, Daley *et al.*, 2009:71). The filter inside the dialyser substitutes for the normal kidney, though imperfectly. Because waste products are removed only three times per week for four hours, haemodialysis patients have to follow a strict diet and limit their fluid intake (Skoumalova *et al.*, 2019:2).

Uremic toxins are practically generated by all the functions in the human body, but are only removed from the blood, which constitutes 8% of the total body fluid. The remaining 92% of body fluid, consisting of intra-cellular cells, interstitial space, and the lymphatic system, are all contaminated with uremic toxins. The blood is used as a transport medium and this explains the long treatment times of haemodialysis and why the highest possible

blood flow has to be achieved in the extracorporeal system. Vascular access is obtained through veins with a large diameter through a central venous catheter, an arteriovenous fistula or an arteriovenous graft (Breuch & Servos, 2010:92).

A kidney transplant is the best renal replacement therapy for an ESRD patient, as the patient has a better chance of survival and better quality of life, and it is only half as costly as dialysis (Czyzewski & Wyzgał, 2012:69; Kazley *et al.*, 2015:85).

2.3.1.3 Transplant

All patients should be counselled about the availability of living related or unrelated donors. Despite the list of contraindications for transplant, appropriate investigations, pre-transplant interventions, and careful counselling could make successful transplantation possible (Levy *et al.*, 2009:286). Intensive patient engagement is required from transplant patients (Dageforde & Cavanaugh, 2013:316), as meticulous adherence to immunosuppressive medication prescriptions is required to prevent rejection of the transplant graft (Patzner, Serper, Reese *et al.*, 2016:1294).

On 25 August 1966, the first kidney transplant operation in South Africa was performed at the old Johannesburg Hospital (Fabian, Maher, Bentley *et al.*, 2016:172). In 2016, the kidney transplant rate was 4.5 per million individuals in South Africa (Davids *et al.*, 2018:67), compared to more than 30 per million individuals in Western Europe, the United States, and Australia (Garcia, Harden & Chapman, 2012:267–277). Across the world, healthcare services are facing challenges in relation to providing expensive treatment (Etheredge & Fabian, 2017:2), of which renal replacement therapy is one.

2.3.2 Renal replacement therapy in South Africa

In South-Africa, renal replacement therapy is not a constitutional right (Etheredge & Fabian, 2017:3). South-Africa's health system is two-tiered, with the private sector serving 16% of the population, while the remaining 84% is serviced by an under-resourced public health system (Wearne *et al.*, 2019:192).

In the private sector, dialysis is considered a prescribed minimum benefit, which means that private healthcare providers are obliged to dialyse those patients who can afford the cost of this treatment, irrespective of age or comorbidities. In the public sector, however, rationing of renal replacement therapy is practiced due to limited national resources. Only

patients who are eligible for a kidney transplant are selected for dialysis (Etheredge & Fabian, 2017:3).

Nonetheless, renal replacement therapy, peritoneal dialysis, haemodialysis, and transplantation require patients to cope with complex medication regimens, dietary restrictions, inflexible dialysis treatment schedules and multiple outpatient appointments. These patients inevitably require health navigation skills, the ability to gain health knowledge, investigative skills, and self-motivation, in other words, personal health literacy (Taylor, Bradley, Bradley *et al.*, 2016:685).

2.4. THE RELATIONSHIP BETWEEN END-STAGE RENAL DISEASE, SELF-MANAGEMENT AND HEALTH LITERACY

Decisions are an essential part of an ESRD patients' treatment journey: changes to lifestyle and diet, medication, long-term dialysis or transplantation, and advance care planning, alongside multiple tests and treatment options regarding the comorbidities of ESRD, are all part of these patients' decision-making (Muscat, Kanagaratnam, Shepherd *et al.*, 2018:2). Thus, self-management and partnership with healthcare management are critical skills required to improve health outcomes in the complex life of an ESRD patient (Adeseun, Bonney & Rosas, 2012:348; Bezerra *et al.*, 2019:3; Taylor, Bradley, Bradley *et al.*, 2019:1070; Taylor *et al.*, 2016:685). Several studies have found an association between self-management in ESRD and limited health literacy (Dodson *et al.*, 2016:95; Lambert *et al.*, 2015:21; Skoumalova *et al.*, 2019:6; Wong, Velasquez, Powe *et al.*, 2018:2).

Dageforde and Cavanaugh (2013:311) detected poor self-management behaviour in patients receiving renal replacement therapy. To understand a complex chronic condition, like ESRD, requires engagement in self-management (Wong *et al.*, 2018:1).

2.4.1 Choosing a treatment modality

When ESRD is diagnosed, patients must decide between transplantation, in-centre haemodialysis, home haemodialysis or peritoneal dialysis (Cassidy, Harwood, Getchell *et al.*, 2018:2). Home dialysis, which includes peritoneal dialysis and home haemodialysis, is underutilised, despite all its quality-of-life benefits, such as continuing employment, mental health wellbeing, cost-effectiveness, and convenience (Abdelaal, Ali

& Baharani, 2017:198; Sukul, Zhao, Fuller *et al.*, 2019:2). Peritoneal dialysis should be the treatment of choice for 30–40% of patients receiving renal replacement therapy (Czyzewski & Wyzgał, 2012:67). Preserving residual renal function through peritoneal dialysis is recognised as one of the reasons why this has to be the first choice of renal replacement therapy (Choy & Li, 2015:67). In a study in Poland, 53% of patients did not have any influence on the choice of their treatment modality (Czyzewski & Wyzgał, 2012:64). In a qualitative study by Winterbottom, Bekker, Conner *et al.* (2014:719), patients' understanding of "dialysis choice", was "dialysis" or "no dialysis". Transplantation is the best option for extending and improving the lives of patients with ESRD (Timmerman, Ismail, Luchtenburg *et al.*, 2015:587). Still, post-transplant outcomes are dependent on a certain level of health literacy (Chisholm-Burns *et al.*, 2018:2326).

Cassidy *et al.* (2018:2) identified health literacy as one of the challenges of choosing a dialysis treatment modality. If patients' decisions are not aligned with their values, patients are less motivated to adhere to their treatment (Cassidy *et al.*, 2018:2).

2.4.2 Self-management and adherence to the chosen treatment

Patients on haemodialysis are often prone to feelings of helplessness, depression and fear, as haemodialysis treatment and ESRD are dictating challenging lifestyle changes, changes in economic status, social roles, activity levels, and normal daily routines (Bezerra *et al.*, 2019:3; Parker, 2019:43). Adherence by ESRD patients depends on their knowledge of the disease; thus, a knowledgeable patient takes the role of a collaborator in ESRD (Alikari, Matziou, Tsironi *et al.*, 2015:515).

2.4.2.1 Peritoneal dialysis

Peritoneal dialysis demands self-management (Warsame, Haugen, Hao *et al.*, 2019:457–465) and the patient's role in this treatment plan is key to its success and sustainability (Choy & Li, 2015:322). Patients are responsible for managing their fluid balance, which is a difficult concept to understand (Sarian *et al.*, 2012:19) and they have to be able to recognise signs and symptoms of peritonitis (Baillie *et al.*, 2018:6).

Although peritoneal dialysis should be a patient's first choice of treatment, more patients are treated on haemodialysis, due to the extreme self-management demands involved in peritoneal dialysis (Warsame *et al.*, 2019:457–465). However, Czyzewski and Wyzgał (2012:67) found that patients on peritoneal dialysis prefer a "partner" model in their

relationship with healthcare workers; thus, they have a higher degree of acceptance of their disease, accept greater responsibility for their treatment, and may also be listed faster for transplantation (Czyzewski & Wyzgał, 2012:67).

Taylor *et al.* (2017:1070–1084) reported the prevalence of limited health literacy of peritoneal dialysis patients between 18% and 49.5%. Taylor *et al.* (2017:1082) confirm that, due to limited health literacy skills, patients' decision-making skills and self-management abilities may not be suitable for either peritoneal or haemodialysis modalities.

2.4.2.2 Haemodialysis

As chronic kidney disease progresses into ESRD, which requires renal replacement therapy, self-management challenges increase. However, due to disease symptoms, patients' capacities to perform these activities decrease (Taylor *et al.*, 2017:1070). Patients on haemodialysis report fatigue, insomnia, pruritis, sexual dysfunction, intradialytic hypotension, as well as orthostatic hypotension post-dialysis (Tannor *et al.*, 2017:6). Haemodialysis patients spend 12 to 15 hours per week in a dialysis centre (Czyzewski & Wyzgał, 2012:63), and have to travel between their homes and dialysis centres (Tannor *et al.*, 2017:6). Generally, they are unable to continue with their employment (Tannor *et al.*, 2017:6). Furthermore, the impact of the dialysis and physical symptoms, and the self-management responsibilities, play a role in the onset of depression amongst ESRD patients (Dodson *et al.*, 2016:91). Despite interventions by healthcare providers, self-management of haemodialysis patients is inadequate (Dageforde & Cavanaugh, 2013:311).

Wong *et al.* (2018:4) report that adequate health literacy is not associated with better self-management by patients with chronic kidney disease – in contrast to findings of other publications, that lower health literacy levels are, indeed, associated with lower treatment adherence (Skoumalova *et al.*, 2019:7; Taylor *et al.*, 2016:685). Taylor *et al.* (2016: 685) documented the prevalence of limited health literacy amongst transplant patients at 12%, which is better than the prevalence of 20% amongst dialysis patients.

2.4.2.3 Transplant

An adequate level of health literacy is required to understand the verbal and written information given to a transplant patient (Gordon & Wolf, 2009:25). Immunosuppression,

cyclosporine, prednisone, and toxicity are vital concepts for an immunosuppressant medication regimen. In the first study done by Gordon and Wolf (2009:25–34), to assess the health literacy of transplant patients, health literacy levels were generally high. Still, more than 20% of the patients were unfamiliar with these vital concepts of an immunosuppressant medication regimen. Almost 25% of kidney transplant patients have limited health literacy, and these patients are more likely to be non-adherent to their complex, multidrug regimens post transplantation (Patzner *et al.*, 2016:1300).

Taylor *et al.* (2016:685–695) studied 6 842 patients, of whom 2 621 were on dialysis, 1 959 were waitlisted for transplant while on dialysis, and 2 262 patients received transplants. Patients who had live-donor transplants pre-emptive to starting dialysis, had better health literacy skills than patients who had live-donor transplants after starting dialysis (Taylor *et al.*, 2016:687–688). Almost one third of a deceased donor organ and one fifth of living donor organs fail within five years of transplant (Patzner *et al.*, 2016:1295).

2.4.3 Self-management of dietary and fluid restrictions

Dietary and fluid restrictions play an important role in reducing complications, enhancing the quality of life, and in decreasing mortality in the life of an ESRD patient (Skoumalova *et al.*, 2019:2). Non-compliance to fluid control is 10% to 60% amongst haemodialysis patients. Interdialytic weight gain between two dialysis sessions must not exceed 5.7% of a patient's dry weight, as it necessitates high rates of ultrafiltration during dialysis sessions (Cosar & Pakyuz, 2016:174). High ultrafiltration volumes may lead to complications, such as a patient experiencing hypotension, nausea/vomiting, muscle cramps, and malaise (Smith, Coston, Glock *et al.*, 2010:335). Additionally, high inter-dialytic weight gain and consequently higher ultrafiltration volumes are associated with complications, such as hypertension, congestive heart failure, ischemic cardiac injury and even death (Cosar & Pakyuz, 2016:174; Mazarova *et al.*, 2017:e137). Fluid non-adherence by dialysis patients was reported at 68.5% and non-adherence to the complicated renal diet, at 31.5% (Skoumalova *et al.*, 2019:2).

High intake of potassium and phosphate may also increase morbidity and mortality of dialysis patients. Hyperkalaemia increases the risk of cardiac arrhythmias and potentially sudden cardiac death. Hyperphosphatemia causes metastatic calcification and progression of atherosclerosis (Mazarova *et al.*, 2017:e137). However, Skoumalova *et al.* (2019:7) found that non-adherence to dietary and fluid restrictions was associated with

the inability to manage health and to find sufficient information, and the failure to engage with healthcare providers. Skoumalova *et al.* (2019:7) recommend, furthermore, that healthcare providers consider patients' socio-economic background when supporting patients with fluid and dietary restrictions. Changing eating and drinking habits is complicated and influenced further by socio-cultural structure and traditions of patients (Cosar & Pakyuz, 2016:175).

2.4.4 Medication adherence

The average number of prescribed tablets for an ESRD patient ranges from 12 to 19, which is higher than for any other chronic disease group (Aspden, Wolley, Ma *et al.*, 2015:2). A large number of medications are needed to control hyperphosphatemia, hypertension, anaemia and other side effects of ESRD (Aspden *et al.*, 2015:2). A systematic review of 19 studies done amongst ESRD patients reports non-adherence to prescribed medications by between 3% and 80% of patients (Aspden *et al.*, 2015:2).

Understanding multiple medication prescriptions depends on a patients' ability to understand and process written and numerical information (Taylor *et al.*, 2018:1546). Limited health literacy is associated with difficulty managing medication prescriptions (Taylor *et al.*, 2016:685). If ESRD patients have limited health literacy, they may become overburdened, and consequently non-adherent to their treatment prescriptions, with inferior clinical outcomes (Taylor *et al.*, 2018:1546). However, Wong *et al.* (2018:6–7) state that a higher health literacy status does not ultimately improve medication adherence, though other factors, such as medication counselling, trust in healthcare providers, and numeracy skills, can be critical contributing factors.

Health literacy, furthermore, plays a vital role in listing a patient for transplantation (Kazley *et al.*, 2015:88).

2.4.5 Listing for transplantation

The evaluation process to be listed for transplantation requires intensive engagement from a patient (Dageforde & Cavanaugh, 2013:316). Patients are referred to a transplant centre for evaluation, which includes extensive medical and psychosocial assessments, transplant education and multiple other tests (Kazley *et al.*, 2015:85). Due to limited health literacy, patients may fail to indicate that they want to be listed for transplantation (Grubbs,

Gregorich, Perez-Stable *et al.*, 2009:195), or may be overwhelmed and discouraged by the complexity of the process (Kazley *et al.*, 2015:85). Nephrologists and transplant centres are less willing to refer or waitlist patients with limited health literacy, due to the complexity of the treatment post-transplant (Grubbs *et al.*, 2009:195).

Access to transplantation is, indeed, affected by health literacy (Chisholm-Burns *et al.*, 2018:2326; Kazley *et al.*, 2014:269; Warsame *et al.*, 2019:457–465). Although kidney transplantation has been found to be superior to dialysis due to the higher quality of life it makes possible, most ESRD patients remain on dialysis (Peipert, Hays, Kawakita *et al.*, 2018:5).

Teerawattananon, Luz, Pilasant *et al.* (2016:1–8) suggest that health literacy of patients should be assessed when they are diagnosed with ESRD. Assessment of their health literacy status could improve the understanding of their own illness, their ability to make informed decisions about their care, and their quality of life.

2.4.6 Quality of life

In the United States, the five-year survival rate of haemodialysis patients is 42%, of peritoneal dialysis patients 52%, of deceased-donor transplant patients 77% and of living-donor transplant patients 84% (United States Renal Data System, 2019:423). In South Africa, the average years of survival on haemodialysis is 3.8 years and 3.5 years on peritoneal dialysis, and 8.1 years for transplant patients (Davids, Jardine, Marais *et al.*, 2019:65). Limited health literacy of ESRD patients is associated with higher mortality rates and lower quality of life (Adeseun *et al.*, 2012:348; Cavanaugh, Wingard, Hakim *et al.*, 2010:1983).

Campbell, Stevenson, Mccaffery *et al.* (2016:2) consider health literacy dually: health literacy is seen as a risk factor or an asset. As an asset, health literacy can improve through patient education. Consequently, the involvement of a patient, and the self-management of chronic disease, like ESRD, can be improved.

2.5. ASSESSMENT OF HEALTH LITERACY IN END-STAGE RENAL DISEASE

In 2012, Fraser *et al.* (2013:1–8), reported a prevalence of 22.7% of limited health literacy amongst 1 405 dialysis and transplant patients. Fraser and colleagues reviewed five studies, all from the United States, in a systematic review. In 2017, Taylor and colleagues

(1070–1084) published another systematic review of 20 studies (including the five studies from the 2012 review), which reported similar limited health literacy levels of 25% amongst 12 324 patients with chronic kidney disease of all stages. These findings correlate with health literacy findings for general populations in the United States (Paasche-Orlow, Parker, Gazmararian *et al.*, 2005:175–184).

2.5.1 Global assessment of health literacy in ESRD

The 2012 systematic review of Fraser *et al.* (2013:1–8) stimulated research in the ESRD population, as well as research outside the United States (Taylor *et al.*, 2017:1071). Of the 20 studies in the systematic review of Taylor *et al.* (2017:1070–1084), one study presented data from the United Kingdom (Taylor *et al.*, 2016:685–695) and the rest were from the United States (Taylor *et al.*, 2017:1071). The measures used by Taylor *et al.* (2017:1070–1084) in their study are discussed in Table 2.1.

Table 2.1: Summary of health literacy measures used in systematic review by Taylor *et al.* (2017:1070-1084)

Health literacy measure	% of studies using the measure	Form	Duration (minutes)	Interpretation of health literacy
STOFHLA	45%	Modified Cloze procedure of 36 reading comprehension items to be selected from four choices	12 min	0–22: Limited 23–36: Adequate
REALM	5%	Pronunciation accuracy of 125 health-related words (66 in more commonly used form)	3 min	0–44: Inadequate 45–60: Marginal 61–66: Adequate (limited=inadequate + marginal)
Rapid Assessment of Adult Literacy – Transplant (REALM-T)	5%	69 Kidney transplant-related terms tested for pronunciation accuracy	3 min	Not clearly defined

Health literacy measure	% of studies using the measure	Form	Duration (minutes)	Interpretation of health literacy
Brief health literacy screener	20%	Three questions. How confident are you filling out forms by yourself? How often do you have someone help you read hospital materials? How often do you have problems learning about your medical condition because you have difficulty reading hospital materials? All graded 1-5; scores range from 3 to 15	<1 min	3–8 (or 0-5): lower 9–14 (or 6-12) moderate/higher (<10/15 or <6/12 indicates limited health literacy)
NVS	5%	Six-item assessment of reading comprehension from an ice cream nutrition label	6 min maximum (average 2.9)	0–1: High likelihood marginal/inadequate 2–3: possible marginal/inadequate 4–6: adequate (score <4 indicates limited health literacy)
Single item literacy screener	10% (English and Spanish)	Question: How often do you need to have someone help you when you read instructions, pamphlets or other written material from your doctor or pharmacy? Answered on a 5-point Likert scale from 1 (never) to 5 (always)	<1 min	<3: Adequate ≥3: Limited
Two-item literacy screener	5% (English and Spanish)	Two questions: What was the last educational grade you completed? Can you estimate	<1 min	Sensitivity/specificity of different cut-off points was tested; use of two-item literacy screener >1 to

Health literacy measure	% of studies using the measure	Form	Duration (minutes)	Interpretation of health literacy
		your reading ability with one of the following: I frequently read complete books, I read the newspaper, or I frequently need help with the newspaper, scored from -4 to +5		indicate limited health literacy is suggested

Taylor and colleagues (2017:1070–1084) found that research into chronic kidney disease and ESRD is limited and that most of the studies’ quality was low. Only five studies were judged to be of moderate quality. A consistent association of non-white ethnicity and low socio-economic status with low health literacy was found in the population of patients with chronic kidney disease (Taylor *et al.*, 2017:1070).

To the researcher’s knowledge, the health literacy status of patients with ESRD in Africa, and South Africa, is unknown. Still, the prevalence of chronic kidney disease in sub-Saharan Africa (13.9%) is equal to global estimates of 13.4% (Etheredge & Fabian, 2017:2). In countries such as South Africa, where treatment is unaffordable and not easily accessible for most of the population (Okpechi, 2017:e373), this burden could benefit from this population’s health literacy being assessed.

2.6. DETERMINANTS OF LIMITED HEALTH LITERACY IN END-STAGE RENAL DISEASE

Limited health literacy of ESRD patients has consistently been found to be predicted by age, lower education levels, ethnicity (Adeseun *et al.*, 2012:351; Cavanaugh *et al.*, 2010:1981; Chisholm-Burns *et al.*, 2018:2327–2330; Green, Mor, Shields *et al.*, 2011:24–30; Gordon & Wolf, 2009:31; Hsu, Iribarren, Mcculloch *et al.*, 2009:6) and by other socio-economic factors, multiple comorbidities, male gender (Cavanaugh *et al.*, 2010:1981; Lambert *et al.*, 2015:21; Warsame *et al.*, 2019:462) and marital status (Chisholm-Burns *et al.*, 2018:2330; Kazley *et al.*, 2014:269).

2.6.1 Age

In general populations, increasing age predicts lower health literacy levels (Okan *et al.*, 2019:153–157). Financial deprivation, the presence of chronic illnesses, and cognitive and physical deterioration are all predictors of limited health literacy in the older population (Okan *et al.*, 2019:157). Age has, similarly, been found by various studies to be a predictor of limited health literacy in the ESRD population (Adeseun *et al.*, 2012:351; Chisholm-Burns *et al.*, 2018:2327; Hsu *et al.*, 2009:347; Kazley *et al.*, 2014:269).

2.6.2 Low education attainment

Low levels of education influence health literacy (Paasche-Orlow *et al.*, 2005:179), and different studies involving the ESRD population confirm this finding (Cavanaugh *et al.*, 2010:1981; Hsu *et al.*, 2009:347; Shih *et al.*, 2016:7; Warsame *et al.*, 2019:462). Lambert *et al.* (2015:22) found that more than 50% of ESRD patients had less than 12 years of schooling. However, education is not a definite predictor of health literacy, as 3–10% of patients with university-level qualifications were identified as having limited health literacy (Taylor *et al.*, 2016:686).

2.6.3 Ethnicity

Ethnic minorities – often those in high-income countries – have disproportionately low health literacy skills (Cavanaugh *et al.*, 2010:1981; Gordon & Wolf, 2009:31; Taylor *et al.*, 2017:1081). Language and culture play vital roles in patients' health literacy (Singleton & Krause, 2010:1–12) and cultural minority status often suggesting the most vulnerable patients (Andrulis & Brach, 2007:2).

2.6.4 Socio-economic factors

Other socio-economic factors, namely income and employment status, also play a role in the prevalence of limited health literacy (Chisholm-Burns *et al.*, 2018:2328) and was confirmed by studies into ESRD patients (Adeseun *et al.*, 2012:351; Gordon & Wolf, 2009:31; Taylor *et al.*, 2016:690).

2.6.5 Comorbidities

As ESRD progresses, a patient's ability to cope may be influenced by symptoms of the illness, increased comorbidities, and by reduced functional status (Taylor *et al.*, 2018:1546). Lambert *et al.* (2015:22) found that more than 50% of patients with ESRD have more than three comorbidities. Cognitive impairment, a common comorbidity of ESRD patients, contributes to low health literacy in this population (Cavanaugh *et al.*, 2015:463; Warsame *et al.*, 2019:465).

2.6.6 Other determinants

Male gender was identified as a predictor of limited health literacy in two studies of ESRD patients (Cavanaugh *et al.*, 2010:1981; Lambert *et al.*, 2015:21). Women are more likely to make decisions regarding healthcare, thus, making marriage another predictor of limited health literacy in men (Chisholm-Burns *et al.*, 2018:2330; Kazley *et al.*, 2014:269). Gordon and Wolf (2009:30) found that patients who are single or without a partner had lower health literacy levels.

2.7. THE ROLE OF CULTURE AND LANGUAGE IN MEASURING HEALTH LITERACY

People respond to health through a *cultural* lens (Singleton & Krause, 2010:9), which affects from whom they seek healthcare, how they describe their symptoms, and how they respond to treatment offered to them (Andrulis & Brach, 2007:2). A patient has to be comfortable about moving from his or her own cultural beliefs and values to those of the dominant healthcare system (Singleton & Krause, 2010:9). Cultural differences have an immense impact on lifestyle, diet, stress and, consequently, on the management of chronic diseases, such as diabetes and hypertension (Shaw *et al.*, 2008:461), and the eating and drinking needs of patients with ESRD (Cosar & Pakyuz, 2016:175).

Researchers agree that ethnic minorities (Gordon & Wolf, 2009:26; Singleton & Krause, 2010:10; Taylor *et al.*, 2018:1546), and non-English speaking patients (Andrulis & Brach, 2007:2; Taylor *et al.*, 2016:693) in the United States have limited health literacy. Translation of health-related material is often seen as a solution for language barriers in healthcare (Andrulis & Brach, 2007:3). Still, language is the primary expression of culture and not all content is easily translated (Singleton & Krause, 2010:2). Neither does the

translation of existing health literacy tools seem to be the solution for measuring health literacy amongst diverse population groups (Dowse *et al.*, 2010:470). The use of the REALM with isiXhosa speakers in the Eastern Cape in South Africa confirmed this limitation (Dowse *et al.*, 2010:464–471). Individual and community contexts have to be considered when measuring health literacy, especially in low- and middle-income countries (Dodson *et al.*, 2015:69), including South Africa.

2.8. SESOTHO-SPEAKING PATIENTS WITH END-STAGE RENAL DISEASE

The South African population is rich in ethnicities and has 11 official languages, of which each is spoken as a first language by a distinct cultural group. Afrikaans and English belong to the Germanic language family, and the other nine languages, spoken by 77.9% of the South African population, are Bantu languages (Nel, Valchev, Rothmann *et al.*, 2012:920).

The Free State is a province in the heart of South Africa and is characterised by cultural diversity (Statistics South Africa, 2016b:1). Sesotho, or South Sotho, one of the country's 11 official languages, is predominantly used by 71.9% of the Free State's population as their home language (Statistics South Africa, 2016b:19). Sesotho is a tonal language that utilises "click" sounds in some words (South African History Online, 2019:Online). Motsei (2013: 620–621) only promotes translation from English to Sesotho if a translator has an adequate understanding and knowledge of the socio-cultural or ethnolinguistic influences of both languages – a prerequisite that applies to all translation.

It is noted in the community survey report of the Free State province that 13.4% of the Free State's population of 20 years and older has no schooling, and another 10.9% only completed primary school (Statistics South Africa, 2016a:36). Thus, at least 20% of the province's population has the potential to have low health literacy levels due to their low education level (Paasche-Orlow *et al.*, 2005:179). In 2016, the poverty rate in the Free State province was 55.5%, and 34.7% of the population was unemployed (Treasury South Africa, 2017:9–19). The socio-economic status of this population could mean this population is vulnerable to having low health literacy levels.

In 2017, 578 patients were treated for ESRD at 19 different dialysis centres in the Free State province, of which six were public and 13 private centres (Davids *et al.*, 2019:64–65). The Renal Registry reported that 51.7% of ESRD patients in South Africa were of

black ethnicity (Davids *et al.*, 2019:65). In the researcher's experience in the dialysis field, the majority of ESRD patients in the Free State province would, indeed, be Sesotho-speaking.

With the emphasis on understanding health literacy in the context of culture and language (Institute of Medicine, 2004:137), the health literacy status of adult Sesotho first-language speaking ESRD patients in the Free State province could possibly benefit from the use of the culture- and language-specific SHLT (Reid *et al.*, 2019:1–13).

2.9. CONCLUSION

This chapter presented an overview of the development of health literacy and the importance of measuring the health literacy of ESRD patients. Self-management, quality of life and health outcomes of ESRD patients are affected by health literacy. Understanding the health literacy of a specific population requires understanding of context-specific aspects, such as culture and language, when choosing a measuring tool. The SHLT could be an effective health literacy tool to measure the health literacy status of Sesotho-speaking patients with ESRD in the Free State province.

The purpose of the next chapter is to describe the research methodology applied by the researcher.

CHAPTER 3: RESEARCH METHODOLOGY

3.1. INTRODUCTION

Research methodology is the systematic, purposeful plan used by a researcher to yield data to investigate a particular research problem. This plan is developed to acquire valid and reliable knowledge (McMillan & Schumacher, 2010:8; Polit & Beck, 2017:734).

Chapter 2 provided an in-depth review of the literature on the general health literacy status of patients with end-stage renal disease. In this chapter, the researcher will present a general overview of the quantitative, descriptive, cross-sectional design the study employed, the research technique used, the population and sampling, the pilot study, and the data collection. It will also report how the data collection strengthened the validity and reliability of the study and will describe how the researcher and fieldworkers adhered to ethical considerations in collecting the data. In the conclusion of this chapter, the data analysis process will be discussed.

3.2. RESEARCH DESIGN

A research design is a step-by-step plan that a researcher applies to reach an intended goal when conducting a study (De Vos *et al.*, 2011:41). Designing occurs at the beginning of a study, though all the steps of the planned research project are included in this process of planning (Babbie, 2016:113). This plan, which forms the backbone of the study, dictates the structure of the methodology to be used, the collection and analysis of data and the interpretation of results (Brink *et al.*, 2012:41; Burns & Grove, 2009:96). In this study, the researcher used a quantitative, descriptive, cross-sectional design to plan, collect and analyse data, and to interpret the results relating to a description of the health literacy of Sesotho-speaking patients with end-stage renal disease in the Free State province.

The research design also refers to the influence the researcher has over factors that could affect the anticipated outcome of a study (Burns & Grove, 2009:49; Maree & Pietersen, 2017b:174). The researcher's presence during data collection aided the researcher to remain in control of the study. The structured guideline for completing the SHLT (Addendum B) assisted the researcher to influence the fieldworkers to be competent and of value to the study, and both these factors strengthened the research design.

A research design is, furthermore, the blueprint for answering a research question (Polit & Beck, 2017:43). The research question of this study, *What is the health literacy status of Sesotho-speaking patients with end-stage renal disease in the Free State province?*, was answered by the meticulous analysis of data, guided by the principles of the Belmont Report (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979:1–10).

3.2.1 Quantitative research

The main characteristics of quantitative research are *objectivity*, *numerical data*, and *generalisability* (Maree & Pietersen, 2017a:162). These three characteristics were emphasised during this study, as discussed in the following paragraphs.

According to Polit and Beck (2017:737), researchers are *objective* when they arrive at similar results independently after collecting data. Before the study commenced, the fieldworkers were trained and evaluated by the researcher to collect data according to the Guideline (Addendum B) and, during the pilot study, findings of the questionnaires the fieldworkers completed, were compared and found similar. The respondents were not known to the fieldworkers, or to the researcher, and during data collection, there was no room to manipulate the respondents. Thus, objectivity was enhanced throughout the study.

In quantitative research, *numerical data* are analysed through statistical procedures (Brink *et al.*, 2012:11). The researcher entered the data into an Excel spreadsheet after data collection; the data were also independently co-captured by a co-data capturer. Analysis of the data was done by a biostatistician of the Faculty of Health Science at the University of the Free State, and the researcher was guided by the biostatistician in interpreting the analysed data.

A quantitative researcher intends to *generalise* research results to larger settings (Botma *et al.*, 2010:83). A convenient sample was drawn from the population of Sesotho-speaking ESRD respondents at six private and four public dialysis centres of four towns in the Free State province. The findings of this study may be considered for generalisation to other Sesotho-speaking ESRD patients. A number of strengths made the quantitative design a good choice for this research, and these strengths will be discussed below.

3.2.1.1 Strengths of quantitative research

This section discusses the strengths of a quantitative research design.

- *Generating scientific nursing knowledge:* Scientific nursing knowledge that is generated by quantitative research inspires continuous improvement in nursing practice, education, and management (Botma *et al.*, 2010:82). By ascertaining the health literacy status of Sesotho-speaking ESRD patients in the Free State province, health outcomes of this population can be improved, as health interventions may be planned according to these patients' health literacy status.
- *Generalising the research results:* Systematic, controlled and objective research conditions are typical aspects of quantitative research, which enable a researcher to draw unbiased conclusions that can be generalised and applied to a larger population (Leedy & Ormrod, 2015:105; Polit & Beck, 2017:11). In this study, data were collected using a typical quantitative methodology, and this means that the study findings may be considered for generalisation to the broader population of Sesotho-speaking patients with ESRD.
- *Quantification:* Data gathered through quantification clearly express observation. Data collection, comparisons and summarising of data are simplified through quantification. It provides the opportunity for statistical analysis and, then, numbers are the measure of quality that can be described clearly (Babbie, 2016:26; Katz, 2006:24). Descriptive statistics were calculated per group. Frequencies and percentages were calculated for categorical data and medians and percentiles for numerical data. The groups were compared by means of the Chi-square test or Fisher's exact test for categorical data and the Kruskal-Wallis test for numerical data.
- *Cost-effectiveness:* Descriptive, cross-sectional studies are considered more economical than experimental designs, as large amounts of data can be collected at one point in time (Brink *et al.*, 2012:101; Polit & Beck, 2017:170). Data were collected over a period of four weeks, and haemodialysis and peritoneal dialysis of ESRD respondents at private and public dialysis centres were compared statistically. Funding was received to cover the costs of data collection and the researcher was able to keep within the allocated budget.

In addition to all the above strengths of quantitative research, there are, unfortunately, also some limitations.

3.2.1.2 Limitations of quantitative research

- *Quantification of data can be challenging:* Unless statistical analysis of data is executed, data can be a disorganised mass of numbers (Brink *et al.*, 2012:179). The data analysis for this study was generated using SAS software (Copyright of SAS Institute Inc. SAS and all other SAS Institute Inc. product or service names are registered trademarks or trademarks of SAS Institute Inc., Cary, NC, United States of America.) The biostatistician assisted greatly in quantifying data, which meant that statistical analysis was not a challenge in this study.
- *Researcher's role:* In quantitative research, researchers are detached from the research process (Botma *et al.*, 2010:42). During this research, the structured questionnaire (Addendum A), necessitated that the researcher play an objective role and, therefore, the researcher was not subjectively involved in data collection. The Sesotho-speaking fieldworkers were strictly guided by the structured guideline for the SHLT (Addendum B) in completion of the questionnaires.
- *Loss in depth:* Numerical data has the potential to lose depth of meaning (Babbie, 2016:26). This study aimed to assess the health literacy status of Sesotho-speaking patients with ESRD in the Free State province, and the validated nature of the SHLT questionnaire assisted the study to focus on answering the research question.
- *The number of concepts investigated:* Only a small number of concepts can be investigated, and not a whole phenomenon (Botma *et al.*, 2010:82). The concepts of appraising and understanding in the SHLT were investigated. The aim of the validated SHLT (Reid *et al.*, 2019:1–13; Reid & Nel, 2021) was to assess the health literacy of Sesotho-speaking patients, and the SHLT could consequently be used to assess the health literacy of Sesotho-speaking ESRD patients in the Free State province.

3.2.2 Descriptive research

Descriptive research, which is included under observational or non-experimental research, summarises the status of phenomena in a natural setting and, then, accurately portrays and documents the characteristics of the situation as it is (Babbie, 2016:91; De Vos *et al.*, 2011:144; Polit & Beck, 2017:206, 213, 726). The need to assess the unknown health literacy status of Sesotho-speaking ESRD patients in the Free State province

made the descriptive design appropriate for this study. The respondents were assessed while they attended the dialysis centres. These types of descriptions are presented through percentages and frequencies for categorical data and medians and percentiles for numerical data.

Comparative descriptive designs explore the differences between two or more groups of the representative sample (Brink *et al.*, 2012:114). This study compared and described the health literacy status of haemo- and peritoneal dialysis ESRD respondents, and between ESRD respondents receiving treatment from private and public sectors of the Free State province, to investigate a possible association. The groups were compared utilising the Chi-square test or Fisher's exact test for categorical data and the Kruskal-Wallis test for numerical data.

3.2.3 Cross-sectional design

Cross-sectional research designs gather data from a cross-section of the study population at one point in time. This implies that data on various characteristics are collected only once from a specific population sample at a specific point in time (Babbie, 2016:106; Brink *et al.*, 2012:101; De Vos *et al.*, 2011:156). Polit and Beck (2017:168) state that cross-sectional designs are a suitable design for describing relationships between phenomena at one point in time. In this study, data were collected with a structured questionnaire, the SHLT (Addendum A), within four weeks, to establish whether there was an association between the health literacy status of haemo- and peritoneal dialysis respondents, and between private and public dialysis centres in the Free State province.

After justifying the research design that was chosen to answer the research question, namely a quantitative, descriptive, cross-sectional design, an explanation of the technique the researcher used, will be provided.

3.3. RESEARCH TECHNIQUE: STRUCTURED QUESTIONNAIRE

The researcher needs an instrument to gather data, and in quantitative research, self-reported, observational and physiological measurements are often used (Botma *et al.*, 2010:133; Brink *et al.*, 2012:149). If a researcher wants to know what a respondent thinks, believes or knows, the easiest and most efficient method to obtain to an answer, is to ask

the respondent personally (Brink *et al.*, 2012:152; Polit & Beck, 2017:243). This answer can be obtained by using a structured questionnaire, which contains fixed questions with pre-coded answers; the questionnaire can be completed face to face (Botma *et al.*, 2010:134). The structured questionnaire, which can be classified under self-reported instruments, seemed to be suitable for use in this study, considering that the research population was too large to observe directly (Burns & Grove, 2009:44).

3.3.1 Development of the questionnaire

The structured questionnaire used in this study was the SHLT (Addendum A). The SHLT (Reid *et al.*, 2019:1-10) was developed locally for testing general health literacy, specifically that of Sesotho-speaking respondents. The SHLT was validated, which indicates good internal reliability (Cronbach's $\alpha=0.77$). Exploratory structural equation modelling demonstrated acceptable fit with a standardised root mean square residual of 0.04. The convergent and predictive validity of the SHLT was good (Reid & Nel, 2021). The questionnaire is intended to be completed face to face by a Sesotho-speaking person.

A well-designed questionnaire is of utmost importance for a research project. The questionnaire should be easy to use and the layout well planned, and it should not take longer than thirty minutes to complete (Maree & Pietersen, 2017b:179). The SHLT was designed by experts in health literacy (Reid *et al.*, 2019:4), resulting in a contextually appropriate, well-designed instrument that was easy to use. Part 1, constructed by the researcher, gathered demographic and general information. Part 2 consisted of ten closed-ended questions, of which the first six questions tested the respondent's ability to appraise information, and the last four questions tested the respondent's understanding of the information. The SHLT (Addendum A), is meant to be completed in five to ten minutes, on average, which enabled the researcher to collect data from at least 250 respondents.

The impact of the advantages and disadvantages of a structured questionnaire will be discussed below.

3.3.1.1 Advantages and disadvantages of questionnaires

Using a structured questionnaire as research instrument has definite advantages (Botma *et al.*, 2010:135; Brink *et al.*, 2012:153; Maree & Pietersen, 2017b:177; Polit & Beck, 2017:243), and also disadvantages (Burns & Grove, 2009:358; Maree & Pietersen, 2017b:177; Polit & Beck, 2017:243), as pointed out below.

a) Advantages of questionnaires

- The response rate on face-to-face interviews is high and refusal to participate tends to be low, which makes it possible to gather a vast amount of data with minimal effort (Botma *et al.*, 2010:135). This was found to be the case in this study, in which only five participants declined to participate.
- When using face-to-face questionnaires, respondents do not need not be literate (Brink *et al.*, 2012:153; Maree & Pietersen, 2017b:177). The respondents' ability to read or write did not influence the data collected during this study, as the fieldworkers read the closed-ended questions to the respondents and completed the answers on their behalf.
- The person administering the questionnaires has the opportunity to establish rapport, explain the purpose of the study and assure completeness of the questionnaires (Leedy & Ormrod, 2015:160). The respondents were provided with information pertaining to the study (Addendum C2), consent was obtained (Addendum D2) and, then, the questionnaires (Addendum A) were completed and checked for completeness by the researcher on site.
- As a well-designed, easy-to-use instrument, a structured questionnaire reduces the opportunity for bias (Botma *et al.*, 2010:135). The fieldworkers read out questions as they appear on the questionnaire, hence, presenting the information consistently to all respondents according to the guideline (Addendum B). By following this structured plan, bias was minimised.
- Closed-ended questions provide data that can be analysed and quantified easily (Botma *et al.*, 2010:134). The closed-ended questions in the SHLT made it easy for the researcher to capture and code data.

b) Disadvantages of questionnaires

- Questionnaires do not probe deeply into human complexities (Burns & Grove, 2009:358). This study aimed to assess what the health literacy status of Sesotho-

speaking patients with ESRD in the Free State province was, and not to assess the reasons for their current health literacy status; thus, the lack of depth of data is not a disadvantage in this study.

- Cost and time needs to train fieldworkers adequately are high (Polit & Beck, 2017:243). The researcher trained the fieldworkers to use the guideline to complete the SHLT (Addendum B). The cost of and time needed to train the fieldworkers were considered before the study commenced and did not negatively affect the study.
- Respondents do not have the opportunity to elaborate on answers or ask for clarification on questions (Brink *et al.*, 2012:153). During the training of the fieldworkers, the researcher emphasised the importance of refraining from elaborating on any questions posed to the respondents, and that the fieldworkers were not allowed to clarify any questions. Clarification of the questions formed part of the validation process of the SHLT (Reid & Nel, 2021).
- A well-designed questionnaire requires considerable effort (Burns & Grove, 2009:358). The SHLT (Addendum A) was developed and validated through immense effort by experts in the field of research (Reid *et al.*, 2019:1–13; Reid & Nel, 2021). The researcher could use this validated instrument and only had to construct part 1, which gathered demographic and general information.

3.4. POPULATION

The population is the totality of persons who meet the criteria to be included in a researcher's study, and aligns with the research problem (Botma *et al.*, 2010:123; Brink *et al.*, 2012:131).

The population of this study comprised Sesotho first-language speaking patients with ESRD receiving treatment at public and private dialysis centres in the Free State province. The total number of Sesotho-speaking ESRD patients in the Free State province was unknown, however, in the South African Renal Registry's annual report (2017), the number of ESRD patients on renal replacement therapy in the Free State province is given as 578 (Davids *et al.*, 2019:64). In total, ten dialysis centres in four towns of the Free State province gave permission to collect data in their centres. Table 3.1 depicts the total number of patients in the four towns at the time of the study, which was confirmed by the unit managers of the centres after the required ethical and managerial

approval had been obtained. The estimated number of ESRD patients was not exclusively applicable to Sesotho-speaking patients. However, in the researcher's experience as a unit manager of a dialysis centre in another province, the profile of ESRD patients encountered in the Free State province suggested the majority to be Sesotho speakers.

Table 3.1: Total number of ESRD patients by town, sector and treatment modality in Town 1, Town 2, Town 3 and Town 4

Towns in the Free State province	Sector	Haemo-dialysis	Peritoneal dialysis	Total
Town 1	Public sector	58	100	158
	Private sector	83	29	112
	Total patients	141	129	270
Town 2	Public sector	11	25	36
	Private sector	34	6	40
	Total patients	45	31	76
Town 3	Public sector	11	0	11
	Private sector	35	6	41
	Total patients	46	6	52
Town 4	Private sector	22	0	22
Total patients in population		254	166	420

3.4.1 Sampling

A sample is a group of subjects selected by the researcher, who are representative of the population being studied, thereby enabling the researcher to generalise findings to the entire population (Brink *et al.*, 2012:132; Burns & Grove, 2009:41; McMillan & Schumacher, 2010:129; Polit & Beck, 2017:249). The sample consisted of respondents selected through a convenient technique. Convenience sampling refers to the availability of respondents who are easily accessible to the researcher (Maree & Pietersen, 2017c:197; McMillan & Schumacher, 2010:137; Polit & Beck, 2017:252). A convenient sample of Sesotho-speaking ESRD patients was drawn from all the dialysis centres in the four towns.

3.4.1.1 Inclusion criteria

Respondents were included in this study if they were,

- Sesotho first-language speakers;
- Diagnosed with ESRD, and being treated on haemodialysis or peritoneal dialysis;
- At least 18 years old; and
- Provided written consent.

3.4.1.2 Exclusion criteria

Respondents were excluded from this study if they,

- Did not meet the above inclusion criteria;
- Did not give consent; or
- Were blind.

Five respondents voluntarily declined to participate.

3.5. PILOT STUDY

A pilot study is a trial run of a planned study, done on a smaller scale to assess the feasibility and to test methodology for a larger study (Polit & Beck, 2017:739). Two Sesotho first-language speaking students, unknown to any of the respondents, were recruited as fieldworkers. They were trained according to the guideline (Addendum B) before the pilot study. The guideline was explained to them, and training involved role play, during which they had the opportunity to complete the SHLT questionnaire in a simulated scenario on each other. The pilot study was done on three respondents. At centre 1, a public sector centre, the two fieldworkers completed a questionnaire on the same peritoneal dialysis respondent and compared their recordings afterwards. Each fieldworker, then, completed an additional questionnaire independently, on a haemodialysis respondent.

During the pilot study, the researcher determined patient willingness to consent, the completion time of the questionnaire, competency of the two trained fieldworkers and if there were any practical issues that had to be taken into consideration. Both fieldworkers were competent, and no further training was required. During the pilot study, only the Sesotho version of the questionnaire was printed. The researcher established that it was difficult to check the questionnaires if only the Sesotho version of the SHLT questionnaire was printed on the questionnaire. As the researcher was not a Sesotho first-language speaker, it would be easier for the researcher to use the questionnaire (Addendum A) if it was depicted with the English and Sesotho versions next to each other. The consent forms were stapled onto the questionnaires, to remind the fieldworkers to obtain consent from respondents before commencing administration of the questionnaire.

During the pilot study, both the researcher and fieldworkers realised that respondents who could speak and understand Sesotho, but for whom Sesotho was not their first language, were also interested in participating in the study. This prepared the fieldworkers to ensure that the respondents were, indeed, only Sesotho first-language speakers.

Data of the pilot study were sent to the biostatistician after the pilot study had been conducted and permission had been granted to continue with the main study. Data from a pilot study can be used in the main study if the intervention used is not changed and if the population is the same (Polit & Beck, 2017:639). As neither the validated SHLT nor the population was changed, the data collected during the pilot study were included in the

main study, as the competency of fieldworkers and practical issues related to data collection did not compromise data quality.

3.6. DATA COLLECTION PLAN

A data collection plan needs meticulous planning during the early stages of a study to ensure that accurate data are collected according to the specific design of the anticipated study. The researcher must be able to answer the following questions during this process: What data are needed? Where will the data be collected? How will the data be obtained? How will the data be interpreted? (Brink *et al.*, 2012:147; Burns & Grove, 2009:383; Leedy & Ormrod, 2015:95–97). Data collection for this study was done in the following sequence.

Upon obtaining permission from the relevant dialysis authorities, the researcher had meetings with the relevant dialysis centres' unit managers. In the meetings, the researcher explained the meaning of the research and how the research would be conducted. The researcher explained that the data collection would take place while respondents were on dialysis and that the researcher and fieldworkers would not disturb the centre's workflow. The researcher also explained that the researcher would travel between different dialysis units between shifts and that a fieldworker would stay at the unit to do the data collection at a specific unit. The researcher would check the completed questionnaires while the respondents were still on dialysis to clarify any uncertainties, as well as ensure the completeness of each questionnaire. During this meeting, the researcher also clarified with the unit manager the estimated number of Sesotho-speaking respondents to expect per dialysis shift. Thus, the researcher could plan how much time was needed per dialysis unit. As the researcher did not reside in the Free State province, meticulous planning had to be done to ensure that the study was completed within the proposed budget while reaching as many respondents as possible.

During data collection at the different centres, the researcher introduced the fieldworker and herself to the identified respondents. The fieldworker explained the purpose of the study to the respondents and after a respondent had agreed to participate, the privacy of the respondent was ensured by closing the curtains around the therapy chair. The fieldworkers then provided the respondents with the information leaflet (Addendum C2) and the consent form (Addendum D2). The documents briefly explained the purpose of

the study, the patient's right to withdraw from the study at any time with no compromise to his/her care, and basic information about how the study would be conducted. The respondents were also assured of confidentiality. To those respondents who could not read or write, the consent form was read out loud and those respondents gave consent by writing an X instead of a signature, as is acceptable in South Africa. Five of the respondents in this study were illiterate and gave permission with an X.

After permission had been obtained, the fieldworker explained to the respondent that no answers could be discussed and that only the available options had to be given as answers. The fieldworker explained to the respondents that she would read the questions out loud and that the answers would be recorded by the fieldworker. Then, the fieldworker completed the SHLT (Addendum A) with each respondent by following the guideline for completion of the SHLT (Addendum B). The structured questions were read to the respondents and the fieldworkers recorded the answers provided by the respondents. The researcher, then, checked each completed questionnaire on site for accuracy. The researcher ensured that each questionnaire was completed fully prior to the fieldworker leaving, and thanked the respondent for his or her time and input.

Afterwards, coded data were entered into an Excel spreadsheet by the researcher, and independently co-captured by a co-data capturer. After the four weeks of data collection, the researcher prepared the coded data for data analysis.

3.7. VALIDITY

The validity of a study is measured directly by the truthfulness and the accuracy of the findings of a study (McMillan & Schumacher, 2010:104) and a researcher aims that the results obtained from the research correlates with the truth (Polit & Beck, 2017:161). Inadequate data collection can lead to biases in a study (Polit & Beck, 2017:162). Alternatively, rigour in a study is enhanced by a researcher who strives to achieve excellence by adhering to planned details, and by following the research plan with meticulous accuracy (Brink *et al.*, 2012:97).

Another aspect of rigour is precision (Burns & Grove, 2009:39). In this research, two Sesotho first-language speaking fieldworkers were trained according to the guideline (Addendum B) and they followed this guideline meticulously throughout data collection. The process of data collection was managed by the researcher being present during data

collection. The researcher assisted with problems arising during data collection and checked each questionnaire on site for completeness. This structured guideline was followed throughout the process of data collection for all the haemo- and peritoneal dialysis respondents in both private and public settings, thus, minimising bias in this study. Furthermore, coding errors were minimised by capturing data into an Excel spreadsheet, while a co-data-capturer repeated the data capturing later. Data analysis was done by a biostatistician of the Department of Biostatistics, School of Medicine, Faculty of Health Sciences at the University of the Free State. These procedures all precisely followed the research design, and thereby ensured rigour in this study.

Validity can differ amongst different samples and from one situation to another, thus, validity testing is done to evaluate the instrument for a specific purpose. The instrument may be valid for a particular situation, but not for another (Burns & Grove, 2009:330). The instrument used in this study, the SHLT (Addendum A), explicitly validated for assessing general health literacy of Sesotho first-language speakers (Reid & Nel, 2021), was suitable for assessing the health literacy status of Sesotho-speaking patients with ESRD in this study. A research instrument can never be proven ultimately valid, but researchers can agree on its relative validity based on face validity, criterion validity, content validity and construct validity (Babbie, 2016:149). From the various methods that can be used to enhance the validity of data collection instruments, face and content validity were used in this study, and will be discussed below.

3.7.1 Face validity

Face validity refers to the degree to which an instrument *looks* as if it is measuring what it is intended to measure. Face validity is often useful for ensuring the participation of respondents (Leedy & Ormrod, 2015:115). Face validity cannot be quantified or tested, but can be enhanced when experts in the field examine the instrument thoroughly (Pietersen & Maree, 2017:241). The SHLT was developed by experts in the field of health communication, including Sesotho first-language experts (Reid *et al.*, 2019:1–13) – Reid *et al.* (2019:4) state that it is essential to assess health literacy in a person's first language. The contextual, culture-related SHLT (Addendum A), was presented by Sesotho first-language speaking fieldworkers to the Sesotho first-language speaking respondents. As pronunciation plays a vital role in this general health literacy measurement tool, the questions were asked by the Sesotho first-language speaking fieldworkers, and not

completed by respondents' reading only. Although the respondents were not allowed to discuss any answers to the questions, the respondents were able to communicate in their home language.

3.7.2 Content validity

Content validity refers to the extent to which the items in an instrument appropriately reflect the construct being measured (Babbie, 2016:150; Pietersen & Maree, 2017:240; Polit & Beck, 2017:724). Again, the SHLT was appropriately developed and theoretically grounded to the context and culture of Sesotho speakers, who primarily use public health services (Reid *et al.*, 2019:5). The content of the SHLT was aligned with the WHO's definition of health literacy. This definition includes characteristics such as accessing, understanding, and appraising health information, as well as the ability to apply this information (Dodson *et al.*, 2015:11-13). The SHLT (Addendum A) consisted of ten comprehensive health literacy questions, and rapidly assessed *appraising* and *understanding* of health information by ESRD respondents who speak Sesotho as their first language (Reid *et al.*, 2019:1–13).

3.8. RELIABILITY

Burns and Grove (2009:327) list *consistency, dependability, accuracy, and comparability* as synonyms for reliability. More specifically, De Vos *et al.* (2011:163) agree that reliability is not concerned with what needs to be measured, but, rather, with the effective measurement of the construct. Although every measurement technique has some kind of measurement error (Burns & Grove, 2009:327), a researcher can enhance reliability if the measurement is done consistently, if objective judgements are made and if specific criteria are established. Furthermore, any researcher or fieldworker should be well trained to obtain consistent results (Leedy & Ormrod, 2015:118).

The following factors increased reliability in this study:

- The SHLT (Addendum A) is a validated research questionnaire;
- The fieldworkers were trained according to the structured guideline for completion of the SHLT (Addendum B);
- The pilot study prepared the fieldworkers for collecting data consistently;

- Data were collected in standardised conditions from both haemodialysis and peritoneal dialysis respondents in both public and private healthcare settings;
- The researcher was present during data collection to ensure the consistent gathering of data by the fieldworkers;
- Before data were collected, the fieldworkers ensured that respondents were aware that the “I don’t know” option was an equally important answer, and no questions were rephrased to any respondent, thus, excluding subjectivity;
- Data was coded by the researcher and the process was independently repeated by a co-data capturer; and
- Data were coded consistently according to a pre-defined set of codes.

3.9. ETHICAL CONSIDERATIONS

In social sciences, human beings are mainly the objects of research, and this illuminates distinctive ethical considerations that would never be applicable in a clinical setting of the natural sciences (De Vos *et al.*, 2011:113). In the health environment, the researcher intends to improve the quality of life of the people being researched, and this situates research in the domain of the ethical: “doing what is *good* and *right*” (Pera & Van Tonder, 2011:326). According to Babbie (2016:62), *ethics* is connected to *morality* in everyday usage, which relates to matters of *right* and *wrong*. In social science research, there are general, shared agreements about ethics that every researcher has to be familiar with.

Internationally, various codes of ethics have been developed to guide researchers in handling ethical dilemmas during the research process (Polit & Beck, 2017:137–138). The Belmont Report, which was adopted in 1978 in the United States, highlights three critical principles to be upheld at all times when human participants are involved in research (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979:1-10). This study was guided by the three principles of the Belmont Report, all based on human rights, which are *beneficence*, *respect for persons* and *justice* (Dhai, 2019:61–63; National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979:1–10).

Prior to commencing the study, permission was obtained from all the relevant role players (Addenda E–G).

3.9.1 Principle of beneficence

Beneficence is regarded as the most fundamental ethical principle for healthcare professionals (Erlich & Joubert, 2014:35). To adhere to this principle, it is the researcher's responsibility to minimise harm to respondents, regardless of their voluntary participation. The physical, emotional, social, and financial well-being of the respondent must be protected (Brink *et al.*, 2012:35; Dhai, 2019:62; Polit & Beck, 2017:139). Physical harm to respondents was prevented by conducting research according to the inclusion and exclusion criteria referred to above. Respondents were given the right to determine their physical ability to participate and had the right to withdraw if they felt incapable of continuing. No discomfort was involved in participation. Emotional harm was minimised when the fieldworkers explained the purpose of the research in Sesotho and issued the Sesotho information leaflet (Addendum C2) and consent form (Addendum D2). The fieldworkers also kept to the agreed time limit. Socially, the respondents were protected by keeping all the information confidential. The questionnaires were completed while haemodialysis patients were on dialysis and when peritoneal dialysis patients reported for their scheduled visits to the unit, to limit intrusion into patients' constraint time as far as possible, thus preventing financial harm. Patients on haemodialysis are generally not in pain and are keen to participate in activities that reduce boredom whilst receiving dialysis (Pedreira-Robles, Vasco-Gómez, Martínez-Delgado *et al.*, 2018:463).

The principle of beneficence, furthermore, implies protection of respondents from exploitation (Polit & Beck, 2017:139). The researcher prevented exploitation by keeping to the agreed time limit of five to ten minutes per questionnaire, as well as other aspects addressed in the information leaflet and consent form. No respondent indicated that they were exploited.

3.9.2 Respect for persons

The second ethical principle in the Belmont Report, respect for persons, entails that respondents have the right to decide whether to participate in a study or not, as well as the right to full disclosure (Burns & Grove, 2009:200; Polit & Beck, 2017:140–141). According to Botma *et al.* (2010:6), respect is demonstrated by a researcher informing the potential respondent of the proposed study and by allowing the respondent to decide to participate or not. Additionally, no coercion may be used to influence a respondent's

decision to participate in a study, neither may the researcher use his/her authority to let anyone feel obligated to participate in a study (Botma *et al.*, 2010:8; Brink *et al.*, 2012:35; Polit & Beck, 2017:140). Informed consent is based on the two elements of respect, namely self-determination and full disclosure (Dhai, 2019:62; Polit & Beck, 2017:140). The principle of respect was upheld in this study by conducting research only after obtaining informed consent (Addendum D2) from the respondents. Before obtaining consent, the purpose of the research was explained in detail to each respondent in Sesotho by the fieldworkers (Addendum C2). Neither the researcher nor the fieldworkers were known to the respondents, and this minimised possible coercion of the respondents. The researcher respected the respondents' decision to decline and did not discriminate against respondents who did not participate in the study. Respondents' decisions to withdraw from the study were respected. No respondents withdrew from the study

3.9.3 Principle of justice

The principle of justice implies that a respondent needs to be selected and treated fairly (Brink *et al.*, 2012:36; Burns & Grove, 2009:205; Polit & Beck, 2017:141) and that arrangements that are made with them will be respected throughout the study (Brink *et al.*, 2012:37).

Furthermore, it would only be fair if participants did have to bear any costs in relation to participating in a study (Dhai, 2019:63). Respondents who met the inclusion criteria were conveniently selected to participate in this study, with no bias towards vulnerable populations, such as elderly or illiterate respondents. Each respondent received a Sesotho information leaflet (Addendum C2), which was explained to them in advance. Although respondents were not remunerated for participating in the study, no costs were incurred either. The right to privacy was included in this principle (Brink *et al.*, 2012:37; Polit & Beck, 2017:141), and this principle was upheld by keeping all information confidential. Confidentiality was ensured by using numerical coding to identify the dialysis centres, as well as the respondents.

3.10. DATA ANALYSIS

Descriptive statistics, namely frequencies and percentages for categorical data and medians and percentiles for numerical data, were calculated per group. The groups were compared by means of the Chi-square test or Fisher's exact test for categorical data and

the Kruskal-Wallis test for numerical data. The Department of Biostatistics in the School of Medicine, Faculty of Health Sciences at the University of the Free State assisted with the analysis of the data utilising computer technology.

3.11. CONCLUSION

This chapter provided a thorough discussion of how the research was conducted by using a quantitative, descriptive, cross-sectional design. A clear motivation for the research method and technique used was given, and the research population and sampling method were discussed in detail. An overview of the pilot study was given, followed by a description of the data collection process. The research aimed to be truthful and meticulous throughout the research process, and, therefore, validity, reliability and ethical principles were discussed as essential components of the study. In conclusion, it was explained how the data were analysed using computer technology. The research findings will be discussed in detail in the Chapter 4.

CHAPTER 4: DATA ANALYSIS

4.1. INTRODUCTION

In the previous chapter, the different aspects of the design of the study, the methodology used to collect the data and the analysis of the data were discussed. The focus of this chapter will be to present and interpret the results of the quantitative data collected by utilising the SHLT (Addendum A). Part 1 of the questionnaire gathered demographic information from the respondents, and Part 2 comprised ten multiple-choice general health literacy questions.

The data analysis for this study was done with SAS software (copyright, SAS Institute Inc. SAS and all other SAS Institute Inc. product or service names are registered trademarks or trademarks of SAS Institute Inc., Cary, NC, United States of America). Frequencies and percentages were calculated per group for categorical data, and medians and percentiles for numerical data. The groups were compared by means of the Chi-square test or Fisher's exact test for categorical data and the Kruskal-Wallis test for numerical data.

4.2. DESCRIPTION OF STATISTICAL ANALYSIS

In this chapter, frequency tables, graphics and discussions will be used to present the content of the findings. The measured characteristics are referred to as *categorical* or *numerical* variables, and the type of variable has an influence on the analysis and the way it is presented (Erlich & Joubert, 2014:132–133). Categorical variables can be presented as numbers or *frequencies* and *percentages* of a study object (Erlich & Joubert, 2014:142). The term frequency refers to the number of times a result occurs, and is systematically arranged from the lowest to the highest levels. These levels can be listed separately or grouped together (Brink *et al.*, 2012:180). Percentages or proportions are informative, as the population or sample is taken into account (Erlich & Joubert, 2014:141).

The *median* is the midpoint value between the lowest and highest point of data. It is not sensitive to outliers of data or skewed distributions, thus, it is the best value to use to describe the central tendency of data (Brink *et al.*, 2012:185; Erlich & Joubert, 2014:143). *Percentiles* divide the sample values into quarters, and the median is the 50th percentile,

which divides the sample in half. The lower and upper quartiles are called 25th and 75th percentiles, respectively (Erlich & Joubert, 2014:137).

When two groups are compared, significance testing is used to test whether the groups are significantly associated or significantly different. A probability known as the p -value is calculated by applying a statistical formula using the sample data, to determine whether there is a difference or association between two groups (Erlich & Joubert, 2014:151). The significance tests were developed to identify meaningful results, and not results that are the result of chance. A 0.05 level of significance means that there is a 95% chance that the results are due to an independent variable and not due to chance, and with a 0.01 level of significance, there is a 99% assertion that the result is not due to chance (De Vos *et al.*, 2011:274). A total (p) value of lower than 0.05 was considered as statistically significant in the results presented.

The Chi-square test was used to assess whether the frequencies and percentages of one variable differs from values for the other variable, and where the Chi-square test was not appropriate, the Fisher's exact test was used (Polit & Beck, 2017: 392-393). Both tests were used in this study for categorical data. The Kruskal-Wallis test was used in this study to compare significant differences between two or more independent groups (Polit & Beck, 2017:733) for numerical data.

4.3. SHLT PART 1: DEMOGRAPHIC INFORMATION OF SESOTHO-SPEAKING PATIENTS IN THE FREE STATE PROVINCE WHO WERE RECEIVING HAEMODIALYSIS AND PERITONEAL DIALYSIS IN THE PRIVATE AND PUBLIC SECTOR

Part 1 (questions 2.1–2.8) of the SHLT (Addendum A) consisted of demographic information and will be discussed as *healthcare sector groups; treatment modality; gender, age; and qualification levels of the respondents; the prevalence of comorbidities; years on dialysis; and reading problems due to inadequate eyesight*. It was important for this study to understand if any of the above categories were associated with limited health literacy levels of ESRD respondents.

4.3.1 Healthcare sector groups

The distribution of the 263 Sesotho-speaking respondents at the private and public healthcare sector dialysis centres who voluntarily participated in the study, are presented in Figure 4.1.

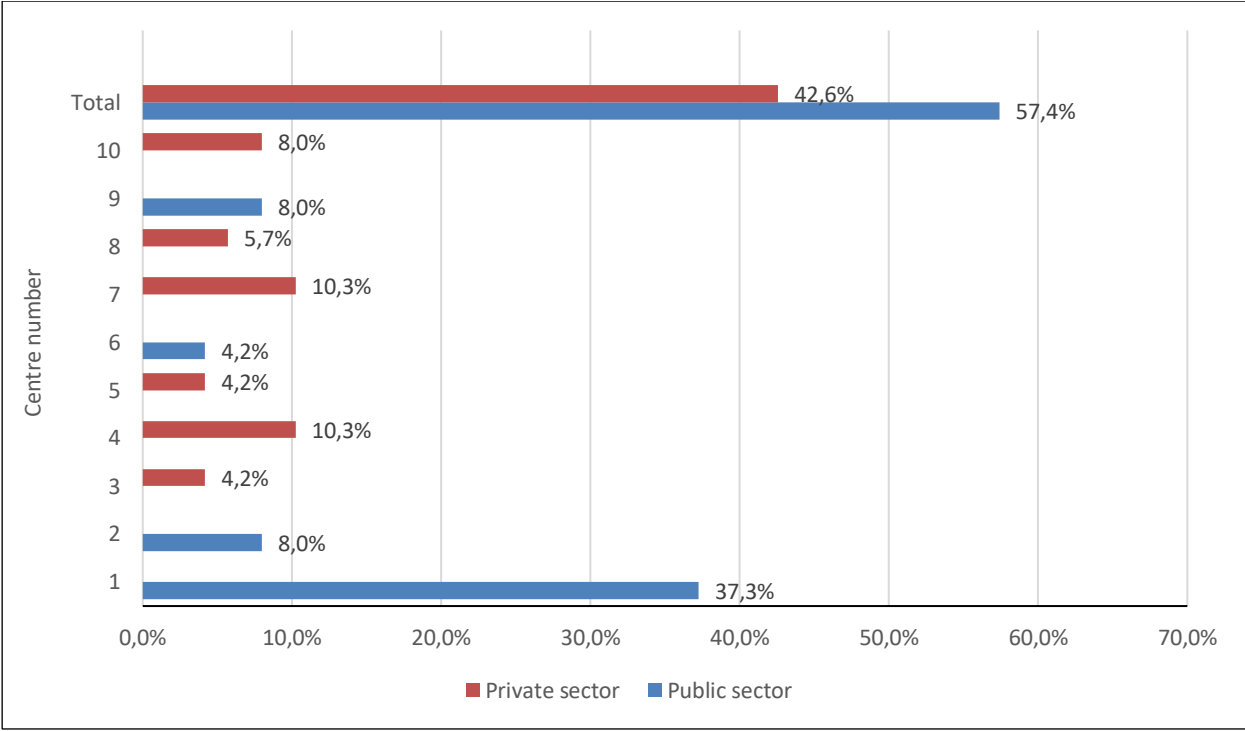


Figure 4.1: Distribution of respondents (n=263) in the private and public sector groups

Data were collected in ten different dialysis centres, based in four towns in the Free State province. Recent (2017) registry data indicates that 19 different operational dialysis centres existed in the Free State province, of which 13 were privately owned (Davids *et al.*, 2019:63). These four towns were conveniently selected for the following reasons: centres from both private and public sectors were present in these towns; the selected centres gave access to more than 50% of the total population of Sesotho-speaking ESRD patients in the province (Davids *et al.*, 2019:63); ten of the dialysis centres in these towns, gave permission for data collection; and to achieve the biggest possible sample size within logistical and financial constraints. Thus, data were collected at more than 50% of the dialysis centres in the Free State province: six in the private sector and four in the public sector (Figure 4.1). All the respondents were *Sesotho first-language speaking*, and 57.4% of the respondents were dialysed in the public sector. The Chi-square test did not

confirm a significant difference between the private and public healthcare sector respondents ($p=0.16$).

Although 84% of South Africa's population relies on the public healthcare sector for health services, most (84%) patients who started renal replacement therapy in 2017 were being treated in the private sector (Davids *et al.*, 2019:63). In this study, more (57.4%) respondents being treated in the public sector were conveniently available, and do not, therefore, present a true reflection of the distribution of patients on renal replacement therapy at the two healthcare sectors in South Africa.

4.3.2 Treatment modality

Figure 4.2 illustrates the distribution of the respondents ($n=263$) between the two different dialysis modalities: haemodialysis and peritoneal dialysis per healthcare sector.

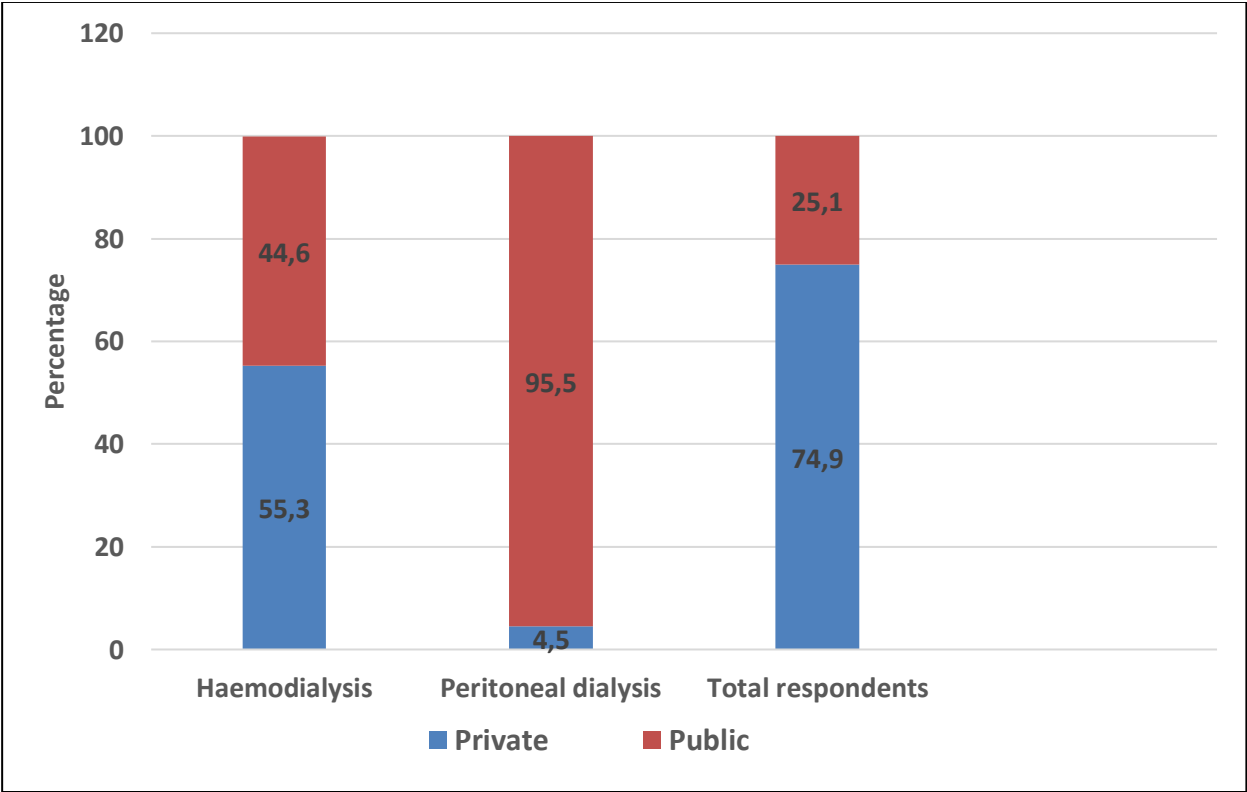


Figure 4.2: Distribution of respondents ($n=263$) per treatment modality and healthcare sector group

Of the 263 respondents, the majority (74.9%) were being treated with *haemodialysis*. Of the *peritoneal dialysis* respondents, most (95.5%) were being treated in the *public sector*.

The Fisher's exact test confirmed a statistically significant difference between the two treatment modalities ($p < 0.01$).

Globally, haemodialysis is the dominant form of renal replacement treatment in the United States (62.7%) (United States Renal Data System, 2019:22), in the United Kingdom (66.6%) (Hole, Gilg, Casula *et al.*, 2018:13) and in South Africa (71.5%) (Davids *et al.*, 2019:65), which confirms the dominance of haemodialysis as a treatment modality in this study.

4.3.3 Gender

Table 4.1 indicates the number of male and female respondents who participated in the research study. The distribution of genders between the two treatment modalities as well between the two healthcare sectors are also discussed.

Table 4.1: Gender distribution of respondents (n=262) per treatment modality and healthcare sector groups

Gender	Total n (%)	Treatment Modality		Healthcare Sector	
		Haemo-dialysis n (%)	Peritoneal dialysis n (%)	Private n (%)	Public n (%)
Male n (%)	158 (60.3%)	128 (65%)	30 (46.2%)	73 (65.2%)	85 (56.7%)
Female n (%)	104 (39.7%)	69 (35%)	35 (53.9%)	39 (34.8%)	65 (43.3%)
Total	262 * (100%)	197 (75.2%)	65 * (24.8%)	112 (42.7%)	150 * (57.3%)

* One of the respondents in the public sector who was receiving peritoneal dialysis did not indicate gender

As indicated in Table 4.1, 60.3% of the respondents were male. This finding reflects the global dominance of the male *gender* among patients within the ESRD population. Both the European Dialysis and Transplant Association and the United Kingdom Renal Association report predominantly male populations, of 62% and 62.9% respectively (Hole *et al.*, 2018:26; Kramer, Pippias, Noordzij *et al.*, 2019:3). The percentage of male respondents in this study concurs with the finding of two other studies (70.7% and 59.6%)

done amongst haemodialysis patients in Bloemfontein, South Africa (Spies, 2018:165; Vermaak, Nel, Botha *et al.*, 2018:Online).

In this study, of the 197 respondents on haemodialysis, 65% were male, while amongst the 65 respondents treated with peritoneal dialysis, more (53.9%) respondents were of the female gender. A significant statistical difference was found between haemodialysis and peritoneal dialysis respondents per gender (Chi-Square test $p < 0.01$). In both the private and the public sector, the male gender was predominant. However, no statistical difference between the private and public sector respondents per gender was found (Chi-square test $p = 0.16$).

4.3.4 Age

Table 4.2 indicates the age distribution of the respondents ($n = 262$). Furthermore, it differentiates between treatment modality and healthcare sectors in terms of age.

Table 4.2: Age distribution of respondents ($n = 262$) according to treatment modality and healthcare sector groups

Treatment modality and healthcare sector group	Total n	Age	Range (Minimum – maximum)	25 th percentile	Median	75 th percentile
All respondents	262 *	Age	19–76	38	49	56
Haemodialysis	196 *	Age	19–76	44	51	59
Peritoneal dialysis	66	Age	23–58	31	38	45
Private	111 *	Age	22–76	48	54	68
Public	151	Age	19–68	32	42	51

* One of the respondents in the private sector who was receiving haemodialysis, did not indicate their age

Table 4.2 indicates that the median age of the respondents was 49 years, ranging between 19 and 76 years, with a lower quartile of 38 years and an upper quartile of 56

years, indicating that the majority of respondents were middle-aged and older. This finding corresponds with two South African studies done with haemodialysis patients in Bloemfontein and Port Elizabeth, which found median ages of 50.5 years and 54.5 years respectively (Botha, 2016:53; Spies, 2018:166).

The haemodialysis group had a median age of 51, compared to a median age of 38 in the peritoneal dialysis group. Furthermore, the median age of the respondents in the public sector was 12 years younger than those in the private sector.

In the public sector, being of a younger age is one of the critical selection criteria that gives a patient a better chance of being selected for renal replacement therapy (Moosa *et al.*, 2016:5). In South Africa's public healthcare sector, renal replacement therapy is limited, and the majority of patients only have access, initially, to peritoneal dialysis, unless it is contraindicated (Musoke, Bisiwe, Natverlal *et al.*, 2020:1). The findings of the current study were that the majority of peritoneal dialysis respondents were of a younger age and received treatment in the public sector. The Kruskal-Wallis test confirmed the significant difference ($p < 0.01$) between haemodialysis and peritoneal dialysis patients, and between the private and public sectors, in terms of age.

4.3.5 Education levels of the respondents

The education levels of the respondents are summarised in Table 4.3 according to treatment modality and the healthcare sector.

Table 4.3: Frequency and percentages of education levels for all respondents (n=262), per treatment modality and healthcare sector groups

Education level	All respondents n (%)	Treatment modality		Healthcare sector	
		Haemo-dialysis n (%)	Peritoneal dialysis n (%)	Private sector n (%)	Public sector n (%)
No schooling	6 (2.3%)	4 (2%)	2 (3%)	1 (0.9%)	5 (3.3%)
Grades 1–8	45 (17.9%)	40 (20.4%)	5 (7.6%)	15 (13.4%)	30 (20%)

Grades 9–12	153 (58.4%)	108 (55.1%)	45 (68.2%)	56 (50%)	97 (64.7%)
Tertiary education	49 (18.7%)	36 (18.3%)	13 (19.7%)	33 (29.5%)	16 (10.7%)
Postgraduate	9 (3.5%)	8 (4.1%)	1 (1.5%)	7 (6.3%)	2 (1.4%)
Total	262 * (100%)	196 *(74.8%)	66 (25.2%)	112 (42.7%)	150*(57.3%)

* One haemodialysis respondent from the public sector did not report his or her qualification

Education levels of the respondents ranged from no schooling (2.3%) to postgraduate level (3.5%), with the majority (58.4%) reporting a Grade 9–12 level of education. More than 20% of the respondents had some degree of tertiary education. In the haemodialysis group, 55.1% of the respondents reported education levels between Grades 9 and 12, and in the peritoneal dialysis group, 68.2% of the respondents indicated education levels between Grades 9 and 12. The Fisher's exact test ($p=0.05$) did not find a significant difference between these two groups. However, a considerable difference was found between the education level of private and public sector patients, as indicated by the Fisher's exact test, at $p<0.01$. In the private sector, 50.0% of respondents reported having education levels between Grades 9 and 12, while in the public sector most (64,7%) respondents reported education levels between Grades 9 and 12. This finding correlates with similar studies done with haemodialysis respondents in Port Elizabeth and Bloemfontein. In the study by Botha (2016:53), 47.1% of respondents had completed secondary school, and Spies, Van den Berg & Nel (2020:3) found that 65.3% of participants had education levels between Grades 9 and 12.

4.3.6 Prevalence of comorbidities

The respondents were asked to list the chronic diseases they had been diagnosed with. Thus, all the data regarding comorbidities were reported by the respondents themselves and not verified by a medical practitioner's notes or by accessing patient files. The prevalence of comorbidities as reported by the respondents are shown in Table 4.4.

Table 4.4: Prevalence of reported comorbidities (n=354) of all the respondents, per treatment modality and healthcare sector groups

Comorbidity	Reported comorbidities n (%)	Treatment modality		Healthcare sector	
		Haemo-dialysis n (%)	Peritoneal dialysis n (%)	Private sector n (%)	Public sector n (%)
Hypertension	240 (91.3%)	180 (91.4%)	60 (90.9%)	105 (94.7%)	135 (89.4%)
Diabetes mellitus	70 (26.6%)	63 (23%)	7 (10.6%)	60 (53.6%)	10 (6.6%)
HIV	15 (5.7%)	10 (5.1%)	5 (7.6%)	6 (5.4%)	9 (6%)
Cancer	2 (0.8%)	2 (1%)	0	2 (0.9%)	0
Auto-immune diseases	1 (0.4%)	1(0.5%)	0	0	1 (0.7%)
Other	12 (4.7%)	10 (5.1%)	2 (3.0%)	8 7.1%)	4 (3.3%)
Unknown	14 (5.3%)	11 (5.6%)	3 (4.6%)	2 (1.8%)	12 (8%)

Only 5.3% of the respondents indicated that they were unaware of any comorbidities that they might have. Some respondents reported more than one comorbidity and, in total, the 263 respondents reported 354 comorbidities.

Only 8.7% of the respondents in this study did not report hypertension as comorbidity. Among the 91.3% who reported hypertension as comorbidity, there was no significant difference between the haemodialysis and peritoneal dialysis respondents ($p=0.91$), or between the private and public healthcare sector ($p=0.22$). This finding supports Meyers' (2015:232) statement that hypertension in South Africa is by far the main cause of chronic kidney disease and ESRD. Furthermore, hypertensive renal disease is reported as the cause of ESRD in 35.1% of the South African ESRD population (Davids *et al.*, 2019:67).

In this study, hypertension was only reported as a chronic disease that a respondent had been diagnosed with; thus, it could be the aetiology or comorbidity of ESRD.

Almost 27% of the respondents reported diabetes mellitus as a chronic disease. More haemodialysis respondents (23.0%) than peritoneal dialysis respondents (10.6%) had diabetes mellitus, and, in the private sector, 53.6% of the respondents had diabetes mellitus compared to only 6.6% in the public sector. Thus, a significant difference is identified by the Chi-square test between haemodialysis and peritoneal dialysis ($p < 0.01$) respondents, as well as between the private and public healthcare sectors ($p < 0.01$).

In developed countries, such as those in North America and Europe, and in Japan, patients with diabetes mellitus are less likely to receive peritoneal dialysis as their first treatment option. This preference could be caused by the fear of worsening glycaemic control on peritoneal dialysis, higher prevalence of peritonitis, fluid overload and rapid renal function decline, visual disorders and peripheral neuropathy (Maruyama, Higuchi, Ito *et al.*, 2019:2). In a study done in Limpopo, South Africa, in a public sector dialysis centre, there was only a marginal difference between haemodialysis respondents (11.3%) and peritoneal dialysis respondents (8.9%) with regard to diabetes mellitus (Isla, Ameh, Mapiye *et al.*, 2016:5), which contradicts this study's finding. In a study done in Bloemfontein, South Africa, amongst haemodialysis respondents to assess socio-demographics and knowledge, attitudes and practices regarding the "renal" diet, 17.3% of the respondents had diabetes mellitus (Spies, 2018:85). In the current study, the researcher reports on the current treatment modality; thus, respondents could have been treated on peritoneal dialysis before being switched to haemodialysis. In the public sector in South Africa, a patient's chances of being accepted for dialysis reduces by 88% if the patient is diagnosed with diabetes mellitus (Moosa *et al.*, 2016:5). This confirms the difference of 47% between private and public sector respondents in the reported study. The South African Renal Registry (Davids *et al.*, 2019:67) also reports a much higher prevalence of diabetes mellitus in ESRD patients in the private sector than in the public sector (50.1% versus 19.1%).

Fifteen respondents (5.7%) in this study reported HIV as comorbidity. The prevalence of HIV (5.1%–7.6%) was equally distributed between haemodialysis and peritoneal dialysis respondents, and between the private sector (5.4%) and public sector (6.0%) respondents. The Fisher's exact tests produced $p = 0.54$ and $p = 0.83$, respectively. In Bloemfontein, South Africa, Spies (2018:88) reports that 7.1% of ESRD respondents

were using anti-retroviral medication, which concurred with the reported study's finding. In South Africa, which has the highest HIV prevalence globally, HIV-related renal diseases overwhelm renal services (Wearne *et al.*, 2019:192), and less than 4% of HIV-positive patients in the public sector in the Western Cape of South Africa who needed renal replacement therapy, were accepted over seven years (Moosa *et al.*, 2016:4).

Two haemodialysis respondents (0.8%) from the private sector reported having been diagnosed with cancer: one with prostate cancer and the other with renal cell carcinoma. No significant difference was found between the two treatment modalities in terms of cancer ($p=1$). However, between the two healthcare sectors, the Fisher's exact test was $p<0.03$. In the public sector, the guideline for rationing is primarily based on whether a patient is transplantable (Moosa *et al.*, 2016:1), which generally excludes patients with malignancies and could explain this significant difference between the two sectors.

Systemic lupus erythematosus, an auto-immune disease, often causes glomerulonephritis, which can progress to ESRD (Breuch & Servos, 2010:18). Glomerular disease, of which systemic lupus erythematosus is only one, was the cause of about 10% of ESRD cases in 2017 (Davids *et al.*, 2019:67). In this study, only one respondent (0.4%) reported being diagnosed with this disease. The Fisher's exact test did not indicate significant differences between the treatment modality groups ($p=1$) or between the two healthcare sectors ($p=1$).

The remaining comorbidities, namely hypercholesterolaemia, cardiac failure, cerebrovascular disease, psoriasis, asthma, bipolar disorder, epilepsy, thyroid disorders and ulcerative colitis, were reported by 12 (4.7%) of the respondents. They were classified as "other" comorbidities. No significant difference was found between the two treatment modalities ($p=0.8$) or between the two healthcare sector groups ($p=0.07$).

A few respondents (5.3%) did not report any comorbidities that were classified as "unknown". The Fisher's exact test did not confirm a significant difference ($p=1$) between the two treatment modalities, but between the private and public sector, a significant difference ($p<0.03$) was confirmed by the Chi-square test: 1.8% of the respondents from the private sector and 8% of the public sector respondents did not report any comorbidities. In South Africa's Renal Registry, 31.9% of reported causes of ESRD were unknown, and was often the case when patients presented with a progressed stage of

ESRD (Davids *et al.*, 2017:61,67). In this study, less than 6% of the respondents did not report any chronic illnesses.

4.3.7 Years on dialysis

The total number of years that respondents had been on renal replacement therapy is depicted in Table 4.5, and it differentiates the years on dialysis for treatment modalities as well as healthcare sectors.

Table 4.5: Median years on dialysis of respondents (n=262), according to treatment modality and healthcare sector groups

Variable	Total (n)	Minimum	Median	Maximum
All respondents	262 * (100%)	0.04	4	26
Haemodialysis	196 * (74.8%)	0.04	4	26
Peritoneal dialysis	66 (25.1%)	3	3	23
Private	111* (42.4%)	0.04	3	21
Public	151 (57.6%)	0.04	5	26

* One of the respondents in the private sector who was receiving haemodialysis did not indicate years on dialysis

Table 4.5 indicates that respondents had been on renal replacement therapy for a median of 4 years. Haemodialysis respondents presented with a median of 4 years on dialysis and peritoneal dialysis respondents with a median of 3 years. The Kruskal-Wallis test ($p=0.04$) confirmed this significant difference. Respondents in the private sector were dialysed for a median of 3 years, and those in the public sector, were dialysed for a median of 5 years. This noteworthy difference is confirmed by the Kruskal-Wallis test, at $p<0.1$.

In Europe, a survival rate of 50.5% is reported for patients who were treated for five years (Kramer *et al.*, 2019:3). In this study, 37% of the respondents had been treated on dialysis for longer than five years. It was remarkable that one of the patients on haemodialysis in the public sector reported having being treated on dialysis for 26 years. In a South African study done in the Limpopo and Gauteng provinces of South Africa, only 8% of

haemodialysis and 3% of peritoneal dialysis patients survived for more than six years of dialysis (Clark, 2013:73).

The survival outcomes of peritoneal dialysis are equal to those of haemodialysis, even when the success of the peritoneal dialysis technique is shorter than that of haemodialysis – it could be the reason for switching from peritoneal dialysis to haemodialysis (Brown *et al.*, 2017:362).

The variance in years (Table 4.5) on dialysis between the private and public sector could be due to the fact that dialysis is a prescribed minimum benefit in the private sector; thus, all patients who can afford dialysis have access to the treatment, while the public sector is driven by the availability of dialysis slots (Etheredge & Fabian, 2017:7). Dialysis in the private sector is "demand-side driven", which demonstrates that patients in the private sector may have more comorbidities, are older and could potentially have a higher mortality rate (Etheredge & Fabian, 2017:6).

4.3.8 Reading problems due to inadequate eyesight

As health literacy could be influenced by a patient's ability to read healthcare material, respondents were asked to indicate whether they had problems reading due to inadequate eyesight (Table 4.6).

Table 4.6: Respondents (n=123) reporting reading problems due to inadequate eyesight

Variable	All respondents n (%)	Treatment modality		Healthcare sector	
		Haemo-dialysis n (%)	Peritoneal dialysis n (%)	Private sector n (%)	Public sector n (%)
Reading problems due to inadequate eyesight	123 (46.8%)	101 (51.3%)	22 (33.3%)	60(53.6%)	63(41.7%)

Fifty-one percent of the haemodialysis respondents reported having reading problems due to inadequate eyesight, compared to 33.3% of peritoneal dialysis respondents – this

difference is statistically significant ($p < 0.1$). However, on assessing the reading ability of the two healthcare sectors, no significant difference ($p = 0.06$) was found between the two groups. Retinopathy, a complication of diabetes mellitus, has been reported to be associated with lower health literacy (AlSayah, Majumdar, Williams *et al.*, 2013:447). For 26.6% of respondents with diabetes mellitus (Table 4.4) in this study, it could possibly have an influence on the respondents' ability to read. Moreover, patients with low health literacy are unwilling to admit that they have trouble reading, due to shame (Pleasant, 2014:1482), which could possibly also be the case in this study. In the reported study, the reading ability of the respondents could have had an influence on the reliability of the test results, as inadequate eyesight might have had an influence on the answers that were given by the respondents to the questions that involved pictures being shown to the respondents.

4.4. SHLT PART 2: HEALTH LITERACY QUESTIONS

Part 2 of the SHLT (Addendum A), consists of ten multiple-choice questions (questions 1–10). The answers to the questions will be discussed in terms of frequencies and percentages.

The questions of the SHLT were adapted for the South African public healthcare system and the Basotho culture (Reid *et al.*, 2019:3), thus, the appraisal questions (1–6) and understanding questions (7–10) asked in the SHLT, are appropriate to the contextual characteristics of the Sesotho population of the Free State province, and the emphasis is on the appraisal being conducted in the public healthcare system (Reid *et al.*, 2019:4).

4.4.1 Frequencies and percentages of answers per SHLT question

The frequencies and percentages of an SHLT answer provided by the respondents ($n = 263$), according to treatment modality group and healthcare sector groups, are presented in Table 4.7, and are followed by the p-values of significance testing per treatment modality and healthcare sector groups in Table 4.8.

Table 4.7: Frequencies and percentages of an SHLT answer provided by respondents (n=263), according to treatment modality and healthcare sector group

Extract of SHLT questions	All respondents	Treatment modality		Healthcare sector	
		Haemo-dialysis	Peritoneal dialysis	Private	Public
	n (%)	n (%)	n (%)	n (%)	n (%)
SHLT Question 1	<i>If I break my leg, I must go to the</i>				
Clinic	61 (23.2%)	32 (16.2%)	29 (43.9%)	11 (9.8%)	50 (33.1%)
Hospital	195 (74.1%)	158 (80.2%)	37 (56.1%)	98 (87.5%)	97 (64.2%)
I don't know	7 (2.7%)	7 (3.6%)	0 (0.0%)	3 (2.7%)	4 (2.7%)
SHLT Question 2	<i>If my brother who stays with me has TB, I must</i>				
Do nothing	5 (1.9%)	4 (2.1%)	1 (1.5%)	3 (2.7%)	2 (1.4%)
Go the clinic for TB testing	242 (93.1%)	177 (91.2%)	65 (98.5%)	100 (89.3%)	142 (96.0%)
I don't know	13 (5.0%)	13 (6.7%)*	0 (0.0%)	9 (8.0%)	4 (2.7%)*
* 3 haemodialysis respondents in the public sector did not answer SHLT question 2					
SHLT Question 3	<i>Look at the sugar measurements. A cup of sugar equals</i>				
5 ml	50 (19.0%)	30 (15.2%)	20 (30.3%)	16 (14.3%)	34 (22.5%)
250 ml	142 (54.0%)	105 (53.3%)	37 (56.1%)	56 (50.0%)	86 (57.0%)
I don't know	71 (27.0%)	62 (31.5%)	9 (13.6%)	40 (35.7%)	31 (20.5%)
SHLT Question 4	<i>Your friend is overweight. She does not have money. Appropriate advice you can give to her to lose weight is to</i>				
To go to a gym	101 (38.4%)	79 (40.1%)	22 (33.3%)	48 (42.9%)	53 (35.1%)
Take long fast walks	144 (54.8%)	103 (53.3%)	41 (62.1%)	56 (50.0%)	88 (58.3%)
I don't know	18 (6.8%)	15 (7.6%)	3 (4.6%)	8 (7.1%)	10 (6.6%)
SHLT Question 5	<i>A person taking a medication for the first time and presents with a skin rash, must</i>				
Finish the medication	20 (7.6%)	15 (7.6%)	5 (7.6%)	5 (4.5%)	15 (9.9%)
Go back to the doctor/clinic	238 (90.5%)	178 (90.4%)	60 (90.9%)	105 (93.8%)	133 (88.1%)
I don't know	5 (1.9%)	4 (2.0%)	1 (1.5%)	2 (1.8%)	3 (2.0%)

Extract of SHLT questions	All respondents	Treatment modality		Healthcare sector	
		Haemo-dialysis	Peritoneal dialysis	Private	Public
	n (%)	n (%)	n (%)	n (%)	n (%)
SHLT Question 6	<i>You have been taking pain pills for 7 days and still have pain. Look at the instructions on the pain tablet and decide what you have to do:</i>				
Take 2 pills	10 (3.8%)	6 (3.1%)	4 (6.1%)	2 (1.8%)	8 (5.3%)
Go to the doctor/clinic	248 (94.3%)	186 (94.4%)	62 (93.9%)	107 (95.5%)	141 (93.4%)
I don't know	5 (1.9)	5 (2.5)	0 (0.0)	3 (2.7)	2 (1.3%)
SHLT Question 7	<i>Look at the instruction on the medication bottle. How many times does Tumelo have to take his multivitamin syrup a day?</i>				
2 times per day	243 (92.4%)	179 (90.9%)	64 (97%)	102 (91.1%)	141 (93.4%)
4 times per day	1 (0.4%)	1 (0.5%)	0 (0.0%)	0 (0.0%)	1 (0.7%)
I don't know	19 (7.2%)	17 (8.6%)	2 (3%)	10 (8.9%)	9 (5.9%)
SHLT Question 8	<i>When we read the following word, which option is best associated with the word, TB</i>				
Cough	248 (94.3%)	184 (93.4%)	64 (97%)	102 (91.1%)	146 (96.7%)
Weight gain	3 (1.1%)	3 (1.5%)	0 (0.0%)	2 (1.8%)	1 (0.7%)
I don't know	12 (4.6%)	10 (5.1%)	2 (3%)	8 (7.1%)	4 (2.6%)
SHLT Question 9	<i>If you take your first dosage of pain medication at 8' o'clock and the nurse tells you to take the pain medication every 6 hours, when can you take your next dosage?</i>				
2 o'clock in the afternoon	148 (56.3%)	111 (56.4%)	37 (56.1%)	71 (63.4%)	77 (51.0%)
6 o'clock in the evening	83 (31.6%)	58 (29.4%)	25 (37.9%)	30 (26.8%)	53 (35.1%)
I don't know	32 (12.2%)	28 (14.2%)	4 (6.1%)	11 (9.8%)	21 (13.9%)
SHLT Question 10	<i>Thabo has to give 2.5 ml of cough syrup to his sister. Choose an option that will indicate that there is 2.5 ml of syrup in the syringe</i>				
Choice A	20 (7.6%)	18 (9.1%)	2 (3.0%)	8 (7.1%)	12 (8.0%)
Choice B	232 (88.2%)	168 (85.3%)	64 (97.0%)	98 (87.5%)	134 (88.7%)
I don't know	11 (4.2%)	11 (5.6%)	0 (0.0%)	6 (5.4%)	5 (3.3%)

The correct answers are highlighted in red (accent 2) for each question option.

Table 4.8: P-values of SHLT questions per treatment modality and healthcare sector group

Number of SHLT Question	Treatment modality	Healthcare sector
	Haemodialysis versus Peritoneal dialysis	Private versus public sectors
	<i>p</i> -value	<i>p</i> -value
1	<0.01	<0.01
2	0.06	0.11
3	<0.01	<0.02
4	0.34	0.40
5	1.00	0.26
6	0.25	0.30
7	0.38	0.54
8	0.68	0.54
9	0.15	0.13
10	<0.04	0.70

As shown in Table 4.7, the majority of questions were answered correctly by more than 85.0% of the respondents. Questions 3, 4 and 9, however, were answered correctly by only 54.0%, 54.8% and 56.3% of respondents respectively.

SHLT question 1 was answered correctly by 74.1% of the respondents and a significant difference was identified between haemodialysis and peritoneal dialysis groups ($p < 0.01$), as well as between the private and public healthcare sector groups ($p < 0.01$). In *SHLT question 1*, a respondent has to assess (*appraise*) whether a clinic or a hospital has to be visited when someone breaks a leg; thus, a respondents' knowledge on what to do in case of an emergency is being tested. Decision-making plays a vital role throughout an ESRD patient's lifetime (Muscat *et al.*, 2018:2) and patients might face the risk of visiting the emergency room or being admitted to the hospital (Parker, 2019:46). Poor adherence to diet and fluid restrictions in dialysis patients could result in an increased risk of death and hospitalisation, and is associated with limited health literacy (Skoumalova *et al.*, 2019:2).

Tuberculosis (TB) is endemic in South Africa, and patients on dialysis are at risk of developing TB due to their impaired immune systems (Musoke *et al.*, 2020:4). Although

three respondents did not answer *SHLT question 2*, 93.1% of the respondents were aware that if you are exposed to a relative with TB, you have to visit a clinic for TB testing. No statistical differences were found between haemodialysis and peritoneal dialysis groups ($p=0.06$) or between the private and public healthcare sectors ($p=0.11$). Almost all the respondents' knowledge regarding TB in the current study seemed to be sufficient.

ESRD patients are at high risk of developing TB in dialysis facilities, due to mycobacterium tuberculosis and the possibility of reactivation of latent tuberculosis infection (Okada, Barry, Skarbinski *et al.*, 2018:1). Okada *et al.* (2018:3–5) report that TB rates in the dialysis population in the United States are 12 times higher, and outside the United States, four times higher, than in the general population. In contrast with this study's findings, in a large study conducted in the Mangaung Municipality area, a high TB burden area in the Free State province, 55.2% of the 507 participants associated TB transmission with strangers rather than with relatives. Their knowledge of the cause of TB and key routes of transmission was poor (Kigozi, Heunis, Engelbrecht *et al.*, 2017:4). Similarly, amongst isiXhosa speakers in the Eastern Cape of South Africa, only 51.7% of respondents had adequate knowledge of the transmission of TB (Marimwe & Dowse, 2017:7). ESRD patients' knowledge of TB could potentially prevent them from developing the illness.

SHLT question 3 assessed the respondents' knowledge of volume measurement. Only 54% of the respondents knew that a cup of sugar equals 250 ml, despite a clear picture provided indicating 250 ml=a cup. This specific picture originates from a well-known sugar brand package that is in general use in South Africa. Respondents are, therefore, exposed to the measurement indication regularly. A significant difference ($p<0.1$) was confirmed with the Chi-square test between the haemodialysis and peritoneal dialysis groups, as well as between the private and public healthcare sectors. Patients on renal replacement therapy must know how to measure their prescribed fluid intake to prevent fluid overload (Parker, 2019:43, 46) and fluid restriction is considered the most crucial restriction in the renal diet (Cosar & Pakyuz, 2016:174). Skoumalova *et al.* (2019:1–10) identified an association between lower health literacy and fluid intake recommendations in a large ($n=542$) study in 20 dialysis clinics in Slovakia. In another study (Smith *et al.*, 2010:339), *volume measurement* was described by patients as one of the barriers that affects their adherence to fluid restrictions. Smith *et al.* (2010:339) indicates that ESRD patients' knowledge about volume measurement and food label interpretations plays a

vital role in their fluid restriction adherence. Verseput and Piccoli (2017:6) state that measuring and weighing of food is an unknown concept in African cultures, which explains why this can be difficult for ESRD patients.

The respondents' knowledge of health, nutrition and exercise is assessed with *SHLT question 4*. Only just over than half (54.8%) of the respondents knew that taking long, fast walks would be better than visiting a gym to lose weight, for someone who does not have money. No significant difference was found between the two treatment sectors ($p=0.34$), or between the two healthcare sectors ($p=0.4$). Exercise has significant, positive effects on the recovery of ESRD patients, such as improving blood pressure, increasing excretion of urea, improving physical fitness, improving quality of life and reducing anxiety and depression (Huang, Lv, Wang *et al.*, 2020:1–2; Zhao, Zhang, Wen *et al.*, 2019:55). Nutrition-related conditions, such as obesity, together with hypertension and diabetes mellitus – the leading risk factors of ESRD – contribute to the rapidly increasing prevalence of ESRD (Anderson & Nguyen, 2018:116), which emphasises the relevance of *SHLT question 4* for an ESRD patient's health literacy level.

SHLT question 5 assessed the respondents' knowledge of the side-effects of medication, and 90.5% of them answered this question correctly. The Fisher's exact test was used to compare the two treatment sectors ($p=1$) and the two healthcare sectors ($p=0.26$), but no significant differences were found. Hypertensive renal disease is the most commonly reported cause of ESRD in South Africa (Davids *et al.*, 2019:67), and patients who have experienced side effects of hypertension medication are reported to be more non-adherent regarding their hypertension medication (Nafradi, Galimberti, Nakamoto *et al.*, 2016:114). Similarly, metformin, a drug used to treat diabetes mellitus, has gastrointestinal side effects, and 5% of diabetes mellitus patients discontinue their treatment due to these side effects (Nasri & Rafieian-Kopaei, 2015:1115). Diabetes mellitus, as well as hypertension, are the most common causes of ESRD in both developed and developing countries (Nasri & Rafieian-Kopaei, 2015:1112) and the high prevalence of both hypertension (91.3%) and diabetes mellitus (26.6%) (Table 4.4) was confirmed by this study.

SHLT question 6 assessed the ability of a respondent to read and interpret instructions on a written medication label for pain medication. In total 94.3% of the respondents realised that, if they still experienced pain after seven days of using the pain medication, they had to return to a doctor or clinic. There were no significant differences between

haemodialysis and peritoneal dialysis respondents ($p=0.25$) or between the private and public sector ($p=0.30$). The abuse of nonsteroidal anti-inflammatory drugs, such as ibuprofen, especially amongst the aged population, is a risk factor for developing ESRD (Iseki, 2005:9; South African Renal Society, 2015:5). After initiation of dialysis, nephrotoxic drugs may reduce residual renal function even further (Chandna & Farrington, 2004:198). According to Davis, Wolf, Bass *et al.* (2006:847), patients' misuse of prescribed medications due to low literacy may be overlooked. ESRD patients' appraisal of their prescribed medication's labels is, thus, an important factor that should not be disregarded.

In *SHLT question 7*, the first of the four questions assessing *understanding*, the respondents were assessed on their ability to read and understand instructions on a medication label. The majority (92.4%) of the respondents were able to interpret the instructions on the medication label, and no differences were identified between the two treatment modalities ($p=0.38$) or between the two healthcare sectors ($p=0.54$). For patients with ESRD, phosphate binders are one of the important classes of medications used for treatment. If a patient does not understand how to take the tablets, critical medical complications can result (Daniels, Robinson & Walker, 2018:562). A systematic review of studies done mostly in the United States reports a 51% non-adherence to phosphate binder medication (Karamanidou, Clatworthy, Weinman *et al.*, 2008:2). Likewise, Spies *et al.* (2020:3) report that 58.7% of haemodialysis patients in their study in Bloemfontein, South Africa, did not know how to use their phosphate binders. The most frequently reported cause of non-compliance to phosphate binder treatment was the incorrect interpretation thereof, despite healthcare workers having explained treatment to patients (Gago, Gruss, González *et al.*, 2000:5). Marimwe and Dowse (2017:7) used a similar question in developing an item bank of health literacy questions for isiXhosa speakers in the Eastern Cape of South Africa, where respondents scored slightly lower – 82.5% – for understanding instructions for taking medication.

Despite a declining global trend in TB numbers, the burden of TB remains unacceptably high in South Africa (Kigozi *et al.*, 2017:2). *SHLT question 8* assessed respondents' knowledge of TB. An overwhelming majority (94.3%) of respondents knew that the word cough is associated with TB. Both haemodialysis and peritoneal dialysis respondents, as well as private and public sector respondents, did well in answering this question. The Fisher's exact test confirmed that there were no significant differences between the

dialysis modalities ($p=0.68$) or the healthcare sector groups ($p=0.54$). In another study, among patients in public healthcare facilities in the Mangaung Municipal area in the Free State province, patients also demonstrated a good understanding of the highly contagious nature and risk factors of TB (Kigozi *et al.*, 2017:7). ESRD patients' knowledge of TB could be beneficial, as they are at risk of developing TB due to their already compromised health.

Understanding medication regimes is crucial in the life of a patient on renal replacement therapy, especially when transplanted (Patzner *et al.*, 2016:1295). *SHLT question 9* assessed the respondents' understanding of instructions on a medication prescription, specifically, calculating the time a next dosage has to be taken. An average of 56.3% of all the respondents answered this question correctly. In the private sector, 63.4% of the respondents answered correctly, compared to 51.0% of the respondents in the public sector. However, the Chi-square test did not indicate a significant difference ($p=0.13$) between the two healthcare sectors, or between the two treatment modalities ($p=0.15$). Similarly, 58.7% of haemodialysis patients in Bloemfontein, South Africa, had inadequate knowledge on the use of phosphate binder medication (Spies *et al.*, 2020:3), which is prescribed to most patients on dialysis to prevent hyperphosphatemia, a secondary complication of renal disease (Reddy, Symes, Sethi *et al.*, 2009:314). A similar question was asked when developing an item bank of health literacy questions for isiXhosa speakers in the Eastern Cape of South Africa (Marimwe & Dowse, 2017:7). In this study, respondents scored even worse when they had to calculate the time of their next medication dose, with only 16.7% getting it right. ESRD patients have a vast number of drugs to take. Comorbid conditions contribute to even more treatment prescriptions, and patients often have to take between 12 and 19 prescribed tablets per day (Aspden *et al.*, 2015:2). Misinterpretation of prescription labels may lead to non-adherence or therapeutic failure of treatment in ESRD patients (Wong *et al.*, 2018:6).

SHLT question 10 assessed the understanding of the respondents to measure medication correctly according to a prescription. The majority (88.2%) of respondents knew what the answer was, though the understanding of the peritoneal dialysis respondents was better than the haemodialysis respondents – a significant difference ($p=0.04$) was identified. There was no significant difference between the two healthcare sector groups ($p=0.70$). Peritoneal dialysis patients are challenged daily by having to choose the correct concentration of their dialysis bags (Sarian *et al.*, 2012:20), which

could have improved their skills and knowledge of measuring over time. In a similar study amongst isiXhosa-speaking respondents of the Eastern Cape province of South Africa, 78.3% could indicate 2ml on a graduated syringe (Marimwe & Dowse, 2017:7) – compared to the current study, demonstrating a 10% lower rate of understanding. Fluid and sodium restriction plays a vital role in an ESRD patient's daily self-assessment of their fluid status (Smith *et al.*, 2010:339). Therefore, knowledge of measurement and interpretation of food labels is crucial for their daily functioning.

4.4.2 Median of correct answers

The median of correct answers is presented in Table 4.9.

Table 4.9: Median of correct answers per SHLT question (n=10) for all respondents (n=263), per treatment modality and healthcare sector group

Variable	Total n (%)	Minimum	Median	Maximum
All respondents	263 (100%)	3	7	9
Haemodialysis	197 (74.9%)	3	7	9
Peritoneal dialysis	66 (25.1%)	4	7	9
Private sector	112 (42.6%)	3	7	9
Public sector	151 (57.4%)	3	7	9

Table 4.9 indicates that, on average, seven questions were answered correctly by all the respondents (n=263). The minimum of correct answers was three, and the maximum of correct answers was nine. Thus, of 263 respondents, no one could answer all 10 the questions correctly, despite their level of education. Although the median of answers in both the haemodialysis and peritoneal dialysis groups was seven, the minimum correct answers in the peritoneal dialysis group was slightly better, with a minimum of four correct answers (Table 4.9). Patients on peritoneal dialysis often have to make decisions on their own about their dialysis treatment and medication – 90% of their treatment is based on self-care (Sarian *et al.*, 2012:18). Thus, their skills and knowledge could have improved over time from taking responsibility for their treatment. However, the Kruskal-Wallis test did not confirm a significant difference between the two groups ($p=0.71$). Similarly, the

median of correct answers between the private and public sectors was seven (Table 4.9), with the Kruskal-Wallis test finding $p=0.25$.

4.4.3 Health literacy levels

The frequencies and percentages of health literacy levels of all respondents ($n=263$), per treatment modality and healthcare sector group, are given in Table 4.10. Each item in the ten-item SHLT questionnaire had a predefined correct answer. Data from the SHLT were interpreted as follows (Reid & Nel, 2021):

<6 Low health literacy

6–8 Moderate health literacy

8 + High health literacy

Table 4.10: Frequencies and percentages of health literacy levels of all respondents ($n=263$), per treatment modality and healthcare sector group

Health literacy levels	All respondents n (%)	Treatment modality		Healthcare sector	
		Haemo-dialysis n (%)	Peritoneal dialysis n (%)	Private sector n (%)	Public sector n (%)
Low health literacy	34 (12.9%)	27 (13.7%)	7 (10.6%)	12 (10.7%)	22 (14.6%)
Moderate health literacy	130 (49.4%)	97 (49.2%)	33 (50%)	55 (49.1%)	75 (49.7%)
High health literacy	99 (37.6%)	73 (37.1%)	26 (39.4%)	45(40.2%)	54 (35.8%)
Total	263 (100%)	197 (74.9%)	66 (25.1%)	112 (42.6%)	151 (57.4%)

Low health literacy was identified for 12.9% of all respondents. No significant differences with regard to health literacy levels were found between the two treatment modalities ($p=0.80$) or between the two healthcare sectors ($p=0.58$). However, amongst the haemodialysis respondents, low health literacy was slightly higher (13.7%) than amongst the peritoneal respondents (10.6%). Similarly, in the private sector, respondents scored marginally better than in the public sector, with 10.7% and 14.6% respectively having low

health literacy levels (Table 4.9). Overall, the peritoneal dialysis respondents had a slightly higher score (50%) of *moderate health literacy* than the haemodialysis (49.2%), the private sector (49.1%) and the public sector (49.7%) respondents. Likewise, the peritoneal dialysis (39.4%) and the private sector (40.2%) respondents had slightly higher levels of *high health literacy* than the haemodialysis (37.1%) and the public sector (35.8%) respondents.

Each health literacy test has its own classification system, and the discussion below has to be seen in that light.

In a study done at a single dialysis centre in Pennsylvania, using the REALM, 16% of peritoneal dialysis respondents had limited health literacy (Jain, Sheth, Bender *et al.*, 2014:28). Taylor *et al.* (2018:1079) report a limited health literacy level of 27% in a systematic review that included mostly respondents from the United States of America on both treatment modalities. Conversely, in a small (n=42) Brazilian study of haemodialysis and peritoneal dialysis respondents, utilising the Brazilian-TOFHLA health literacy test, 80.9% of the respondents presented with inadequate health literacy (Bezerra *et al.*, 2019:5). There is a shortage of assessments of health literacy levels in South Africa, and no data could be found by the researcher of the health literacy levels of ESRD patients in South Africa. However, similar to the low literacy levels of the public respondents in the current study, Mafutha, Mogotlane and De Swardt (2017:1–8), report a 19% limited health literacy level in hypertension respondents in the public sector of Tshwane, in the Gauteng province of South Africa. In another study, done in the public sector of the Eastern Cape province of South Africa in developing a health literacy test for isiXhosa speakers, limited health literacy levels of 41.7% and 9.2% were reported respectively for the two comparative tests used (Marimwe & Dowse, 2017:8). Lower health literacy levels could imply worse health outcomes and higher medical costs for ESRD patients (Stømer, Gøransson, Wahl *et al.*, 2019:2). Consequently, health literacy plays an essential role in the care of ESRD patients.

4.4.4 Association of SHLT questions reflecting appraisal and understanding according to health literacy levels

SHLT questions 1 to 6 (n=6) assessed the respondents' appraisal of information, and SHLT questions 7 to 10 (n=4) assessed their understanding of information. The median

of SHLT questions that reflect appraisal and understanding by all the respondents (n=263), per treatment modality and healthcare sector groups, will be discussed below.

Overall, all the respondents had a median score of five for the six appraisal questions, and a median score of three for the four understanding questions. Both treatment modality respondents had a median score of five for the six appraisal questions. For the understanding questions, the peritoneal dialysis respondents scored marginally better, with a median of four. In contrast, the haemodialysis respondents had a median score of three for the four understanding questions. However, the Kruskal-Wallis test confirmed no significant differences between the two treatment modalities ($p=0.77$ and $p=0.7$) or between the healthcare sector groups ($p=0.46$ and $p=0.61$) for appraisal and understanding questions.

The median of appraisal and understanding questions were compared per SHLT health literacy level, and is presented in Table 4.11

Table 4.11: Association of SHLT questions reflecting appraisal and understanding according to health literacy level

Low health literacy (n=34)				
Variable	n	Median	Minimum	Maximum
Appraisal	34	3	1	5
Understanding	34	2	0	4
Moderate health literacy (n=130)				
Variable	n	Median	Minimum	Maximum
Appraisal	130	4	3	6
Understanding	130	3	2	4
High health literacy (n=99)				
Variable	n	Median	Minimum	Maximum
Appraisal	99	5	4	6
Understanding	99	4	3	4

As shown in Table 4.11, the median scores for appraisal and understanding questions in the low health literacy group were three and two correctly answered questions respectively, compared to five and four correctly answered questions in the high health literacy group. Thus, the lower the respondents' health literacy, the lower they scored on appraisal and understanding. This significant difference was confirmed by the Kruskal-Wallis test ($p < 0.01$).

Chronic kidney disease patients in a Norwegian study obtained lower scores for appraising health information and the ability to find useful health information, than for their ability to engage with healthcare providers. The lower the health literacy level of a respondent, the lower their understanding of their chronic illness or the health consequences of the decisions made by the respondent. Self-management is, thus, also influenced by a respondents' understanding of health information (Stømer *et al.*, 2019:4).

4.4.5 Association between the health literacy levels of respondents and demographic variables

Demographic variables, such as gender (Figure 4.3), age; years on dialysis; and the number of comorbidities (Table 4.12), and whether a respondent had a problem reading (Figure 4.4), were not associated with low health literacy levels in this study.

4.4.5.1 Association between the health literacy level of respondents and gender

The association between the health literacy level of respondents and gender is illustrated in Figure 4.3.

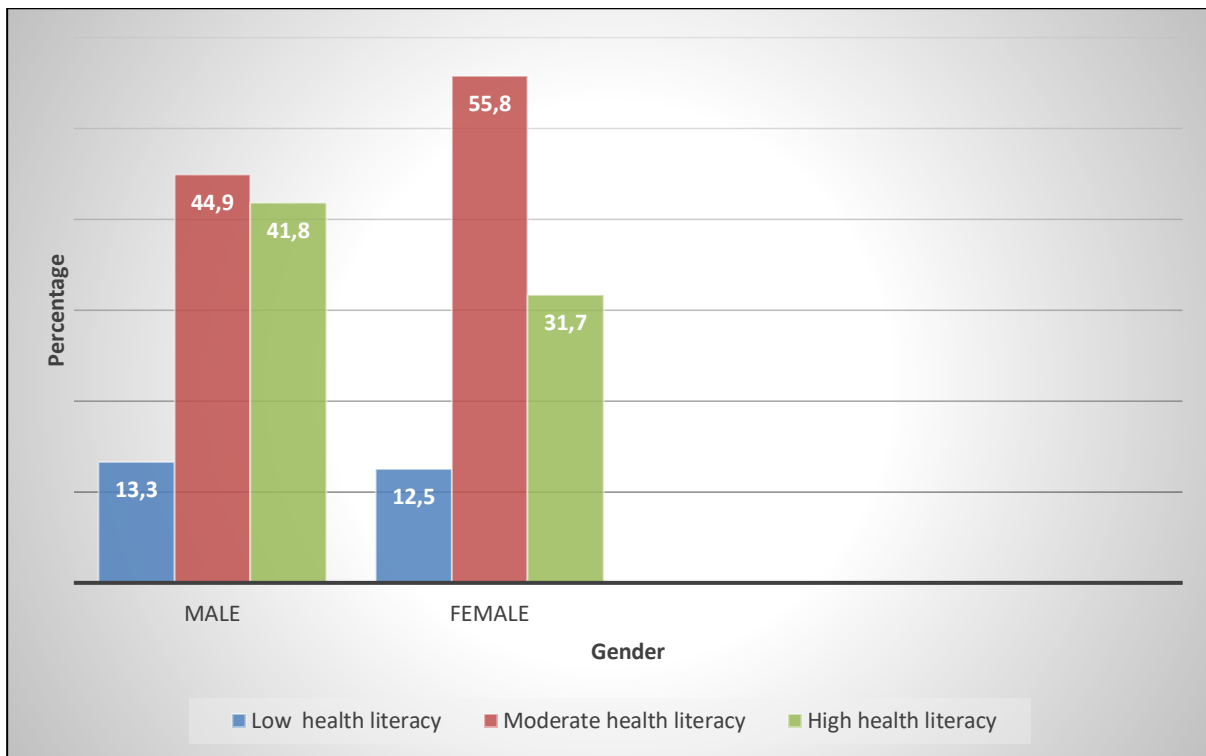


Figure 4.3: Association between the health literacy level of respondents and gender

In the current study, no significant difference between health literacy levels of men and women was identified. The Chi-square test confirmed this finding, with $p=0.2$. A United States-based systematic review of health literacy studies in the general population confirms that low health literacy was not associated with gender ($p=0.38$) (Paasche-Orlow *et al.*, 2005:179). A Norwegian study of people with chronic kidney disease reports the female gender to be associated with lower health literacy (Stømer, Wahl, Gøransson *et al.*, 2020:5). In contrast, Mafutha *et al.* (2017:6) reported that men in South Africa are at higher risk because of low hypertension health literacy than women, due men's lack of health-seeking behaviours. Hypertension was found to be the most prevalent comorbidity in the respondents of the current study. Thus, it is essential to take note of the possible influence low hypertension health literacy could have had on this sample of Sesotho-speaking ESRD patients.

4.4.5.2 Association between the health literacy level of respondents and age, years on dialysis and comorbidities

Low health literacy levels were not associated with age ($p=0.06$), years on dialysis ($p=0.50$) or with the number of comorbidities a respondent reported ($p=0.81$) (Table 4.12).

Table 4.12: Association between the health literacy level of respondents and median age, years on dialysis and the number of comorbidities

Low health literacy (n=34)				
Variable	n	Median	Minimum	Maximum
Age	34	52	19	76
Years on dialysis	34	4.5	0.04	19
Number of comorbidities	34	1	0	3
Moderate health literacy (n=129*/ 130)				
Variable	n	median	Minimum	Maximum
Age	129 *	51	22	76
Years on dialysis	129 *	4	0.1	21
Number of comorbidities	130	1	0	3
High health literacy (n=99)				
Variable	n	Median	Minimum	Maximum
Age	99	47	20	71
Years on dialysis	99	4	0.04	26
Number of comorbidities	99	1	0	3

* One respondent did not indicate age and one respondent did not indicate the number of years on dialysis

Globally, limited health literacy levels are associated with age (Adeseun *et al.*, 2012:351; Chisholm-Burns *et al.*, 2018:2327–2330; Mazarova *et al.*, 2017:e140; Shih *et al.*, 2016:7), years on dialysis (Gordon & Wolf, 2009:31; Kazley *et al.*, 2014:269), and a higher number of comorbidities (Chisholm-Burns *et al.*, 2018:2327–2330; Lambert *et al.*, 2015:21; Taylor *et al.*, 2016:690). In the Eastern Cape province of South Africa, limited health literacy levels were also associated with increased age of isiXhosa-speaking respondents (Marimwe & Dowse, 2017:8). These findings contradict the findings of the current study. Chisholm-Burns *et al.* (2018:2327) state that patients 65 years and older are associated with lower health literacy levels. The median age of the ESRD respondents in the current

study was 49 years, which could imply the possibility of higher health literacy levels in this study.

4.4.5.3 Association between the health literacy level of respondents and reading problems due to inadequate eyesight

Figure 4.4 illustrates that the health literacy levels of the respondents who had problems reading due to inadequate eyesight were similar to those who did not have problems reading due to inadequate eyesight.

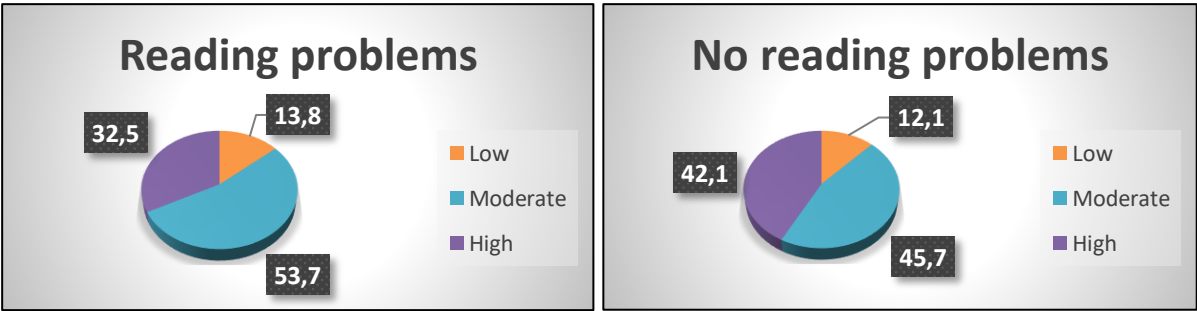


Figure 4.4: Association between the health literacy level of respondents and reading problems due to inadequate eyesight

The Chi-square test ($p=0.27$) did not indicate a significant difference between respondents who had problems reading due to inadequate eyesight and those who did not have problems reading due to inadequate eyesight in terms of health literacy status. This finding probably indicates that inadequate eyesight does not influence the respondents' answers to the SHLT questions.

On the other hand, in this study, the level of education (Table 4.13) was significantly associated with limited health literacy levels on the SHLT.

4.4.5.4 Association between the health literacy level of respondents and their education level

Table 4.13 presents the association between the health literacy level of respondents and their education level.

Table 4.13: Association between the health literacy level of respondents and education level

Health literacy levels	All respondents n (%)	Level of education				
		No schooling n (%)	Grades 1–8 n (%)	Grades 9–12 n (%)	Tertiary education n (%)	Post-graduate education n (%)
Low health literacy	34 (12.9%)	1 (16.7%)	11 (24.4%)	21 (13.7%)	0 (0.0%)	1 (16.7%)
Moderate health literacy	130 (49.4%)	4 (66.7)	28 (62.2%)	73 (47.7%)	23 (45.2%)	2 (38.9%)
High health literacy	98 * (37.6%)	1 (16.7%)	6 (13.3%)	59 (38.6%)	26 (54.8%)	6 (55.6%)
Total	262 * (100%)	6 (2.3%)	45 (17.2%)	153 (58.4%)	49 (18.7%)	9 (3.4%)

* One respondent with high health literacy did not report his or her level of education

In the United States, a lower education level of ESRD patients was consistently associated with limited health literacy levels (Cavanaugh *et al.*, 2015:464; Taylor *et al.*, 2017:1081). In South Africa, Marimwe (2018:133) observed a similar association in isiXhosa speakers attending public healthcare clinics in the Eastern Cape province. In the current study, this significant association between lower education levels and SHLT health literacy levels was confirmed by the Fisher's exact test ($p < 0.01$). With the majority (62.3%) (Table 4.13) of the ESRD respondents in this study falling in the low and moderate health literacy level groups, it could imply that they do not fully understand their treatment and dietary prescriptions, and their adherence to their treatment could, thus, be influenced negatively by their lower health literacy levels.

The majority (62.3%) of all respondents had low and moderate health literacy levels, despite their education levels (Table 4.13). An interesting observation is that, out of nine respondents with postgraduate qualifications, one had low health literacy, two had moderate health literacy and only six had high health literacy (Table 4.13). This confirms

the statement by Taylor *et al.* (2016:686) that 3–10% of patients with university-level education qualifications have limited health literacy. Most healthcare professionals overestimate patients' health literacy levels (Dickens *et al.*, 2013:65). This could imply that an ESRD patient's health literacy level should not be estimated by the education level of the ESRD patient.

4.5. SUMMARY

This chapter reviewed the demographic data of Sesotho-speaking patients with ESRD in the Free State province. An analysis of the health literacy levels of this sample was done. Associations of patients receiving haemodialysis and those receiving peritoneal dialysis as well as associations between those in the private sector and those in the public sector were discussed. In this study, low health literacy is not associated with gender, age, years on dialysis, the number of comorbidities or with reading problems due to inadequate eyesight, though an association with lower education was identified. The chapter, furthermore, provided an analysis of the *p*-values found across the two different groups, and indicated statistical significance when present. The researcher is convinced that the aim and objectives stated in Chapters 1 and 3 were addressed and successfully described.

Chapter 5 will present a summary of the research findings, recommendations and limitations of the study, which will be followed by the value of the study, reflections on the conclusion of the study and a conclusion.

CHAPTER 5: SUMMARY OF RESEARCH FINDINGS, RECOMMENDATIONS, LIMITATIONS, VALUE AND CONCLUSION OF THE STUDY

5.1. INTRODUCTION

Chapter 4 comprised an analysis of the demographic data of Sesotho-speaking ESRD respondents in the Free State province. The analysis of their health literacy levels was also discussed. In this chapter, a summary of the research results, recommendations based on the study findings, limitations and the value of the study will be reported. The researcher will conclude with her reflections on the study.

5.2. SUMMARY OF RESEARCH RESULTS

By using the SHLT, the researcher assessed the health literacy of 263 Sesotho first-language speaking ESRD respondents in the Free State province of South Africa. The respondents were receiving treatment in either the private or public healthcare sector, and were being treated with either haemo- or peritoneal dialysis.

5.2.1 Demographics

Although six out of ten of the dialysis centres were in the private sector, more (57.4%) of the total respondents who participated in the study, were from the public healthcare sector. Almost 75% of the respondents were being treated with haemodialysis, with a statistical difference of $p < 0.01$ between the two treatment modalities. Although the majority (60.3%) of the total respondents were of the male gender, the female gender predominated (53.9%) in the peritoneal dialysis group. The median age of the ESRD respondents in this study was 49 years. The public healthcare sector respondents (median of 42 years) and those on peritoneal dialysis (median of 38 years), were much younger than respondents treated with haemodialysis (median of 51 years) and those in the private sector (median of 54 years). Another interesting finding is that respondents in the public sector dialysed significantly longer (median of 5 years) than the respondents in the private sector (median of 3 years).

Slightly more than 20% of the respondents had equal or less than primary school education. The majority (58.4%) of the total respondents had an education level between Grades 9 and 12. Only 12.1% of the respondents treated in the public sector had more

than a Grade 12 qualification, while 35.8% receiving treatment in the private sector had post-matric qualifications.

Hypertension (91.3%) and diabetes (26.6%), were the most prevalent comorbidities. Diabetes was much more common in the haemodialysis (23.0%) and the private sector (53.6%) patients. This finding indicates the influence of rationing and exclusion criteria applied on the basis of age and comorbidities in the public sector.

An interesting observation is observed in these respondents that experienced problems reading due to inadequate eyesight. The haemodialysis respondents' eyesight was significantly worse (51.3%) than those on peritoneal dialysis (33.3%), probably due to being older and the possible prevalence of diabetic retinopathy.

5.3. SESOTHO HEALTH LITERACY TEST

The SHLT is a general health literacy test and is not explicitly intended for ESRD respondents. However, the contextually and culturally appropriate principles assessed by the SHLT means that it was suitable for this Sesotho first-language speaking ESRD population.

SHLT question 1, which tested respondents' *appraisal* of an emergency situation, was correctly answered by 75% of the respondents. Almost 45% of the respondents could not answer SHLT questions 3 (*appraisal* of knowledge about volume measurement), 4 (*appraisal* of knowledge about health, nutrition and exercise) and 9 (*understanding* of instructions on a medication prescription) correctly. A significant difference ($p < 0.01$) was observed between the two treatment modalities as well as the healthcare sectors regarding SHLT questions 1 and 3. All the other SHLT questions were answered correctly by an average of 90% of the respondents. However, a significant difference ($p < 0.04$) was identified for SHLT question 10 (respondents' *understanding* how to measure medication correctly according to a prescription) between the two treatment modalities.

The prevalence of low health literacy in these 263 Sesotho-speaking ESRD respondents was 12.9%. Almost 50% of the respondents had moderate health literacy levels, and this is confirmed by a median of seven questions correctly answered. Although no significant difference was identified, low health literacy levels were slightly more prevalent amongst the haemodialysis (13.7%) and public sector (14.6%) respondents. Interestingly, no respondent could answer all 10 SHLT questions that assessed general health literacy,

correctly. The lower the health literacy of respondents, the lower their score of appraisal and understanding questions.

Demographic factors, such as gender; age; years on dialysis; the number of comorbidities; and whether a respondent had inadequate eyesight, were not associated with limited health literacy in these specific ESRD respondents. However, the level of education was significantly ($p<0.01$) associated with a lower level of health literacy.

5.4. RECOMMENDATIONS

Based on the findings of the current study, the majority (62.3%) of this ESRD population were classified as having low to moderate health literacy and, therefore, they could be at risk of poor health outcomes. The following recommendations are made in relation to the findings of this study, and are discussed in Table 5.1.

Table 5.1: Recommendations related to findings

Recommendations for specific role-players in the dialysis field
The South African Renal Society
<ul style="list-style-type: none"> The South African Renal Society could be encouraged to implement the assessment of ESRD patients’ health literacy levels as part of the guideline for the optimal care of patients on chronic dialysis in South Africa when patients are diagnosed with ESRD. In the case of Sesotho first-language speakers, the SHLT could be used as a health literacy test. For other language groups, further research has to be conducted in light of very few contextualised health literacy tests being available in the South African context.
The Colleges of Medicine of South Africa and institutions facilitating the Diploma in Nephrology for Nursing and Clinical Technologist training
<ul style="list-style-type: none"> Training institutions should consider integrating health literacy training into the education of nephrologists and dialysis staff to improve their ability to identify vulnerable patients with low health literacy levels.

Private and public healthcare sector dialysis providers

- Dialysis providers should consider developing educational and training material appropriate to the South African context, cultural background, education level and patients' health literacy status. All ESRD patients, and specifically those with limited health literacy levels, could potentially benefit if they receive training material in their home languages. Self-managing skills, adherence to treatment, quality of life and, thus, their health outcomes, could improve if ESRD patients' understanding of their chronic illness improves.
- According to the South African Renal Society, the current staff-to-patient ratio should be 1:4 (South African Renal Society, 2015:10). Understaffing of dialysis centres might have a significant impact on health outcomes of dialysis patients (Thomas-Hawkins & Clarke, 2008:128). Dialysis providers should acknowledge the commitment and extra time it takes staff to assist patients with limited health literacy. Health outcomes of ESRD patients could be improved if ESRD patients' health literacy levels could be improved. It is, therefore, recommended that dialysis centres should not be understaffed.

Nephrologists

- It is recommended that health literacy levels should be considered when selecting ESRD patients for renal replacement therapy in the public sector and transplantation in both the healthcare sectors. In this study, no significant differences were identified between the two treatment modalities ($p=0.80$) or the two healthcare sectors ($p=0.58$) in terms of health literacy status. If the health literacy levels of patients could be available, it could possibly have an effect on the selection criteria applied to patients in the public sector, and on the selection criteria for transplants in both the private and public sectors. (See the recommendation for South African Renal Society to implement assessment of ESRD patients' health literacy levels.)

Unit managers of dialysis centres

- Unit managers of dialysis centres can take up the responsibility to educate other dialysis staff about the influence of limited health literacy on patient health outcomes. Education must include encouraging good communication between

patients and dialysis staff. Dialysis staff must be trained to take the language and culture of the patient and context in which the patient lives into consideration when giving education and training to a patient. If the training cannot be done in the home language of a patient, simple language has to be used, and complicated medical terminology avoided. This education can be part of the orientation programme of newly appointed employees. All employees can undergo follow-up training every year.

- Unit managers can identify patients with limited or moderate health literacy levels and appoint a specific dialysis staff member to give education and training to these patients. Extra time will have to be scheduled, as these patients will need additional time, patience, skills and reinforcement when being educated and trained. Planning for these training sessions can be done monthly.

Dialysis staff (professional nurses, clinical technologists and dieticians)

- It is advised that the following aspects be taken into consideration before starting education and training of every patient admitted on dialysis:
 - The language, cultural and environmental context of living of the patient;
 - The education level of the patient;
 - The age of the patient;
 - Whether the patient has inadequate eyesight; and
 - The health literacy status of the patient, if available.
- It is advised that certain knowledge is reinforced during the training and education sessions of ESRD patients:
 - Ensure that ESRD patients know what they have to do in case of emergencies.
 - Make patients aware of the influence their lifestyle had and still has on their chronic illness, especially for patients with hypertension and diabetes.
 - Ensure that patients understand their prescriptions: dialysis regimes and medication prescriptions. Explain to patients how their health outcomes could be compromised if they do not adhere to their prescriptions.
 - Dialysis staff must ensure that ESRD patients understand the concept of volume measurement. Volume measurement can be a potential obstacle when giving training regarding fluid restrictions. An assistive device, like a 250 ml plastic cup, could be used as part of the training. The device can be

given to the patient to use for measurement at home. Furthermore, patient's self-management could be improved if a good understanding of the risks and benefits related to fluid control is reinforced during the training sessions.

- Reinforce patients' knowledge regarding highly transmittable diseases, such as TB and hepatitis B. Patients have to be made aware that they are at risk of developing these diseases due to their compromised immune systems and their exposure to other patients in the dialysis centres.
- Reinforce patients' knowledge of nephrotoxic medications and the influence it could have on reducing their residual renal function further.
- The "teach-back" method might be useful to ensure understanding of the crucial information above, and patients should be encouraged to ask questions.
- It is advised that education and training of these ESRD patients is commenced on admission to the dialysis centre, and preferably completed during the first three months, but not longer than six months after admission. Reinforcement and follow-up can be done monthly, when dialysis staff should discuss a patients' blood results with them to ensure their understanding of what they had been taught.

The ESRD patients

- If health literacy assessment could be part of the screening of newly admitted ESRD patients, patients' health literacy status could be discussed with them. Self-awareness may improve patients' understanding and self-management of their chronic disease.

Future research

- Future researchers could possibly use the methodology used to develop the SHLT, to develop more general health literacy tests for other languages and population groups in the South African context.
- The focus of future research could be to develop a disease-specific health literacy test for use with ESRD patients in the languages of the South African context.
- Future researchers could collaborate with dialysis providers to develop language and culture-sensitive training and education material for use in the South African

context. If ESRD patients' understanding of their chronic disease could improve, self-management skills and health outcomes could also be improved.

- Future researchers could aim to develop an assistive device that could help patients with fluid measurement, for instance, a 250 ml tool that could be used by ESRD patients to assist with fluid control during the initial phase of their chronic disease.
- This study only focused on haemodialysis and peritoneal dialysis patients. Future researchers could include renal transplanted patients for assessing health literacy, as limited health literacy is associated with being disqualified for wait-listing for transplant.
- The focus of future research studies could, thus, shift to designing and implementing suitable interventions to improve the health literacy of ESRD patients. Post-intervention studies could assess the outcomes of the interventions.

5.5. LIMITATIONS

This research study faced limitations that have to be acknowledged, and which will be discussed below.

The SHLT is not an ESRD-specific health literacy test. Still, a general test contextualised and validated for use with Sesotho-speaking individuals attending the public healthcare sector in the Free State province of South Africa proved helpful in this study. Therefore, ESRD-specific health literacy aspects were not assessed.

Health literacy is not stagnant and can change over time. By utilising a cross-sectional design, only a snapshot of the health literacy status of Sesotho-speaking ESRD patients was captured. However, with no other health literacy research being done with Sesotho-speaking ESRD patients, the results still give insight into the current health literacy status of this group of ESRD patients.

Due to the number of Sesotho first-language speaking ESRD patients being unknown to the researcher, as well as the proximity of the patients, convenience sampling was used. This could possibly have introduced bias.

The researcher is not a Sesotho first-language speaker, and Sesotho first-language speaking fieldworkers were trained to complete the questionnaires. Although the

fieldworkers were trained and had to collect the data according to the guideline for completing the SHLT (Addendum B), the possibility of bias was present. However, the researcher was present during the data collection process and checked the questionnaires for completeness and clarified any uncertainties while the respondents were still on dialysis.

Two private dialysis providers did not permit the researcher to collect data at their centres. Thus, data from the private sector were only collected from three of the five private dialysis centres in the Free State province. The public sector represented 57.4% of the sample, which is not a true reflection of the private-public ratio of ESRD respondents in the Free State province. The data could present some bias in underreporting of health literacy levels of the private sector ESRD population in the Free State province. However, more than 50% of the estimated number of ESRD patients in the Free State province participated in the current study.

Another limitation that could possibly have biased the results of the study was the failure to include transplant patients. Although studying the health literacy of transplant patients was not one of the objectives of this study, they form a part of the ESRD population. The researcher recommends that transplant patients are included in future health literacy studies into the ESRD population in South Africa.

Almost 50% of the patients in this study reported that they had problems reading due to inadequate eyesight. Four of the questions of the SHLT were based on pictures or prescriptions being shown to patients. The pictures were close to the actual size used in the healthcare sectors. Researchers need to take note that the data may not only reflect a patient's health literacy status, but may be influenced by the patient's ability to see.

5.6. VALUE OF THE STUDY

To the researcher's knowledge, this is the first study to describe the health literacy status of Sesotho-speaking ESRD patients in South Africa. To date, there are no health literacy data available for ESRD patients in South Africa. Although this is a subpopulation of ESRD patients, it gives some insight into the current health literacy levels of the Sesotho-speaking ESRD population.

Although the SHLT is a general health literacy test, the principles of the SHLT were found to be applicable to Sesotho-speaking ESRD patients of both the private and public

healthcare sectors. The problem statement of this study was based on the definition of the WHO (Dodson *et al.*, 2015:Online) and the questions of the SHLT are based on a patient's ability to "access, understand, appraise and use information and services to make decisions about health". The results of this study could, indeed, answer the research question of this study.

Answers to questions in the SHLT highlighted that ESRD patients had difficulties with measurement, had inadequate knowledge about health, nutrition and exercise and experienced problems following medication prescriptions. Patients must be encouraged to empower themselves with knowledge to address their lack of ability in this field.

The majority of patients are affected by hypertension, and diabetes is one of the most prevalent comorbidities. Thus, dialysis providers can now also focus on improving the health literacy levels of patients on renal replacement therapy, and those treated in pre-dialysis stages.

With the insight gained in relation to the health literacy status of Sesotho-speaking ESRD patients, their self-management skills, adherence to treatment prescriptions, quality of life, overall health, and health outcomes can be improved.

5.7. REFLECTIONS ON THE CONCLUSION OF THE STUDY

Undertaking this research study was an invaluable learning experience. The researcher gained *some* understanding of the complexity of and challenges posed by the research process. The exposure to experienced researchers, academic writing and the description of quantified data was immensely stimulating and rewarding. The researcher is motivated to explore the health literacy levels of ESRD patients further, since she is now more aware of the impact it might have on the health outcomes of ESRD patients.

The most rewarding experience, however, was the insight gained by reviewing the literature on the health literacy of ESRD patients. After years of exposure to the lives of ESRD patients, the researcher has been encouraged to exhibit greater empathy and understanding of their lifelong endurance. The researcher realised that dialysis staff, with little effort, can make a massive difference in the life of an ESRD patient with a limited health literacy level.

5.8. CONCLUSION

This study provides insight into the health literacy status of Sesotho-speaking ESRD patients in the Free State province of South Africa. The context and culture-related perspective place medical practitioners in a better position to identify vulnerable patients and to develop interventions to improve patients' ability to access, understand, appraise and use information. ESRD patients with lower levels of education have lower health literacy levels, and would need special attention. Appraisal and understanding of health information are critical aspects for ESRD patients with low health literacy levels. Designing and developing health literacy tests should be language, culture and context-specific. The research done in this study suggests that self-management and health outcomes will improve if the health literacy levels of ESRD patients were known.

“Knowledge isn’t power, applied knowledge is power”

– Eric Thomas –

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ADDENDA

ADDENDUM A: SESOTHO HEALTH LITERACY TEST

SESOTHO HEALTH LITERACY TEST

(Only the Sesotho version will be used in the study)

Only interview respondents where the following is applicable / Bankakarolo ba puisano ena kabathobae kgetheleng

Consent document signed	Yes	No	Foromo ya tumellano e tekenwe
Older than 18 years	Yes	No	Ka hodima leshome le metso e robedi
Sesotho first language speaking patient with ESRD	Yes	No	Mokudi ya nang le ESRD eo Puo ya lapeng e leng Sesotho
Information leaflet given to respondent	Yes	No	Monkakarolo o fumane lengolo la tlhahiso leseding
1.1 Date questionnaire is completed	____ / ____ / ____ Dd mm yy		1.1 Letsatsi la getelloya teko
1.2 Name of the dialysis centre			Sebakase 1.2 hlatswang diphio ka motjhine

Instructions – Read the questions out loud to the respondent and circle the appropriate answer. Do not rephrase any question to a respondent.

Ditaelo - Balla monkakarolo dipotso o etse sedikadikwe karabong e nepahetseng. O se behe potso ka mokgwa o mong

Part 1			
Demographic Information		Data ya babaptsi	
In the following section, I will be asking you some general information		Karolong ena ke tlo o botsa dipotso	
2.1	Gender	2.1	Tekano
	Male Female		Monna Mosadi
2.2	How old are you in years?	2.2	Dilemo tse kae?
2.3	What is the highest grade you have passed in school?	2.3	Grade eo felletseng ho yona sekolong ke efe?
2.4	If matric was the highest grade you passed, did you obtain any degree/diploma/certificate?	2.4	Ha e ba o na le lengolo la degree/certificate ngola mofuta wa le ngolo e sebaka mo o le fumaneng?
2.5	Which treatment option are you being treated with?	2.5	Ke mofuta e feng ya ho fodisa eo e kgethang?
	Haemodialysis Peritoneal dialysis		Haemodialysis Peritoneal dialysis
2.6	List the chronic diseases you are diagnosed with	2.6	Mefuta ya mafu eo o nang le yona e sa foleng
2.7	How many years have you been on dialysis?	2.7	Ke dilemo tse ka oleng sebakeng seo sa ho hlokisa diphio?
2.8	Do you have problems reading because you cannot see?	2.8	O na le bothatha ba ho bala hobane o sa bone
	Yes No		Yes No

Part 2

Sesotho Health Literacy Test

<p>1 If I break my leg, I must go to the</p> <p>a) Clinic</p> <p>b) Hospital</p> <p>c) I don't know</p>	<p>1 Ha nka robaha leoto, ke tlameha ho ya</p> <p>a) Tlilinking</p> <p>b) Sepetlele</p> <p>c) Ha ke tsebe</p>
<p>2 If my brother who stays with me has TB, I must</p> <p>a) do nothing</p> <p>b) go to the clinic for TB testing</p> <p>c) I don't know</p>	<p>2 Ha moholwane wa ka ya dulang le nna a na le TB, ke tlameha ho</p> <p>a) Sa etse letho</p> <p>b) Ho ya tlilinking bakeng sa diteko tsa</p> <p>c) TB</p> <p style="text-align: center;">Ha ke tsebe</p>



= 1 standard cup

Note: 1 teaspoon of sugar = 5ml or 4.2g

1 cup of sugar = 250ml or 212g

<p>3 Look at the sugar measurements. A cup of sugar equals</p> <p>a) 5 ml</p> <p>b) 250 ml</p> <p>c) I don't know</p>	<p>3 Sheba ditekanyetso tsa tswekere. Kopi ya tswekere e lekana le</p> <p>a) 5 ml</p> <p>b) 250 ml</p> <p>c) Ha ke tsebe</p>
<p>4 Your friend is overweight. She does not have money. Appropriate advice you can give her to lose weight is to:</p> <p>a) To go to a gym</p> <p>b) Take long fast walks</p> <p>c) I don't know</p>	<p>4 Motswalle wa hao o nonne. Ha a na tjelete. Keletso e tshwanelehang eo o ka mo fang yona ho theola boima ba mmele ke</p> <p>a) Ho lefa ho ya boikwetlisong</p> <p>b) Ho tsamaya ka potlako nako e telele</p> <p>c) Ha ke tsebe</p>

5	A person taking a medication for the first time and presents with a skin rash must	5	Motho a nwang moriana lekgetlo la pele ha a ba le lekgopo o tlameha ho
a)	Finish the medication	a)	Ho qeta moriana
b)	Go back to doctor/clinic	b)	Ho kgutlela ngakeng/ tlilining
c)	I don't know	c)	Ha ke tsebe

PAIN TABLETS

Per Tablet: paracetamol 500mg;

Potassium sorbate 0.12% m/m Sugar free

Warning: Do not use continuously for longer than 7 days (adults) or 5 days (children) without consulting your doctor. Store below 25 C in a well-closed container protected from light and air.

KEEP OUT OF REACH OF CHILDREN

6	You have been taking pain pills for 7 days and still have pain. Look at the instructions on the pain tablet label and decide what you have to do:	6	O nwele dipilisi tsa mahlaba matsatsi a 7 empa o ntse o opelwa. Sheba ditaello tse na mme o etse qeto ka seo o tlamehang ho se etsa
a)	Take 2 pills	a)	Enwa dipilisi tse 2
b)	Go to the doctor/clinic	b)	E ya ngakeng/tlilining
c)	I don't know	c)	Ha ke tsebe

BEA HOLE LE BANA · MAING
 ANELE EZINGANELI · BEKA KUDE EBANTWANENI · KEEP OUT OF CHILDREN'S REACH

It is dangerous to exceed the stated dose.

Hoef/Qty Produk/Product

MULTI-VITAMIN SYRUP

2 Teaspoons 2 TIMES PER DAY
 MAKGETLO KA LETSATSI

NA ETES / AFTER MEALS / MORAHO HA DIJO

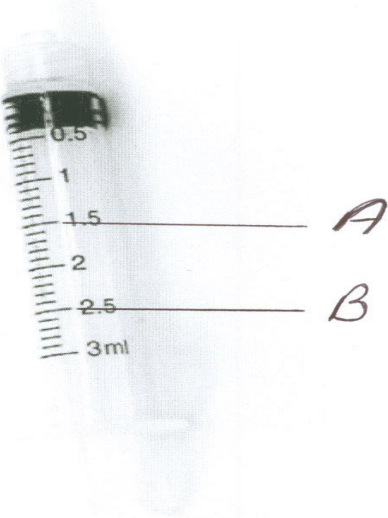
Lot/Batch: Verval/Expiry:

NAME: No:

Tumelo

PRIMARY HEALTH CARE
 FREE STATE

<p>7 Look at the instruction on medication bottle. How many times does Tumelo have to take his multivitamin syrup a day?</p> <p>a) 2 times per day b) 4 times per day c) I don't know</p>	<p>7 Sheba ditaelo tse botlolong ya moriana. Tumelo o tlameha ho nwa moriana wa di-aha mmele ha kae ka letsatsi?</p> <p>a) 2 ka letsatsi b) 4 ka letsatsi c) Ha ke tsebe</p>
<p>8 When we read the following word, which option is best associated with the word:</p> <p style="text-align: center;">TB</p> <p>a) Cough b) Weight gain c) I don't know</p>	<p>8 Ha re bala mantswe a latelang, kgetho nyallanang le lentswe leo ke e fe:</p> <p style="text-align: center;">TB</p> <p>a) Ho hohlola b) Ho eketseha mmele c) Ha ke tsebe</p>
<p>9 If you take your first dosage of pain medication at 8 o'clock and the nurse tells you to take the pain</p>	<p>9 Ha o nwa tekanyetso ya pele ya moriana wa mahlaba ka 8 hoseng mme mooki a o bollela ho nwa moriana</p>

<p>medication every 6 hours, when can you take your next dosage?</p> <p>a) 2 o'clock in the afternoon</p> <p>b) 6 o'clock in the evening</p> <p>c) I don't know</p>	<p>wa mahlaba ka mora hora tse 6, o ka nwa neng tekanyetso e latelang?</p> <p>a) Hora ya bobedi motshehare</p> <p>b) Hora ya botshelela mantsiboya</p> <p>c) Ha ke tsebe</p>
 <p>The image shows a 3ml oral syringe. The scale is marked from 0 to 3ml in increments of 0.5ml. Handwritten lines indicate two specific volumes: 'A' is drawn at the 1.5ml mark, and 'B' is drawn at the 2.5ml mark.</p>	
<p>10 Thabo has to give 2,5ml of cough syrup to his sister. Choose an option that will indicate that there is 2,5ml of syrup in the syringe</p> <p>a) Choice A</p> <p>b) Choice B</p> <p>c) I don't know</p>	<p>10 Thabo o tlameha ho nwesa kgaitsemi ya hae moriana wa sefuba wa 2.5ml. Etsa kgetho ho bontsha 2.5ml sepeiting</p> <p>a) Kgetho A</p> <p>b) Kgetho B</p> <p>c) Ha ke tsebe</p>

Fieldworker's signature:



= 1 standard cup

Note: 1 teaspoon of sugar = 5 ml or
4.2 g

1 cup of sugar = 250 ml or 212 g

BEA HOLE LE BANA ·MAING

ANELE EZINGANELI · BEKA KUDE EBANTWANENI · KEEP OUT OF CHILDREN'S REACH

It is dangerous to exceed the stated dose.

Hoef/Qty

Produk/Product

MULTI-VITAMIN SYRUP

2

Teaspoons

2

TIMES PER DAY

MAKGETLO KA LETSATSI

NA ETES / AFTER MEALS / MORAHO HA DIJO

Lot/Batch:

Verval/Expiry:

NAME:

Tumelo

No:

PRIMARY HEALTH CARE

FREE STATE

PAIN TABLETS

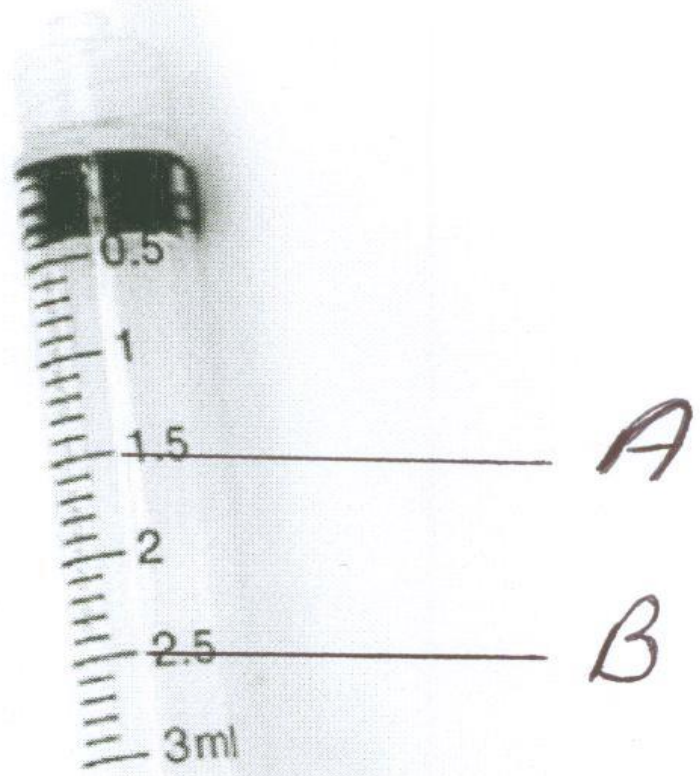
Per Tablet: paracetamol 500mg;

Potassium sorbate 0.12% m/m Sugar free

Warning: Do not use continuously for longer than 7 days (adults) or 5 days (children) without consulting your doctor.

Store below 25 C in a well-closed container protected from light and air.

KEEP OUT OF REACH OF CHILDREN



ADDENDUM B: GUIDELINE FOR THE COMPLETEION OF THE SHLT

Guideline for the completion of the SHLT

Familiarize yourself with the content of this guideline prior to the completion of the SHLT.
Only interview patients who meet all the inclusion criteria namely:

Patients:

- who have signed the consent form
- who are older than 18 years old
- who are Sesotho first language speaking
- who are diagnosed with end-stage renal disease and treated with haemodialysis or peritoneal dialysis

Use the following instructions as a guideline when completing the SHLT:

1. Before the completion of the questionnaire starts, explain to the respondent that the value of the study will be to improve the health outcomes of patients with ESRD.
2. Explain to the respondent that the completion of the questionnaire will only take 10 to 15 minutes.
3. Explain to the respondent that the fieldworker will read the questions and the available answers out loud.
4. Explain to the respondent that no answers will be discussed and that only the three available options A (Yes), B (No) or C which is "I don't know", will have to be given as an answer. The "I don't know" option is equally important to improve the health outcomes of patients with ESRD.
5. Explain to the respondent that the fieldworker will complete the given answer on the questionnaire.
6. Make sure that the respondent has received the information leaflet.
7. Make sure that all the questions are answered.

8. If any problem arises that you are not sure how to handle, please ask the researcher who will be available on the site.

Question by question guide:

Below in boldface type are the questions found in the SHLT:

1.1 Date questionnaire is completed ____/____/____(dd/mm/yy)

Write the date on which the questionnaire is completed. Start with the day, month and then year.

1.2 Name of the dialysis centre _____

Write the name of the dialysis centre where the test is conducted.

Part 1: Demographic data

2.1 Gender

Please select male or female and mark the indicated box.

2.2 How old are you in years?

Ask the respondent what their current age is in years.

2.3 What is the highest grade you have passed in school?

Ask the respondent what the highest grade passed, is. Please make sure that the respondent does not indicate the highest grade attended, but confirm that the respondent passed the grade.

2.4 If matric was the highest grade you passed, did you obtain any degree/diploma/certificate? (Specify which degree/diploma or certificate and from which institution).

Please confirm from which institution this qualification has been obtained.

2.5 Which treatment option are you being treated with?

Confirm if the respondent is treated with haemodialysis or peritoneal dialysis and tick the appropriate box.

2.6 List the chronic diseases you are diagnosed with.

Ask the respondent with which other chronic diseases he/she are being diagnosed with and write it on the form.

2.7 How many years have you been on dialysis?

Ask the respondent how many years he/she has been treated for ESRD.

2.8 Do you have problems reading because you cannot see?

Ask the respondent if he/she has problems to read whether wearing glasses or not. Tick “yes” or “no” in the appropriate box.

Part 2: Sesotho Health Literacy Test

1. If I break my leg, I must go to the

- (a) Clinic**
- (b) Hospital**
- (c) I don't know**

With this question, you would like to assess the knowledge of the respondent on what to do in case of an emergency. Read the question to the respondent. Then circle the given answer.

2. If my brother who stays with me has TB, I must

- (a) do nothing**
- (b) go the clinic for TB testing**
- (c) I don't know**

With this question, you would like to assess the respondents' knowledge regarding TB. Read the question to the respondent. Then circle the given answer.

3. Look at the sugar measurements. A cup of sugar equals:

- (a) 5ml**
- (b) 250ml**
- (c) I don't know**

Here the respondents' knowledge about measurement is assessed. Show the laminated picture of the standard cup and other measurements to the respondent. Do not read the word on the picture to the respondent or translate it into Sesotho. Read the question to the respondent. Then circle the given answer.

4. Your friend is overweight. She does not have money. Appropriate advice you can give her to lose weight is to:

- (a) Go to a gym**
- (b) Take long fast walks**
- (c) I don't know**

The respondents' knowledge of health and nutrition is assessed with this question. Read the question to the respondent. Then circle the given answer.

5. A person taking a medication for the first time and presents with a skin rash must:

- (a) Finish the medication**
- (b) Go back to the doctor/clinic**
- (c) I don't know**

With this question, the respondent's knowledge about the side-effects of medication is assessed. Read the question to the respondent. Then circle the given answer.

6. You have been taking pain pills for 7 days and still have pain. Look at the instructions on the pain tablet label and decide what you have to do:

- (a) Take 2 pills**
- (b) Go to the doctor/clinic**
- (c) I don't know**

With this question, we would like to assess if the respondent is able to read and interpret instructions as written on a medication label. Show the laminated label to the respondent.

Do not read the words to the respondent and do not translate them into Sesotho. Read the question to the respondent. Then circle the given answer.

7. Look at the instruction on the medication bottle. How many times does Tumelo have to take his multi-vitamin syrup a day?

- (a) 2 times per day**
- (b) 4 times per day**
- (c) I don't know**

This picture assesses the ability of the respondent to read and interpret instructions on a medication label. Show the laminated picture of the medication bottle to the respondent. Do not read the words to the respondent and do not translate them into Sesotho. Read the question to the respondent. Then circle the given answer.

8. When we read the following word, which option is best associated with the word:

TB

- (a) Cough**
- (b) Weight gain**
- (c) I don't know**

With this question, the respondents' knowledge regarding TB is assessed. Read the question to the respondent. Then circle the given answer.

9. If you take your first dosage of pain medication at 8 o'clock and the nurse tells you to take the pain medication every 6 hours, when can you take your next dosage?

- (a) 2 o'clock in the afternoon**
- (b) 6 o'clock in the evening**
- (c) I don't know**

With this question, the respondents' ability to follow and apply instructions on medication prescriptions is assessed. Read the question to the respondent. Then circle the given answer.

10. Thabo has to give 2.5ml of cough syrup to his sister. Choose an option that will indicate that there is 2.5ml of syrup in the syringe:

(a) Choice A

(b) Choice B

(c) I don't know

With this question, we would like to assess if a respondent is able to measure medication correctly according to a prescription. Show the picture of the syringe to the respondent. Do not give any explanation about the image or provide the respondent with an indication of what the answer may be. Read the question to the respondent. Then circle the given solution.

Ensure that all answers have been completed and thank the respondent for his or her participation in the study.

ADDENDUM C1: ENGLISH INFORMATION LEAFLET

TITLE OF RESEARCH: HEALTH LITERACY OF SESOTHO-SPEAKING END-STAGE RENAL DISEASE PATIENTS IN THE FREE STATE PROVINCE

Good day

I, Elsabet van Rensburg, am researching the health literacy status of Sesotho-speaking patients with end-stage renal disease in the Free State Province.

Research is just the process to learn the answer to a question. In this study, we want to assess what the health literacy status of Sesotho first language speaking patients with end-stage renal disease are, by using the Sesotho Health Literacy Test. This knowledge will be communicated to all the authorities of the relevant dialysis providers to improve health outcomes for patients on dialysis.

Invitation to participate: We are asking/inviting you to participate in a research study out of a free will.

What does the study involve? – You will be asked ten questions in Sesotho, by a Sesotho first language speaking fieldworker, regarding general knowledge about health. Your answer, “yes”, “no” or “I don’t know”, will be written on the questionnaire by the fieldworker. It will take about 10 to 15 minutes to complete the questionnaire. The aim is to recruit 250 Sesotho first language speaking patients with end-stage renal disease in the Free State.

There are NO RISKS involved in taking part in the study.

Benefits of taking part in the study are that the information gathered from the research may lead to improve future care for patients with end-stage renal disease.

Participation is out of a free will, and refusal to take part will involve no punishment or loss of benefits to which the respondent is otherwise entitled; the respondent may discontinue participation at any time without penalty or loss of benefits to which the participant is otherwise entitled. You will not be paid for taking part in the study.

ADDENDUM C2: SESOTHO INFORMATION LEAFLET

SEHLOHO SA DIPATLISO: TSEBO YA TSA BOPHELO YA BATHO BAO SESOTHO ELENG PUO YA LAPENG BATSHWERWENG LEFU LA DIPHIO MO PROFISENG YA FREISTATA

DUMELANG

Nna, Elsabet van Rensburg, ke etsa dipatliso ka tsebo ya ka tsa bophelo ya batho bao Sesotho eleng Puo ya lapeng ba tshwerweng ke diphio.

Dipatliso tsena ke tsela ya ho ithuta ho araba potso. Mona thutong re batla ho hlahloba batho bao sesotho e leng puo ya lapeng ba tshwerweng ke lefu la diphio, re sebedisa teko ya bophelo bo botle.

Tsebo ena e tla fetisetswa mafapheng a ikarabellang tshebeletsong tsa ho hlatswa madi (Dialysis), morero e le hotlafatsa qetello ya bakudi ba tshwerweng diphio ba fumanwang tlhomelo ya ho hlatswa madi.

Memo ya ho nka karolo: Re o mema hore le wena o ithaope ho nka karolo dipatlisong tsena.

Dipatliso di kentse eng? - O tlo botswa dipotso tse leshome ka sesotho tse tla botswang ke mosebeletsi ya buong sesotho, mabapi le tsebo ya hao ka bophelo ka kakaretso. Karabo ya hao. Ya eya, tjhee“ kapa ha ke tsebe , e tla ngolwa ke moseletsi wa dipatliso.

Ho nka metsotso e leshome ho isa ho moshome a bebedi ho araba dipotso. Morero ke ho thaatha bakudi bao sesotho eleng puo ya lapeng ba 250 mona Free State.

Kotsi. Thuto ena ha ena kotsi.

Melemo ya ho nka karolo ke hore tlhahisoleseding e fumanweng dipatlisong e ka ntlafatsa tlhokomelo ya bakudi ba tshwerweng ke lefu la diphio le bokamoso.

Ha o ya tlangwa ho nka karolo: O ka nna wa ikhula ho nka karolo neng kapa neng

Ha o ka ke wa tadingwa hampe kapa wa songwa. Ha hona tefo ha o nka karolo dipatlisong.

Lekunutu: Ha hona lesedi ka bophelo ba hao le tla pepeswa ntle le dilemo le boemo ba thuto ya hao. Pokelletso ena ya hao e ka arolelwa feela le ba ithutang ka taba tsena moo University ya Foreistata le lefapheng la bophelo bo botle profeseng ya Freistata.

Dintlha tsa puisono tsa mofuputsi bakeng sa tlhahiso leseding e eketsehileng.

Elsabet van Rensburg [Tel:083 500 7683](tel:083 500 7683) Dintlha tsa puisano tsa mongodi wa komiti ya boitshwaro ya dipatliso- Ha ona le ditletlebo 051 4017794/5, ethicsfhs@ufs.ac.za.

ADDENDUM D1: ENGLISH CONSENT FORM

CONSENT TO PARTICIPATE IN RESEARCH

I have been asked to take part in a research study titled: ***Health literacy of Sesotho-speaking patients with end-stage renal disease in the Free State Province.***

I realize that I may not take part in this study if I am younger than 18 years, do not have end-stage renal disease and do not speak Sesotho as my first language.

I realize that the knowledge gained from this study may help either me or other patients with end-stage renal disease, to improve their health outcomes in the future.

I realize that my participation in this research is entirely out of a free will, and I may withdraw from the study at any time I wish. If I decide to discontinue my participation in the study, I will not be penalized in any way. If I agree to take part, I will be given the respondent information leaflet, which is a written summary of the research.

I understand that I will not receive any payment for taking part in this study and it will not cost me anything.

If I need to, I can contact the researcher, Me Elsabet van Rensburg at 083 500 7683 at any time during the study. I may also contact the Secretariat of the Health Sciences Research Ethics Committee, UFS at the telephone number (051) 401 7794/5 if I have questions about my rights as a research subject.

This study has been explained to me by I have read and understood this consent form, and I agree to participate. I know that I will be given a copy of this signed consent form.

ADDENDUM D2: SESOTHO CONSENT FORM

FOROMO YA TUMELLANO

O ile wa kotjwa ho nka karolo diphuputsong tsa sehloho sa phuputso ***Bophelo bo botle ba ho bala le ho ngola ho bakudi ba na le lefu la diphio mohatong wa o qetela proviseng ya Freistata.***

Ke ya utlwisisa ho re ha ke ya tshwanela ho nka karolo thuthong ena ha ke le ka tlase ho dilemo tse leshome le metso e robedi, ke se mohatong wa o qetela wa lefu wa diphio le ha Sesotho e se puo ya lapeng.

Ke lemoha ho re tsebo e fumanehang thuto ena e ka thusa nna kapo bakudi ba bang ba na le lefu la diphio mohatong wa o qetela le ho ntlafasta bokamoso ba maphelo a bona.

Ho nka karolo diphuputsong tsa ha se qobello, mme ha o kake wa qoswa kapa wa lahlehelwa ke maemo ha o sa nke karolo. O tla newa lengolo la tlhahiso leseding e leng kakaresto ya phuputso ena.

Ke ya utlwisisa ho re, ha ke tlo patalwa ha ke nka karolo thuthong ena.

O ka nna wa ikopanya le mme Elsabet van Rensburg mona 083 500 7683 neng kapa neng ha o ena le dipotso kapa o tswile kotsi ka baka la phuputso ena. O ka nna wa ikopanya le mongodi wa tsa bophelo le mohlale a phuputso le boitswaro komiting ya UFS nomorong ena (051) 4017794/5 ha o ena le dipotso ka ditokelo tsa hao jwaleka ya fupuditsweng.

O bolelletswe ka thuto ena ke.....

Ke utlwisisa hore ho nka karolo thuthong ena ha ka qobellwa me ke dumetse ho nka karolo. O tla newa tokomane e tekenuweng e le karolo ya yona.

Mosaeno wa monkakarolo

Letsatsi

Mosaeno wa paki

Letsatsi

ADDENDUM E: HSREC APPROVAL



Health Sciences Research Ethics Committee

14-Jun-2019

Dear Mrs Elsabet Van Rensburg

Ethics Clearance: **Health literacy of Sesotho-speaking patients with end-stage renal disease in the Free State Province**

Principal Investigator: Mrs Elsabet Van Rensburg

Department: School of Nursing Department (Bloemfontein Campus)

APPLICATION APPROVED

Please ensure that you read the whole document

With reference to your application for ethical clearance with the Faculty of Health Sciences, I am pleased to inform you on behalf of the Health Sciences Research Ethics Committee that you have been granted ethical clearance for your project.

Your ethical clearance number, to be used in all correspondence is: **UFS-HSD2019/0398/2506**

The ethical clearance number is valid for research conducted for one year from issuance. Should you require more time to complete this research, please apply for an extension.

We request that any changes that may take place during the course of your research project be submitted to the HSREC for approval to ensure we are kept up to date with your progress and any ethical implications that may arise. This includes any serious adverse events and/or termination of the study.

A progress report should be submitted within one year of approval, and annually for long term studies. A final report should be submitted at the completion of the study.

The HSREC functions in compliance with, but not limited to, the following documents and guidelines: The SA National Health Act. No. 61 of 2003; Ethics in Health Research: Principles, Structures and Processes (2015); SA GCP(2006); Declaration of Helsinki; The Belmont Report; The US Office of Human Research Protections 45 CFR 461 (for non-exempt research with human participants conducted or supported by the US Department of Health and Human Services- (HHS), 21 CFR 50, 21 CFR 56; CIOMS; ICH-GCP-E6 Sections 1-4; The International Conference on Harmonization and Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH Tripartite), Guidelines of the SA Medicines Control Council as well as Laws and Regulations with regard to the Control of Medicines, Constitution of the HSREC of the Faculty of Health Sciences.

For any questions or concerns, please feel free to contact HSREC Administration: 051-4017794/5 or email EthicsFHS@ufs.ac.za.

Thank you for submitting this proposal for ethical clearance and we wish you every success with your research.

Yours Sincerely

Dr. SM Le Grange

Chair : Health Sciences Research Ethics Committee

Health Sciences Research Ethics Committee

Office of the Dean: Health Sciences

T: +27 (0)51 401 7795/7794 | E: ethicsfhs@ufs.ac.za

IRB 00006240; REC 230408-011; IORG0005187; FWA00012784

Block D, Dean's Division, Room D104 | P.O. Box/Posbus 339 (Internal Post Box G40) | Bloemfontein 9300 | South Africa

www.ufs.ac.za



ADDENDUM F: APPROVAL FROM DEPARTMENT OF HEALTH



health

Department of
Health
FREE STATE PROVINCE

03 June 2019

Mrs. E Van Rensburg
School of Nursing
UFS

Dear Mrs. E Van Rensburg

Subject: Health literacy of Sesotho-speaking patients with end-stage renal disease in the Free State Province.

- Please ensure that you read the whole document, Permission is hereby granted for the above – mentioned research on the following conditions:
- Participation in the study must be voluntary.
- A written consent by each participant must be obtained.
- Serious Adverse events to be reported to the Free State department of health and/ or termination of the study
- Ascertain that your data collection exercise neither interferes with the day to day running of the **Bongani, Pelonomi, Universitas & Dihlabeng Hospital** nor the performance of duties by the respondents or health care workers.
- Confidentiality of information will be ensured and please do not obtain information regarding the identity of the participants.
- **Research results and a complete report should be made available to the Free State Department of Health on completion of the study (a hard copy plus a soft copy).**
- Progress report must be presented not later than one year after approval of the project to the Ethics Committee of the University of Free State and to Free State Department of Health.
- Any amendments, extension or other modifications to the protocol or investigators must be submitted to the Ethics Committee of the University of Free State and to Free State Department of Health.
- **Conditions stated in your Ethical Approval letter should be adhered to and a final copy of the Ethics Clearance Certificate should be submitted to sebeclats@fshealth.gov.za or lithekom@fshealth.gov.za before you commence with the study**
- No financial liability will be placed on the Free State Department of Health
- Please discuss your study with the institution manager/CEOs on commencement for logistical arrangements
- Department of Health to be fully indemnified from any harm that participants and staff experiences in the study
- Researchers will be required to enter in to a formal agreement with the Free State department of health regulating and formalizing the research relationship (document will follow)
- You are encouraged to present your study findings/results at the Free State Provincial health research day

Trust you find the above in order.
Kind Regards

Dr D Motau
HEAD: HEALTH
Date: 7/6/19

Head : Health
PO Box 227, Bloemfotein, 9300
4th Floor, Executive Suite, Bophelo House, cnr Maitland and, Harvey Road, Bloemfotein
Tef: (051) 408 1646 Fax: (051) 408 1556 e-mail: khusemi@fshealth.gov.za / fshealth.gov.za@fshealth.gov.za / chikobvup@fshealth.gov.za

www.fs.gov.za

**ADDENDUM G1: PERMISSION LETTER: UNIVERSITAS ACADEMIC
HOSPITAL**



health

Department of
Health
FREE STATE PROVINCE

24 June 2019

Mrs E van Rensburg
School of Nursing
University of the Free State

Dear Mrs van Rensburg

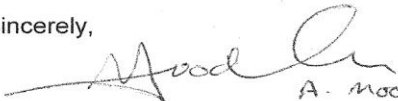
**RESEARCH PROJECT: HEALTH LITERACY OF SESOTHO – SPEAKING PATIENTS
WITH END – STAGE RENAL DISEASE IN THE FREE STATE PROVINCE**

Herewith permission for the mentioned project to be done at Universitas Academic Hospital on the following condition:

1. The researcher/s should comply with all the conditions referred to in the approval letter obtained from the HOD's Office: Dr D Motau on 7 June 2019.
2. Your research should not interfere with or disrupt the day to day running of the Departments at UAH.
3. The Researcher shall be held personally liable for any additional costs that are incurred by this research and that are not a part of the day to day running of the Departments where the research is conducted.
4. A progress report must be submitted to HOCD: Clinical Services every 3 months.
5. A copy of the results must be submitted to HOCD: Clinical Services once your research is completed.

The Chief Executive Officer and HOCD: Clinical Services must be notified of the findings of the project upon completion.

Yours sincerely,

 (ACTING HOCD: CS)
A. MOODY

R DR RITA NATHAN
B.MedSc, MBCHB, M.MedComm Health, FCPHM(SA), MBA
HOCD: CLINICAL SERVICES
UNIVERSITAS ACADEMIC HOSPITAL

HOCD: CLINICAL SERVICES: DR RITA NATHAN
Private Bag X20660, Bloemfontein, 9300. Tel. No.: 051-4053496,
Fax: 051-4053500, Room 1077, First Floor, Universitas Academic Hospital
Email: nathanr@fshealth.gov.za

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ADDENDUM G2: PERMISSION LETTER: PELONOMI HOSPITAL



pelonomi hospital

Department of Health
Pelonomi Tertiary Hospital
FREE STATE PROVINCE

DATE: 10 JULY 2019	ENQUIRIES
TO: Elsabet van Rensburg elsabetvr@gmail.com School of Nursing Faculty of Health Sciences University of the Free State	FROM: Dr B.A Benganga Head: Clinical Services Bengangaba@fshealth.gov.za 051 405 1936 Bloemfontein

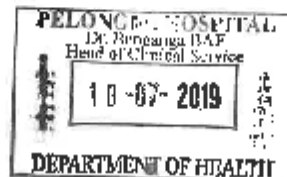
SUBJECT: Request to conduct research in Pelonomi Hospital's Dialysis Unit

Pelonomi Tertiary Hospital grants you permission to conduct researches/studies and the following criteria must be met.

- That you obtain ethical clearance from the human research ethics committee of the relevant university.
- That the Hospital incurs no cost in the course of your research.
- That access to the staff and patients at the Pelonomi Hospital will not interrupt the daily provision of services.
- That prior to conducting the research you will liaise with the supervisors of the relevant sections and introduce yourself with permission letter and to make arrangements with them in a manner that is convenient to the sections.

Yours Sincerely

Dr Benganga B.A
Director: Clinical Services



ADDENDUM G3: PERMISSION LETTER: BBRAUN AVITUM (PTY) LTD

B BRAUN	Stellungnahme Studienvorhaben / <i>Statement</i> <i>Study Projects</i>	1 von / of 2
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1. Studienbasisdaten /

Basic Study Elements

Name der Studie / <i>Title of the Study</i>	Health literacy status of Sesotho speaking patients with end-stage renal disease in the Free State Provinc
Leiter und Sitz der Studie / <i>Principal Investigator and Site of Study</i>	IIT: Elsabet van Rensburg Supervisor: Dr M Reid Co-supervisor: Me M Pienaar
Verantwortlicher Projektmanager MSA / <i>Responsible Project Manager MSA</i>	Karishma Singh Managing Director B Braun Avitum ZA Contact MSA: Dr. B. Weise, MM Nephrology
Verwendetes Medizinprodukt Verwendetes Arzneimittel / <i>Studied Medical Device</i> <i>Studied Medicinal Product</i>	none

2. Kosten /

Cost

Pro Patient / <i>per patient</i>	none
Gesamt / <i>Sum</i>	Must be assessed by: Karishma Singh Managing Director B Braun Avitum ZA
Kostenträger, Kostenstelle <i>Budget responsible/Cost Center</i>	none

3. Stellungnahme /

Statement

Medizinische Originalität, Wichtigkeit / <i>Clinical Originality, Relevance</i>	Clinically relevant
Notwendigkeit für das Unternehmen / <i>Necessity for the Company</i>	Study has the potential to improve patient care
Studienplanung, methodische Durchführung / <i>Study Planning/ Methodological Conduct</i>	Logical, accountable, reliable
Angemessenheit der Leistungen / <i>Adequateness of Costs</i>	Must be assessed by Karishma Singh Managing Director B Braun Avitum ZA

B BRAUN	Stellungnahme Studienvorhaben / <i>Statement</i> <i>Study Projects</i>	2 von / of 2
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Qualifikation des Studienzentrums zur Durchführung der Studie/ <i>Qualification of the Study Site for the Study Conduct</i>	GCP required
Fazit / Conclusion	We recommend the conduct of the study

Für die Stellungnahme standen folgende wichtige Eckdaten zur Verfügung: / *The statement is based on the following information:*

- X Study
 - Hypothesis and Design
 - X Indications
 - X Objectives
 - Variables
 - X Inclusion /Exclusion Criteria
 - X Number of Sites
 - X (Calculated) Sample Size
 - X Study Schedule
 - X Statistical Methods

4. Unterschriften / Signatures

Karishma Singh
Managing Director
B Braun Avitum ZA
Contact MSA: Dr. B. Weise

Project manager MSA: First name, last name 2019-08-22 B. Weise
Date, Signature

Karishma Singh
Managing Director
B Braun Avitum ZA
Contact MSA: Dr. B. Weise

Budget responsible: First name, last name 2019-08-22 B. Weise
Date, Signature

Prof. Dr. C. Barth

Chief Medical Officer : First name, last name 2019-08-23 C. Barth
Date, Signature

Anhänge/Appendix (optional): Study synopsis or other study-relevant documents

ADDENDUM G4: PERMISSION LETTER: ROSE PARK HOSPITAL

From: Oberholzer,Lida <Lida.Oberholzer@lifehealthcare.co.za>
Sent: Monday, 15 July 2019 15:34
To: Elsabet van Rensburg <elsabetvr@gmail.com>
Subject: RE: Request for permission to conduct research study

Goeiemiddag Elsabet,

Ek is jammer dat jy moes wag vir terugvoer, maar die hospitaalbestuurder, mnr Rossouw, het vanmiddag laat weet dat jy kan voortgaan met jou navorsing. Jy kan my maar net laat weet van jou verdere reëlings en wanneer jy dit wil doen.

Vriendelike Groete
Lida

Lida Oberholzer
Nursing Standards Manager : Rosepark Hospital Bloemfontein



Tel : +27 51 505 5386
Fax : +27 51 522 0977
Email : lida.oberholzer@lifehealthcare.co.za
Website : www.lifehealthcare.co.za

ADDENDUM G5: PERMISSION LETTER: BONGANI HOSPITAL

From: Noge, S <NogeS@fshealth.gov.za>
Sent: Thursday, 20 June 2019 09:36
To: Elsabet van Rensburg <elsabetvr@gmail.com>
Cc: Sibaya, Martie <SibayaEM@fshealth.gov.za>
Subject: RE: Permission to conduct research

Good day

Kindly be informed permission is granted to do research in the hospital. Me Martie Sibaya will assist you as she is Operational Manager of the Unit.

Regards

Dr. SR Noge (PhD)
Chief Executive Officer
Bongani Regional Hospital

ADDENDUM G6: PERMISSION LETTER: DITHLABENG HOSPITAL

From: Makume, TE <MakumeT@fshealth.gov.za>
Sent: Thursday, 08 August 2019 12:09
To: Elsabet van Rensburg <elsabetvr@gmail.com>
Cc: Royi, ME <RoyiME@fshealth.gov.za>; Selfridge, Liam <SelfridgWJ@fshealth.gov.za>
Subject: RE: Research In Dithlabeng Dialysis Unit

Good day,

Permission is hereby granted for the study at Dithlabeng Regional Hospital.

Please indicate tentative dates for your visit.

Regards

Tsietsi E. Makume
Chief Executive Officer
Dithlabeng Regional Hospital
Tel: (058) 307 1251
Fax: (058) 303 2090



dithlabeng hospital

Department of Health
Dithlabeng Regional Hospital
FREE STATE PROVINCE

ADDENDUM G7: PERMISSION LETTER: TALITHA KOUM

Talitha Koum Dialysis Unit
Bloemfontein
10 August 2019

To: Elsabet van Rensburg
elsabetvr@gmail.com
School of Nursing
Faculty of Health Sciences
University of the Free State


REQUEST TO CONDUCT RESEARCH IN TALITHA KOUM DIALYSIS CENTRE

Talitha Koum Dialysis Centre **grants you permission** to conduct research in our dialysis centre and the following criteria must be met:

- Access to the staff and patients at Talitha Koum Dialysis Centre will not interrupt the daily provision of services.
- Participation in the study must be voluntary.
- Written consent must be obtained from each participant.
- Confidentiality of information will be ensured, and please do not obtain information regarding the identity of the participants.

I trust you find the above in order.

Kind regards.



Mr Obakeng Tshipa