DURBAN UNIVERSITY OF TECHNOLOGY
INYUVESI YASETHEKWINI YEZOBUCHWEPHESHE

# Primary Caregiver Experiences and Perspectives on Caring for a Child with Chronic Kidney Disease within a South African context

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**DURBAN UNIVERSITY OF TECHNOLOGY**

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# AUTHOR'S DECLARATION

I declare that the above dissertation is my own work and that all sources that I have used have been indicated and acknowledged by means of complete references.

I further declare that I have not previously submitted this work, or part of it, for examination at this university for another qualification or at any other higher education institution.

Professor J. K. Adam (IREC: Chairperson): Research and Postgraduate Support, at the Durban University of Technology, provided academic support.

17 June 2024

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# DEDICATION

I dedicate this doctoral thesis to Almighty Lord Ganesha, remover of all obstacles, who has guided and blessed me throughout my life, studies and career.

Sri Sathya Sai Baba my existence is always at your divine lotus feet.

I pay homage to my father and mother, Nithia and Shanoo, who have showered their children with an abundance of love and support, to succeed in all of our endeavours. My heart is full of gratitude for all your guidance and inspiration. To my sisters, Devashya and Komeshni, who have been my biggest supporters; and I also wish to acknowledge my brother-in-law, Jerosh, thank you all for your love, patience and celebrating every little milestone throughout my studies. It is with a smile that I thank my beautiful fur-nephew, Jadoo, whose magic paw has guided me throughout this journey.

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# CONFLICT OF INTEREST

The researcher declares no conflict of interest in the data collection or compilation of this thesis.

# ABSTRACT

Background: Informal and unpaid caregivers play an important role in the management of paediatric patients who have chronic kidney disease (CKD). The burdens that the caregivers experience during their caregiving roles and responsibilities have not been extensively researched, particularly within this patient population. The high physical, psychosocial and economic burdens experienced by the caregiver can in turn lead to negative impact on the child's health outcomes and medical treatment. This study ascertained the burdens that caregivers experienced, in their care of paediatric CKD patients, who were receiving haemodialysis, in the renal unit of a large public hospital in KwaZulu Natal, South Africa. Methods of communication and types of information provided by the renal healthcare team and the support needs of caregivers to reduce burden, anxiety and social dysfunction was elicited.

Methods: Two standardized instruments, namely, the General Health Questionnaire - 12 and the Paediatric Renal-Care Burden Scale were used to ascertain burden, anxiety, and social dysfunction experienced among caregivers of CKD paediatric patients on haemodialysis. Two semi-structured questionnaires were administered. In the first instance, caregivers were asked to provide information on areas that could assist them to alleviate the burden of caregiving and the second questionnaire was used to ascertain from renal staff, the methods they used to communicate with, and the information they provided to caregivers.

Results: Twenty-one caregivers participated in the study, with females providing most of the caregiving duties (76.2%). Using the PR-CBS, financial burden emerged as the highest burden experienced (mean = 4,86 and SD = 0,77). The use of the GHQ – 12, revealed that anxiety and distress were significantly high in caregivers (mean = 0.95 and 0.85) respectively. Overall, 18 caregivers had moderate to high burden._The total mean burden score for the PR-CBS for females was significantly higher than that for males (11.30; SD = 6.11 vs 7.83; SD = 4.70). This is confirmed by the total mean burden score declared by females for GHQ – 12, which was also significantly higher than that declared by males (6.58; SD = 2.83 vs 3.75; SD = 1.80)._There was significant positive correlation between GHQ-12 anxiety score (p= 0.003) and PR-CBS burden score (p = 0.005).

Conclusion: The prevalence of burdens, anxiety and social dysfunction was significantly high among caregivers of CKD paediatric patients and is often overlooked by the renal healthcare team. The experiences of this unique population of caregivers are complex and multifaceted, but despite the various challenges they encounter, they continue to provide care and support for their young patients. Renal healthcare practitioners may use the findings to develop and provide suitable supportive interventions and resources for these caregivers. It is essential that these be included in treatment guidelines for the ill child, not only to reduce caregiver burdens but also to improve the overall CKD paediatric patient outcomes.

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# DEFINITIONS

*Caregivers* can be identified as an unpaid person, (usually a family member or close friend) who is most closely involved in caring for the patient and helps the patient cope with and manage the chronic illness.  In this study, the caregiver is conceptualized as an adult with whom the child permanently resides and who is actively involved in and takes responsibility for the child's care and CKD treatment and who has not been formally trained as a caregiver.

*Caregiver burden* is seen as a multidimensional construct and is defined as 'an individual's subjective perception of overload in one or more of four perspectives: physical, psychological, social and financial through the caregiving processes" (Chou, 2000: 405).

*Caregiver stress* is defined "as a response to caregiving resulting from a cognitive imbalance between the perceived nature of a demand and the perceived capabilities of the person to cope with such a demand" (Pearlin et al., 1990).

*Stressors* are seen as the circumstances, activities, roles, and responsibilities that are challenging for the individual (Pearlin et al., 1990).

*Coping strategies* are those behaviors and thoughts that an individual use to reduce, eliminate or tolerate the situation that is causing stress (Lazarus and Folkman, 1984).

*Child* is seen for the purposes of this study, as a person under the age of 18 years.

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# LIST OF ABBREVIATIONS

| | |
|---|---|
| CAKUT | Congenital abnormalities of the kidney and urinary tract |
| CKD | Chronic Kidney Disease |
| eGFR | Estimated glomerular filtration rate |
| GHQ – 12 | General Health Questionnaire - 12 |
| GN | Glomerulonephritis |
| HRQoL | Health Related Quality of Life |
| HUS | Haemolytic uraemic syndrome |
| IALCH | Inkosi Albert Luthuli Central Hospital |
| KDOQI | Kidney Disease Outcomes Quality Initiative |
| KDIGO | Kidney Disease Improving Global Outcomes |
| NKF | National Kidney Foundation |
| nGap | New Generation of Academics Programme |
| PR-CBS | Paediatric Renal Caregiver Burden Scale |
| RRT | Renal Replacement Therapy |
| SASSA | South Africa Social Security Agency |
| SSA | Sub-Saharan Africa |
| SARR | South African Renal Registry |
| WHO | World Health Organization |

# 1 CHAPTER ONE

# STUDY OVERVIEW AND ORIENTATION TO THE STUDY

## 1.1 Introduction

Chronic kidney disease (CKD) is a global health issue and is associated with high treatment costs (Sari et al., 2018; Etheredge and Faban, 2017). Davids (2020), states that by 2017, there were 207 children in South Africa that had CKD. This low number may be a result of many factors, such as lack of early detection for CKD, and inadequate resources for renal replacement therapy (Ashuntang et al., 2017; Iorga et al., 2014; Gayomali et al., 2008; van Biljon, 2008; Bhimma et al., 2008). Although paediatric CKD is relatively rare and comprises a relatively small population, its implications are nonetheless pervasive (Parham et al., 2016; Aldridge, 2008; Goldstein et al., 2006), not only for the child but also for the primary caregiver. A key focus of this study was to investigate the burdens the primary caregiver experiences because of their changing roles and responsibilities regarding the care of the paediatric CKD patient. The combination of physical exertion, emotional challenges, social limitations, and economic constraints that caregivers face, undoubtedly causes a decline in caregiver's health (Toledano-Toledano and Luna, 2020; Adib-Hajbaghery and Ahmadi, 2019; Parham 2011; Tong et al., 2008; Tsai et al., 2006).

## 1.2 Brief background of the study

Although there have been several studies of CKD in children (Ingelfinger et al., 2016; Kayange et al., 2015; van Biljon and Meyers, 2015; Asinobi et al., 2014; Carolan et al., 2014), the main foci of research in paediatric CKD are the disease itself, medical treatment regimens and management thereof. However, within the South African context, there is currently no research on how the primary caregivers are affected in caring for a child with CKD. The Constitution of the Republic of South Africa, Act 108 of

1996, Section 28 (3), defines a *'child'* as a "person under the age of 18 years of age". Children by their very nature are unable physically, mentally, and economically to provide treatment for themselves and therefore the primary caregiver assumes major responsibilities for their treatment (Gayomali et al., 2008).

The kidneys play a vital regulatory function in the body. For example, the kidneys filter metabolic waste, toxins, excess ions and fluid from the blood while returning needed substances to the blood. The kidneys maintain the correct balance of water and salts and acids and bases (Kumar and Clark, 2012: 562). CKD is a progressive, irreversible, decline in glomerular filtration rate (GFR) and describes irreversible kidney damage or reduced kidney function for more than three months and which eventually leads to end-stage renal disease (Parham, 2020; Becherucci et al., 2016; van Biljon and Meyers, 2015, Haramabat et al., 2012; Rosenberg et al., 2008; Daugirdas et al., 2015).

Caregivers can be identified as an unpaid person who is most closely involved in caring for the patient and helps the patient cope with and manage the chronic illness (Adejumo et al., 2019; Brown and Brown, 2014; Belasco et al., 2006; Chou, 2000; Hileman et al, 1992; Cantor, 1983). The caregiving process for the child with CKD, includes many intensive duties, for example, medication regime, adhering to dietary requirements and transportation to the dialysis sessions (Tong et al., 2010; Friedman, 2006) and caregivers find these processes to be complex and intrusive. Due to these additional demands imposed on them, the primary caregivers have reported, amongst other factors, significant financial difficulties, social isolation, poor physical and mental health, and lower health-related quality of life (HRQoL) (Bauer et al., 2020; Wightman et al., 2019; Nagasawa et al., 2018; Geense et al., 2017; Parham et al., 2016; Medway et al., 2015; Tong et al, 2010; Tsai et al; 2006). Chou (2000: 405), views caregiver burden as a multidimensional construct and defines it as 'an individual's subjective perception of overload in one or more of four perspectives: physical, psychological, social, and financial through the caregiving processes”.

It is not surprising then, that the burden on the primary caregiver, caring for the child with CKD, is high (Mitra and Banerjee, 2011; Friedman, 2006): parents are exhausted, depressed, and are stressed to live with sustained emotional uncertainty about their child’s future and permanent nature of CKD (Mitra and Banerjee, 2011; Swallow et al., 2011; Tong et al., 2010; Abrahao et al., 2010; Tong et al., 2008; Aldridge, 2008; Cimete, 2002). This high caregiver burden can in turn lead to negative impact on the child’s health, medical treatment and personal development and can be disabling for the caregivers themselves (Cousino and Hazen, 2013; Mitra and Banerjee, 2011; Tong et al., 2008; Alridge, 2008; Gayomali et al., 2008; Friedman, 2006).

## 1.3 Research purpose

Children with CKD are dependent physically, emotionally, and financially on the primary caregiver to manage their condition. A child cannot be expected to manage the complexities of their disease without the help of a competent adult and the primary caregiver has a crucial role in the daily management of the child’s disease (Swallow et al., 2014; Friedman, 2006). The primary focus of this study will be to assess the perceptions and lived experiences of the primary caregiver, for example, on their physical health, and the emotional, psychosocial, and financial burdens experienced. This is primarily due to their changing roles and responsibilities owing to the provision of complex care to the child with CKD.

Burdens experienced by the caregivers are often overlooked and unmet by the healthcare workers attending to the paediatric CKD patient because most renal teams do not fully include the caregivers in their management plan (Adejumo et al., 2019). To date, there has been no research in South Africa, on the perceptions and lived experiences of the primary caregiver and how they adjust and cope with their stressors in the care of the child with CKD. Therefore, there is a need for evidence–based means of eliciting the burdens experienced by caregivers of children with CKD, with a further view of prioritizing areas of need and recommending targeted interventions where necessary. This study therefore is a holistic and critical evaluation of the perspectives and lived experiences of the caregivers of children on dialysis, the burdens they experience, their coping strategies and the type of support systems they encounter and may need.

An important objective of this study is to investigate whether there are screening tools at the renal center to assess possible caregiver burdens and areas of concern and to recommend interventions, if necessary, that could be used to alleviate any burdens. Kuo et al. (2012), and Aldridge (2008), claim that a collaborative partnership between primary caregivers and the health care providers is central to caring for children with CKD, to not only prolong the child’s QoL but to ensure that the primary caregiver burdens are recognized and supported. Ultimately, the quality of care provided by primary caregivers of children with CKD is an important determinant in the child’s outcome, both medically and developmentally (Reiss, 2005; Gerson et al., 2004; Watson, 1997; Brownbridge and Fielding, 1994).

## 1.4 Research topic

Primary caregiver experiences and perspectives on caring for a child with chronic kidney disease within a South African context.

## 1.5 Research objectives

1.5.1 To describe the changing roles and responsibilities of the caregiver that contributes to the burden experienced during care of the child who has CKD

1.5.2 To critically evaluate the coping mechanisms used by the primary caregiver to alleviate the burden imposed by managing the child’s treatment regimen

1.5.3 To recommend a framework that supports, improves and empowers the overall quality of life for both the primary caregiver and the child with CKD

## 1.6 Conclusion

For children with CKD, the primary caregiver has a crucial role in the daily management of the child’s disease (Swallow et al., 2014; Friedman, 2006). From the above information, it is clear that the treatment processes are complex, intrusive, expensive and time-consuming and place enormous burdens on the caregiver. Optimal health care is not only about the dialysis and preventing infections in the child, but should be focused also on the physical, psychological and social well-being of the primary caregiver.

This chapter presented a brief contextual background on paediatric chronic kidney disease and the changing and demanding roles and responsibilities of the primary caregiver. The determinants of caregiver burden and the adverse outcomes thereof were concisely mentioned. The research topic, the research purpose and objectives were stated. Furthermore, the need to develop an integrated renal management approach that includes the paediatric patient, (in particular the adolescent patient) the caregiver and the renal healthcare team was highlighted.

# 2 CHAPTER TWO
# LITERATURE REVIEW

## 2.1 Paediatric chronic kidney disease

Chronic kidney disease (CKD) is a global health issue with high treatment costs and is fast becoming a disease of public health importance (Sari et al., 2018; Etheredge and Faban, 2017; Jha et al., 2013). Davids (2020), states that by 2017, there were 207 children in South Africa that had CKD. A key focus of this study will be on investigating the burdens the primary caregiver experience because of their changing roles and responsibilities regarding the care of the paediatric CKD patient. The combination of physical exertion, emotional pressures, social restrictions, and economic constraints that caregivers face, undoubtedly leads to a decline in the caregiver's quality of life and status of health (Toledano-Toledano et al., 2020; Adib-Hajbaghery and Ahmadi, 2019).

The Constitution of the Republic of South Africa, Act 108 of 1996, Section 28 (3), defines a *'child'* as a "person under the age of 18 years of age". Children by their very nature are unable physically, mentally, and economically to provide treatment for themselves and therefore the primary caregiver assumes major responsibilities for their treatment (Gayomali et al., 2008). However, according to The Children's Act 38 of South Africa (2005), there could be various people who could assume responsibility for the care of the child. *Inter-alia* these could include:

1. The parents are the primary caregivers of the child
2. If divorced, the parent is the primary caregiver with whom the child permanently resides
3. If the biological parent/s are unfit to take care of the child, or if both parents are deceased, a legal guardian can be appointed by the High Court
4. Adoptive parents are legal guardians

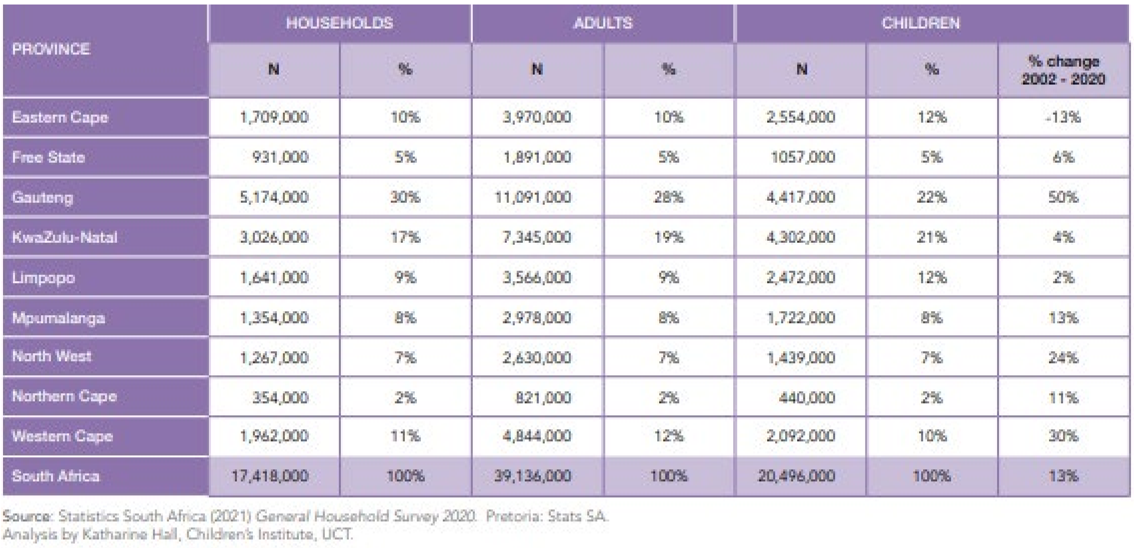
5. The child in foster care
6. The child (for example, orphan) is a ward of the state
7. A close family member, for example, grandmother or aunt

Caregiving is increasingly falling upon informal, unpaid family or friends who find themselves in this role unexpectedly, without preparation and training (Affinito and Louie, 2018). They are not remunerated for their caregiving duties. In this study, the term “primary caregiver” will be used and is conceptualized as an adult with whom the child permanently resides and who is actively involved in and takes responsibility for the child’s care and CKD treatment.

## 2.2 Child population in South Africa

By mid-2018, South Africa’s total population was estimated at 60 million people (SSA, 2020), of whom 20 million were children under the age of 18 years. Children therefore make up 34% of the total population of the country (Hall, 2021). From Table 1 below, KwaZulu Natal (KZN) has one of the highest numbers of children at 21%, just slightly below that of Gauteng, which has 22% of the total number of children in the country (SSA, 2021).

Table 1: Distribution of households, adults and children in South Africa, by province, 2020



| PROVINCE | HOUSEHOLDS |  | ADULTS |  | CHILDREN |  |  |
|---|---|---|---|---|---|---|---|
|  | N | % | N | % | N | % | % change 2002 - 2020 |
| Eastern Cape | 1,709,000 | 10% | 3,970,000 | 10% | 2,554,000 | 12% | -13% |
| Free State | 931,000 | 5% | 1,891,000 | 5% | 1057,000 | 5% | 6% |
| Gauteng | 5,174,000 | 30% | 11,091,000 | 28% | 4,417,000 | 22% | 50% |
| KwaZulu-Natal | 3,026,000 | 17% | 7,345,000 | 19% | 4,302,000 | 21% | 4% |
| Limpopo | 1,641,000 | 9% | 3,566,000 | 9% | 2,472,000 | 12% | 2% |
| Mpumalanga | 1,354,000 | 8% | 2,978,000 | 8% | 1,722,000 | 8% | 13% |
| North West | 1,267,000 | 7% | 2,630,000 | 7% | 1,439,000 | 7% | 24% |
| Northern Cape | 354,000 | 2% | 821,000 | 2% | 440,000 | 2% | 11% |
| Western Cape | 1,962,000 | 11% | 4,844,000 | 12% | 2,092,000 | 10% | 30% |
| South Africa | 17,418,000 | 100% | 39,136,000 | 100% | 20,496,000 | 100% | 13% |

**Source:** Statistics South Africa (2021) *General Household Survey 2020.* Pretoria: Stats SA.
Analysis by Katharine Hall, Children's Institute, UCT.

## 2.3 Brief overview of the renal system

The kidneys play a vital regulatory function in the body. For example, the kidneys filter metabolic waste, toxins and excess ions and fluid from the blood while returning needed substances to the blood and the kidneys maintain the correct balance of water and concentration of solutes and acids and bases. The kidneys also convert vitamin D to its active form and carry out gluconeogenesis during prolonged fasting. The kidneys are an endocrine organ that produces the hormone erythropoietin which stimulates red blood cell production in bone marrow (Kumar and Clark, 2012: 562).

## 2.4 Pathophysiology of the renal system

In susceptible adult populations, for example, those with diabetes mellitus and hypertension, loss in renal function may occur and the kidneys cannot eliminate the body's metabolic wastes or execute their regulatory functions. Other reasons include glomerulonephritis, pyelonephritis, polycystic hereditary or congenital disorders, accidents, drug addictions and renal cancers (Harambat et al., 2012; Daugirdas et al., 2015; Warnock, 1996). CKD is defined as “the presence of markers of kidney damage for three months, with structural or functional abnormalities of the kidney, with or without decreased eGFR, that can lead to decreased eGFR, manifest by either pathological abnormalities or other markers of kidney damage, including abnormalities in the composition of blood or urine, or abnormalities in imaging tests” (National Kidney Foundation, 2002: 47).

## 2.5 Definition of chronic kidney disease in the paediatric population

The eGFR varies in children because of age, gender, and body size. Thus, to identify children with CKD, the Schwartz estimated creatinine clearance formula of [40 x height (cm)] + serum creatinine (µmol/L) (ml/min/1,73m$^2$) is used (Schwartz et al., 2012; van Biljon, 2015; Harambat et al., 2012; Warady et al., 2007; Miller et al., 2004). The K/DOQI classification does not apply to children under the two years of age as eGFR increases from birth and reaches normal adult values by two years of age (Hogg et al., 2003). Except for infants less than 3 months old, the structural or functional damage of the kidneys, must be present (Beng-Ongey et al., 2022).

## 2.6 Aetiology of chronic kidney disease in children

Van Biljon (2008), states that early-stage Chronic Kidney Disease (CKD) is generally a silent disease, which may only become symptomatic in its advanced stages. Symptoms are often non-specific, for example, infants usually present with feeding-related complaints. Poor growth is the single most common, and an almost universal feature in these children. In infants with CAKUT, the disease may be discovered by routine antenatal ultrasound scanning during pregnancy. In older children, the diagnosis may come as a complete surprise when a pathological condition is discovered co-incidentally (van Biljon, 2008).

Harambat et al. (2012), reported a consistent predominance of male: female ratio ranging from 1.3: 2.0 reflecting, in particular, the higher incidence of CAKUT in boys than girls. The leading causes of CKD are more commonly congenital abnormalities of the kidney and urinary tract (CAKUT), genetic or inherited disease (nephropathies and glomerulonephritis), or diseases acquired later in childhood (Berherucci et al., 2016; Harambat et al., 2012; Hari et al., 2003). Table 2 below shows an international, provincial and local comparison of the aetiology of paediatric CKD.

Table 2: Aetiology of CKD in children

| | **Lewis et al., 2010**<br>**(UK Renal Registry 2009).** | **Bhimma et al., 2008**<br>**(KwaZulu Natal, 2008)** | **Govender, 2022**<br>**(Current Study, IALH)** |
|---|---|---|---|
| | N=582 | N=126 | N=21 |
| CAKUT | 36% | 12,9% | 28,6% |
| GN | 22% | 22.5% | 4.8% |
| HUS | 2% | 12.4% | 9.5% |
| NS | 22% | 71.7% | 42.9% |
| Other | 14% | 25.4% | 14.3% |

The table above, reveals not only a lack of longitudinal data, but it is also evident that data concerning the aetiology of acute renal failure in children, particularly in developing countries, including South Africa, are scanty (van Biljon, 2008).

## 2.7 Stages of CKD in children

The progression of CKD can be, based on the kidney function and level of eGFR, subdivided into five different stadia, ranging from chronic kidney damage with near normal kidney function (CKD stadium 1) through to end-stage renal disease (ESRD) which is classed as CKD stadium V, for which renal replacement therapy (RRT) is necessary (K/DOQI, 2013) or transplantation is required to sustain life (Parham et al., 2016). Using the Updated Bedside Schwartz formula (Schwartz et al., 2012), where (eGFR (ml/min per 1.73m$^2$) = (height/Scr), height is in meters and Scr (serum creatinine) is in mg/dl, the stages of paediatric CKD are depicted in Table 3 below:

Table 3: Stages and Glomerular filtration rate categories in paediatric chronic renal failure (Darwish et al. (2020), van Biljon (2015), K/DIGO (2012), Schwartz et al. (2012), Harambat et al. (2012), Warady et al. (2007), Miller et al. (2004).

| **STAGE** | **GFR (m/min/1.73m$^2$)** | **TERMS** |
|---|---|---|
| Stage 1 | >90 | Normal or high |
| Stage 2 | 60-89 | Mildly decreased |
| Stage 3a | 45-59 | Mildly to moderately decreased |
| Stage 3b | 30-44 | Moderately to severely decreased |
| Stage 4 | 15-29 | Severely decreased |
| Stage 5 | <15 | Kidney failure |

## 2.8 Prevalence of CKD in children

According to Harambat et al. (2012), little is known about the epidemiology of CKD in the paediatric population, particularly in developing countries. Although several paediatric CKD registries, using K/DOQI categorization, has recently emerged such as the United States Renal Data System (USRDS), European Renal Association (ERA-EDTA), and the

Australia and New Zealand Dialysis and Transplant Registry (ANZDATA), the prevalence and incidence of paediatric CKD worldwide remains largely unknown. The scarce available population-based data suggests that CKD might affect up to 1% of children and adolescents, globally (Harambat and Ekulu, 2016; Soylemezoglu et al., 2012; Bukabau et al., 2012).

According to Hariparshad et al. (2023), and Bhimma et al. (2008), there is a dearth of epidemiological data from most of the African continent and therefore the prevalence of CKD in Africa, particularly SA, remains inconsistent. Hariparshad et al. (2023), reports that the variable prevalence rates between regions in Sub-Saharan Africa, may further be due to disparities in sample sizes, definitions of CKD, lack of chronicity testing and heterogeneous laboratory estimations of eGFR.

Similar to other developing countries, there is a lack of screening programmes in SA for the early detection of CKD in children. Additionally, the lack of comprehensive CKD registries in SA and the rest of Africa have limited the knowledge of paediatric CKD prevalence (Bhimma et al., 2008). The SARR (2017), does not disaggregate the statistics for the paediatric renal patient with respect to epidemiology, prevalence, treatment, and outcomes and only indicates total numbers of patients (adults and children) once they have initiated RRT. Thus, the true prevalence of CKD in children in underdeveloped countries is still largely unknown. However, RRT-treated CKD in children has a global median incidence of 9 pmarp in age related children. Furthermore, higher incidence and prevalence rates have been recorded in the US, for example, between 1994 and 2005 the incident of paediatric dialysis patients increased by > 30% (Gayomali, et al., 2008; USRDS, 2007). This is attributed to fact that RRT is started at higher eGFR levels in the US than in other countries, and to the technological advances in treatment that have led to increased survival, and access to these treatments in the

US is high for paediatric dialysis. According to the USRDS report (2007), 1 292 children (19 years old or younger) were receiving haemodialysis. The childhood rates of CKD are estimated at about 11-12 per million age-related population (pmarp) in Europe for stages 3-5, and 8 pmarp for CKD stages 4-5 (Harambat et al., 2012; Halle et al., 2017). The UK reported a mean annual incidence and prevalence of <100 cases per million children and adolescents (UK Renal Registry, 2009; Ardissino et al., 2008).

In Sub-Saharan Africa, CKD incidence was about 3 pmarp in Nigeria, which offered no paediatric RRT, and 1 to 2 pmarp in SA (Bhimma et al., 2008; Anochie and Eke, 2005). Children constitute approximately 21% of the total population of KZN, SA, (SSA, 2021). According to Bhimma et al., (2008), this gives the best – guess estimate of an incidence of CKD in the region of 1-2 per million age-related population. Of the total number of children screened in a single-center study conducted by Bhimma et al., (2008), 8,8% of children had CKD (stages 2-5). By 2012, the SARR showed that only 43 children received RRT (van Biljon and Karusseit, 2017). Due to the resource limitations, transplantability is a prerequisite for access to treatment (Jardine and Davids, 2020). Thus, the true prevalence of paediatric CKD in SA is unknown. Davids (2020), states that by 2017, there were 207 children in South Africa, who had CKD.

## 2.9 Approaches to treatment regimens for CKD paediatric patients

Initial treatment is aimed at eliminating the underlying cause, avoiding complications, maintaining fluid balance, avoiding fluid excess and when indicated, starting RRT (Hinkle and Cheever 2014). Once the child has been diagnosed with renal impairment, it is recommended that a treatment regimen be started. Organ transplant is the first choice of RRT in children due to its improved survival rates and quality of life. If transplantation is not possible, peritoneal dialysis (PD) and haemodialysis (HD) are two dialysis options (Rees et al., 2017). Under certain circumstances, conservative treatment without dialysis is an option (van Biljon, 2015), for example, particularly in SA, where patient access to long-term dialysis in the public sector is restricted to a limited number of dialysis slots, high costs (van Biljon, 2008;), and if the child has life-threatening co-morbidities. The Table below shows the scarcity of renal treatment centers in the public health sector in the country.

Table 4: Number of treatment centers (for adult and children CKD patients) by province and sector in South Africa (Davids et al., 2017).

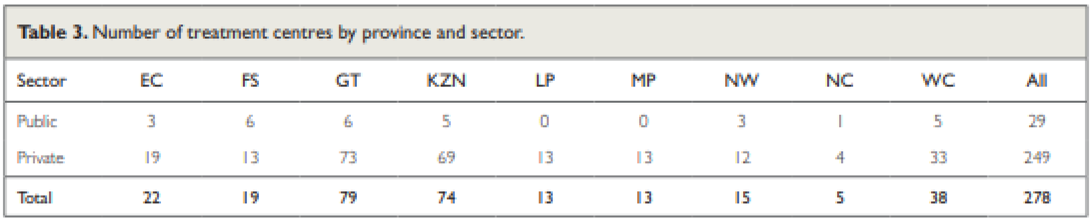


**Table 3.** Number of treatment centres by province and sector.

| Sector | EC | FS | GT | KZN | LP | MP | NW | NC | WC | All |
|---|---|---|---|---|---|---|---|---|---|---|
| Public | 3 | 6 | 6 | 5 | 0 | 0 | 3 | 1 | 5 | 29 |
| Private | 19 | 13 | 73 | 69 | 13 | 13 | 12 | 4 | 33 | 249 |
| Total | 22 | 19 | 79 | 74 | 13 | 13 | 15 | 5 | 38 | 278 |

Jardine and Davids (2020), state that eighty five percent of people living in SA depend on the public sector for health care, and despite the growing demand for RRT, there are major barriers to equitable provision of treatment due to under-resourcing; chief among these are financial constraints, insufficient trained renal staff, and a lack of CKD facilities, particularly in the rural areas of the country. According to Sangweni (2019), there are nine public hospitals providing paediatric dialysis in South Africa. Inadequate resources are linked to financial burden and psychological distress. Due to the lack of paediatric renal care facilities in many of the provinces, families may have to re-locate to meet medical needs of the child, all of which increases burden, anxiety and social dysfunction, not only for the caregiver but the entire family.

Although RRT has meant that survival for these children is possible, the mortality remains 30 times higher than children without kidney disease (Tong et al., 2008; McDonald and Craig, 2004). Gayamoli et al. (2008), warns that with a predictable increase in prevalence of children with CKD, the growing decrease in days of hospital stays and challenges of funding and budgetary cuts, families will take on greater responsibility for providing informal care for chronically ill paediatric CKD patients.

## 2.10 Consequences of CKD for the paediatric patient

Children suffering from CKD are subjected to taxing therapies, frequent venipunctures and painful procedures, strict diets, liquid restrictions, and a variety of medications each day (Aparicio López et al., 2010). CKD in children and young people is a significant health problem associated with impaired growth, cardiovascular morbidity, and a reduced life expectancy (Plumb et al., 2020; Kaspar et al., 2016; Warady et al., 2015; Wong et al., 2009; Groothoff et al., 2005; Furth et al., 2002). According to Mohamad (2022), their nutrition is severely affected, namely, caused by a lack of appetite due to uremia, metabolic acidosis and salt-losing nephropathies. Anaemia is another serious complication that must be treated as it is linked to a low quality of life and neurocognitive deficit (Kaspar et al., 2016). Anaemia has important implications for cardiac health, energy levels, immune function, and intellectual functions as well as neurological development and growth in paediatric patients (NKF-K/DOQI, 2000). CKD in these patients is associated with a decreased resistance to infection (Miller and MacDonald, 2006; Taylor, 1996).

Psychosocial issues emerge due to slow growth development and physical limitations, and children with CKD are unable to perform many activities of their healthy peers and thus may not make friends easily (Cimete, 2002). Adolescents especially stay away from their peers because they feel shy about their physical appearance as children with CKD may be short and have a strange appearance (Neul et al., 2013; Tjaden et al., 2012; Tsai et al. 2006; Miller et al. 2004). Children with CKD face lifelong morbidity and mortality that may affect their quality of life (Mohamad et al., 2022).

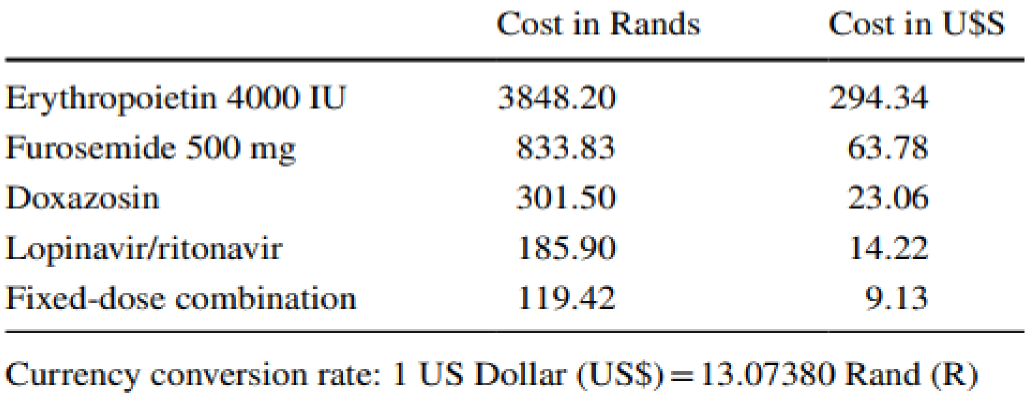
The goal of paediatric CKD involves decreasing hyper-filtration, controlling nephron injury, delaying progression of the disease and decreasing the impact of associated complications (Beng-Oney et al., 2022; Miller and MacDonald, 2006). The renal team need to equip families for the challenges of managing the child's long-term care such as medication compliance, nutritional needs, and clinic visits (Miller and MacDonald, 2006) including the challenges that the caregiver may experience in carrying out their duties. Thus, it is vital that the renal healthcare team include the primary caregiver to be part of the development of the treatment plan that best suits them. An inclusive, planned consultation can help the caregiver balance family functioning, and treatment regimen, school performance and other areas of concern pertaining to the needs of the ill-child (Miller and MacDonald, 2006), together with balancing their own work-life-caregiving roles.

## 2.11 Cost of dialysis

Jardine and Davids (2020), report that there is a high level of inequality in SA, reflected in a GINI coefficient of 0.63 and an unemployment rate of 30% (The World Bank, 2020; SSA, 2021). Furthermore, the inequality is also reflected in a two-tiered health system. The first being private health care, which depends on members ability to pay for services via a medical insurance. Treatment for CKD is included in the set of "prescribed minimum benefits" that all medical insurance schemes in SA are obliged to provide for members. The second tier, on which the majority of South Africans (±84%) are dependent, is the under-resourced, government-funded, public health care sector (Jardine and Davids (2020).

Dialysis is extremely expensive and is conservatively estimated to cost approximately ZAR450 000 per annum per patient in the public health sector (Chothia (2023). Public health care facilities use a sliding scale, where the fees are charged dependent on income. Indigent patients can access services free of charge (Leatt et al., 2006). For example, Table 5 below, clearly indicates that medication is a high-cost factor in public hospitals (Makhele et al., 2019). However, the signs for anemia in HD patients are closely monitored during their three sessions per week, thus limiting the use of the medication (Makhele et al., 2019).

Table 5: Cost comparison of five essential medicines for both HD and PD per month (Makhele et al., 2019). NB: 2019 currency conversion rate is indicated.



| | Cost in Rands | Cost in U$S |
|---|---|---|
| Erythropoietin 4000 IU | 3848.20 | 294.34 |
| Furosemide 500 mg | 833.83 | 63.78 |
| Doxazosin | 301.50 | 23.06 |
| Lopinavir/ritonavir | 185.90 | 14.22 |
| Fixed-dose combination | 119.42 | 9.13 |

Currency conversion rate: 1 US Dollar (US$) = 13.07380 Rand (R)

Furthermore, late presentations of the ill child add significantly to costs in several ways: prolonged hospitalization, need for temporary vascular access and more intensive dialysis (Chothia, 2023; Plumb et al., 2020; Moosa et al., 2016). Plumb et al. (2020), and ESCAPE, (2009), state that when detected early, inexpensive measures can delay or slow disease progression to kidney failure for the child, thus mitigating costs associated with RRT provision. Implementing these strategies, however, is dependent both on timely recognition of CKD and appropriate access to healthcare. For many children, diagnosis of CKD occurs when kidney function is already severely reduced, one of the main reasons being that early stages are symptomless in children (Pruthi et al., 2016).

## 2.12 Theoretical framework for the study

### 2.12.1 Caregiver Stress Process Theory

This theory suggests that caregiver stress occurs over time with various experiences contributing to the stressful situation (Pearlin et al., 1990; Lazarus and Folkman, 1984). Stress occurs when the individual perceives that the demands of the situation exceeds their abilities and available resources and can be detrimental to the person's physical and psychosocial well-being (Pearlin et al., 1990; Lazarus and Folkman, 1984). For example, caregiver stress arises where an increased number of caregiving duties conflicts with other responsibilities, for instance, feelings of guilt about not spending adequate time with their other children or spouse or the caregiver's stress may be aggravated by inadequate caregiving skills.

Researchers have continued to expand on the nature, cause, and management of stress among informal caregivers (Parham; 2011; Melnyk et al., 2001; Chou, 2000; Raina, 2004; Pearlin et al., 1990; Zarit et al., 1980). Thus, in order to provide a holistic account of caregiver burden, in this study, consideration was given to practitioners who have offered various theories not only to characterize caregiver burden but also on providing effective ways to assess and reduce caregiver burden (Parham, 2011; Raina 2004; Chou, 2000; Pearlin et al., 1990; Zarit et al., 1980). These are highlighted below:

2.12.1.1 Zarit et al. (1980), developed the Caregiver Burden Interview to measure the change in perceived stress and burden over time as well as to measure the benefits of stress reduction interventions (Wilborn-Lee 2015; Zarit et al., 1980).

2.12.1.2 Chou (2000: 405), views *caregiver burden* as a multidimensional construct and defines it as 'an individual's subjective perception of overload in one or more of four perspectives: physical, psychological, social and financial through the caregiving processes'. Several factors contribute to the high caregiver burden including, for example, their financial situation, occupation, availability of supportive resources and culture (Adib-Hajbaghery and Ahmadi, 2019; Mwenda et al., 2019). It is not surprising that the burden on the primary caregiver, is high (Mitra and Banerjee, 2011; Friedman, 2006): caregivers are exhausted, depressed, and are stressed to live with sustained emotional uncertainty about their child's future and permanent nature of CKD (Mitra and Banerjee, 2011; Swallow et al., 2011; Tong et al., 2010; Abrahao et al., 2010; Tong et al., 2008; Aldridge, 2008; Cimete, 2002).

2.12.1.3 *Caregiver coping* is a process of managing the external and / or internal demands by constantly changing thoughts and behaviours (Lazarus and Folkman, 1984: 141). For example, due to their inability to cope with the exhaustive CKD duties, the caregiver experiences lack time for their own relaxation. The caregiver may therefore take up offers of help from family or friends to take care of the ill child so that they can pursue personal activities.

2.12.1.4 An important part of caregiver burden that is often overlooked is that of *caregiver grief* (Doka and Aber, 2002). Olshansky (1962), regards chronic sorrow as a coping mechanism that allows for periodic grieving; in the context of caring for a child with chronic illness, a reaction of chronic sorrow is viewed as one of functional adaptation (rather than acceptance of the child's condition). Parham (2011) and Melnyk et al. (2001), suggest a hybrid model whereby the caregiver (usually) parents, progress through stages of chronic sorrow, acceptance of the child's CKD condition, episodes of functional adaptation and coping (when the caregiver functions 'normally'). However, they may re-experience peaks in the grieving process during high-risk periods.

2.12.1.5 A major contribution, which is specifically relevant to this study, to inform burdens experienced by caregiver for the paediatric CKD population, is the Paediatric Renal-Caregiver Burden Scale (PR-CBS) developed by Parham (2011). Despite the recognized demands faced by the caregivers of CKD and the emphasis to monitor outcomes, there was no specific tool to measure caregiver burden within the context of caregiving and the paediatric patient. Existing measures of caregiver burden had been largely developed for family caregivers of adults' post-stroke or with dementia (Visser-Meily et al., 2004; Schene et al., 1994; Robinson, 1983). Furthermore, the instruments existing at that time for investigating stress in the paediatric population namely, the Pediatric Inventory for Parents (Streisand et al., 2001), and the Parent Experience of Child Illness (Bonner et al., 2006), were not developed for the paediatric CKD population. Thus, the PR-CBS (Parham, 2011) developed specifically for this unique category of caregivers could allow clinicians to qualify areas of stress and to implement targeted intervention that may assist both the ill child and the primary caregiver.

### 2.12.2 Major components of the caregiver stress process theory

These include the variables described below:

#### 2.12.2.1 Sociodemographic factors

2.12.2.1.1. Age: Researchers suggested that age played a significant role in how the caregiver perceived caregiving as stressful. There was an increased likelihood that an older caregiver would experience physical health problems after providing care to an individual with a chronic health condition for an extended period (Soto et al., 1996; Pearlin et al., 1990). Younger caregivers reported higher levels of emotional distress (Kim et al., 2012). Pinquart and Sorenson (2003), found that younger caregivers may experience less detrimental burden, as they are more likely to have alternative roles and social activities outside the home that serve as a buffer against severe and long-lasting caregiving stress.

2.12.2.1.2 Gender: Caregiving literature shows consistently that female caregivers are more burdened than male caregivers (McDonnell and Ryan, 2013; Pinquart and Sörensen, 2006; Marks et al., 2002; Yee and Schulz, 2000). These authors suggest that this could be due to, for example, the unequal distribution of opportunities and responsibilities that may push women into the caregiver role more often than men and which could hamper their functioning at work or that women provide more hours of care and therefore experience more negative effects of caregiving. Furthermore, societal views on gender consider caregiving as women’s work (Glauber, 2016). Thus, because of greater commitment to the caregiving role, women may spend more time on caregiving and less time for other activities, leading to high burdens (Swinkels et al., 2019).

#### 2.12.2.2 Length or duration of caregiving

Dorfman et al. (1996), found that although caregivers reported higher burdens at the beginning of their caregiving responsibilities, they reported less burdens over time, as they may get used to the caregiving tasks over time (Dorfman et al., 1996).

#### 2.12.2.3 Nature of patient impairment

Haley et al. (1987), and Monteko (1989), found that caregiver’s experienced frustration and burdens due to a disruption of their plans in the initial phases of the illness. As the caregiver developed a routine, frustration diminished, although the demand for care increased. A similar finding was evident in research by Aronson (1997), who found that the decline of quality of life of the caregiver was related to providing care for longer durations of time with worsening symptoms in the patient.

#### 2.12.2.4 Economic factors

Substantial financial burden was placed on caregivers and economic cost is a significant feature of caregiver burden (Lai, 2012; Covinsky et al. 1994; Pearlin et al., 1990). In several cases, a family member had to quit their job or relocated to provide the required care. Financial burden of caregiving also resulted in family members selling assets, taking out loans or taking on an additional job to supplement the needs of the patient (Covinsky et al., 1994).

#### 2.12.2.5 Stressors in the caregiving process

2.12.2.5.1 Primary stressors: Rivera (2009), states that the patient’s inability to perform daily living activities and the extent of dependency can create extreme stress for the caregiver. Pearlin et al. (1990), state that the constant vigilance that the caregiver has to maintain so that the patient neither harms him / herself nor others, can be regarded as a formidable stressor. As the caregiving process is extended, caregivers increasingly feel separated from previous aspects of their lives that they had shared and enjoyed with the relative who is now chronically ill.

2.12.2.5.2 Secondary stressors: These are emotional stressors that may arise from old family conflicts and conflicts that might resurface between the caregiver and the non-caregiver family members (Pearlin et al., 1990). Conflicts might also arise from the lack of consideration and acknowledgment of the care given to the patient by the caregiver (Pearlin et al., 1990). Role strain can also be the result of the dual role of caregiving and maintaining employment outside, and thereby creating additional strain for maintaining a wholesome work-life balance (Duxbury et al., 2011).

2.12.2.5.3 Intrapsychic strain: the caregiver experiences a sense of loss of identity due to reduction in social activities and roles in which the caregiver previously found validation (Pearling et al., 1990).

2.12.2.5.4 Preparedness for caregiving: this relates to the caregiver's preparedness for caregiving in the domains that involves providing physical, emotional, and social support while simultaneously coping with the stress of caregiving (Schumacher et al., 2008).

#### 2.12.2.6 Mediating factors

Mediators lessen or block the increase between primary stressors and secondary stressors. Buffering is assumed to take place when the cushioning effect of the mediators increases with the severity of the stressor. Coping, appraisal, and caregiver networks are the principal mediators (Pearlin et al., 1990) and are described as follows:

#### 2.12.2.6.1 Coping

Coping is seen as a means of managing the challenges faced by the individual and is associated with active or passive behaviours to alleviate or remove the stressors. Coping refers to thoughts and actions to manage, decrease, or tolerate the internal or external demands causing stress (Lazarus and Folkman, 1984). Several researchers have expanded the concept of coping to include the following components:

2.12.2.6.1.1 Problem-focused coping which is generally considered most adaptive and associated with less psychological distress and more positive outcomes (Pakenham and Bursnall, 2006; Bachanas et al., 2001). Some problem-focused strategies used by caregivers to reduce their burden includes, for example, accepting financial hardship, integrating care into family culture and daily routines, using social support and carefully planning activities and the care duties, and researching the health condition to increase sense of control (Williams et al., 2014; Sun, 2014; Kita and Ito, 2013; Dickson et al., 2012).

2.12.2.6.1.2 Emotion-focused coping strategies: This is related to the caregivers' inclination to managing emotions, including for example, grieving, reframing the problem and focusing on the sick child (del-Pina-Casada et al., 2011; Tong et al., 2010). Other strategies that were found to be helpful included venting emotions, taking time out and having 'a good cry' to release emotional energy (Azman et al., 2017; Dickson et al., 2012; Figueiredo et al., 2014).

2.12.2.6.1.3 Cognitive coping strategies include, for example, caregivers valuing their role, identifying benefits, or finding humour when feeling helpless, helped them adjust to their situation (Kitter and Sharman, 2015; Zegwaard et al., 2013; Thornton and Hopp, 2011). It is associated more with the thoughts surrounding caregiving rather than behaviours and involves a conscious effort to alter perceptions and appraisals of caregiving to promote a greater sense of well-being. The use of acceptance is the most used means of cognitive coping and is an indication that the caregiver accepts the challenges of the situation (Azman et al., 2017; Williams et al., 2014; Zegwaard et al., 2013; Dickson et al., 2012; McCausland and Cavanaugh, 2001).

2.12.2.6.1.4 Self-efficacy is the caregiver's perceived ability to cope with the demands of caregiving and has a beneficial effect on the caregiver's physical and psychological health (Epiphaniou et al., 2012; Gallagher et al., 2011; Chronister et al., 2010; Bourgeoise et al., 1996; Pearlin et al., 1990; Hayley et al., 1987). Although excessive stress is related to increased burden, high self-efficacy for managing patients was linked to lower levels of burden (Romero-Moreno et al., 2011).

2.12.2.6.1.5 Adjustment or adaptation: This concept can be described when the caregiver has suitably or successfully adjusted or adapted to challenging new roles and responsibilities. Adaptation occurs over a period of time and is associated with a positive quality of life and increased self-esteem. Maladjustment is associated with depression and anxiety (Sharpe and Curran, 2006).

#### 2.12.2.7 Caregiver appraisal

The caregiver assesses the stressful situation and their coping abilities. This involves information seeking and problem-solving which are useful for managing caregiving responsibilities to decrease burdens.

#### 2.12.2.8 Caregiver network composition

This refers to networks (including family), the composition of the networks and the nature and frequency of contacts with the members. It is different to social support. Network represents the totality of one's relationships, whereas social support refers to the assistance received from a portion of the network (Pearlin, 1989). The author further clarifies that although the caregiver cannot have social support without having a network, one may conceivably have a network without social support (Pearlin et al., 1990).

Social support is seen as "the number of people outside the caregiver's household that the caregiver had been in contact with over the previous few weeks and included visits to or from friends or relatives and contacts with neighbours as well as more casual contacts" (Miller et al., 1996). These interactions can assist the primary caregiver in a variety of ways including psychological, emotional, instrumental support, and daily living care activities (Bourgeoise et al., 1996). However, it is worth noting that social networks can also be a source of additional stress when the caregiver believes that the social network can help but fails to do so, thereby leading to conflict within the network (Chang et al., 2001). The nature of the support includes the extent to which it is helpful and the level of difficulty that the caregivers' experiences in arranging it (Cohen, 2004; Chang et al., 2001).

#### 2.12.2.9 Use of resources

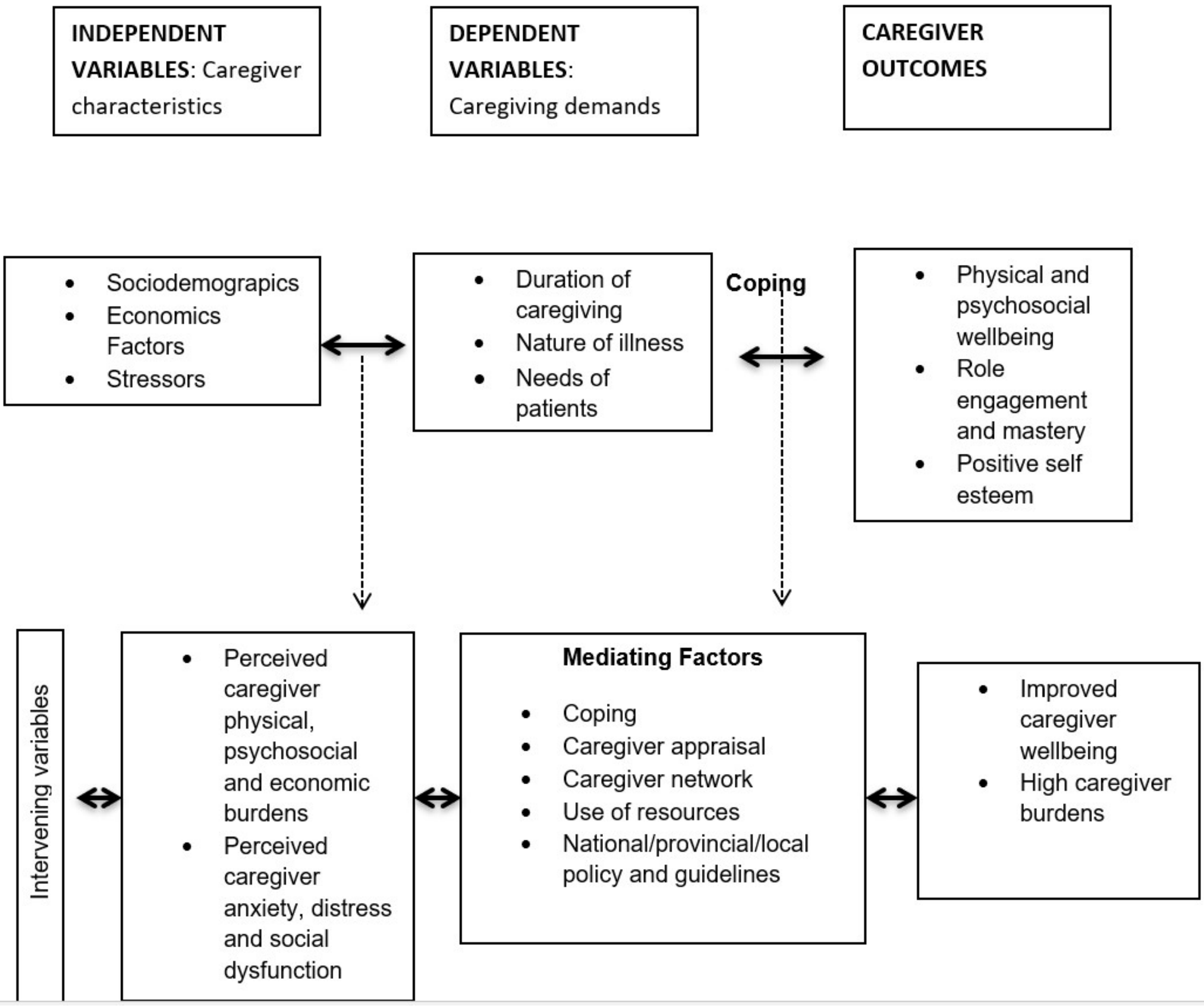
Caregivers who had social support resources at the beginning of their caregiving responsibilities had an improved quality of life over time (Goode et al., 1998). In contrast, caregivers who reported limited social support resources and engaged in limited self-care practices, reported an increase in physical health symptoms. Caregivers who shared their experiences and information with other carers found it beneficial, confirming the protective nature of social support (Beck, 2007).

#### 2.12.2.10 Caregiver outcomes

Caregiving to individuals with a chronic health condition can have an adverse effect on caregivers that put them at risk of psychological morbidity and physical health problems (Zarit et al., 2010; Pinquart and Sörenson, 2003; Hayley et al., 2001; Pearlin et al., 1990). The Caregiver Stress Process Theory emphasizes that caregiver stress is a mix of circumstances, experiences, responses and resources that vary amongst caregivers and thus vary in their impact on the caregivers' health and behaviour (Pearlin et al, 1990). Caregiving is not a fixed stable situation as a change in one of its components can result in the change in others. Furthermore, coping and social support can intervene at different points along this process thereby mediating the outcomes (Raina, 2004). Thus, this theory is appropriate to provide a framework for recognizing burdens experienced in unpaid, informal caregivers of paediatric CKD patients. The figure below provides further clarity:

Figure 1: A conceptual model of Caregiver Stress Process.

This iteration created by Govender (2023), adapted from (Oyegbile, 2017; Raina, 2004; Pearlin et al., 1990).



The above diagrammatical version of the Caregiver Stress Process Model highlights conditions leading to caregiver burdens and anxiety (Oyegbile, 2017; Raina et al., 2004; Pearlin et al., 1990) and furthermore, mediating factors to ameliorate the caregiver burdens are depicted. From Figure 1 above, it is clear that the caregiver burdens are not linear but rather that the relationships are reciprocal in nature. Although the entire

Caregiver Stress Process Model itself was not evaluated within the scope of this study, it provided a holistic account of caregiving experiences that contribute to caregiver burden, anxiety and social dysfunction. Furthermore, it provides a useful signpost to guide recommendations to improve the overall well-being for the caregivers.

## 2.13 Role of caregivers in caring for children with CKD

Children by their very nature are dependent and unable physically, mentally, and economically to provide treatment for themselves and therefore the primary caregiver assumes major responsibilities for their treatment (Gayomali et al., 2008). Viljoen (2019), comments that the duties and tasks of the caregiver begin from the moment of diagnosis of the disease, to discharge, and home care and these duties continue for the rest of the child's life. Caregivers continuously monitor the child's health and prepare for episodes of infection and other life-threatening complications (Tong et al; 2010; Nicholas, 2017). Ensuring hospital appointments are made and adhered to, symptom management and keeping track on all expenditures are other important duties of the caregiver (Oyegbile, 2017; Girgis et al., 2012). Caregivers tend to ignore their own burdens and provide a significant positive influence to help these young patients cope with their anxieties (Grapsa and Georgianni: 2018: 75).

The focus of research in paediatric CKD, is the disease itself, the effects the disease has on the child, medical treatment regimens and management thereof. However, the intensive and complex caregiving processes that is provided by the caregiver is often overlooked by the renal healthcare team and the burdens the caregiver experience are largely ignored (Wee et al., 2022; Wightman et al., 2019; Parham et al, 2016; Tong et al., 2010; Aldridge, 2008; Tsai et al., 2006). Within the South African context there is currently no research on the burdens the primary caregivers experience in caring for a child with CKD. Wee et al. (2022), found that caregiver burden was experienced through the demands of medical management (enforcing medication compliance and side effects, learning new procedures, diet and fluid restrictions); uncertainty and unpredictability of the rate of disease progression (uncertainties of the child's future, and no respite from caregiving); personal sacrifices and losses (less time, energy and freedom for other commitments, such as leisure activities, possibility of leaving careers and sacrificing income); and disruptions to the family dynamics (focused time and energy on caregiving role and neglecting other children and / or partners).

## 2.14 Burdens experienced by caregivers for paediatric CKD patients

Most studies conducted on caregiver burden in the care of chronically ill *adult* patients, focused on fields such as Alzheimer's, geriatrics, stroke survivors, dementia, or cancer (Boakye et al., 2017; Parham et al., 2016; Raina et al., 2004; Hepburn et al., 2001). Research on caregiver burden relating to paediatric patients pertain mainly to, for example, children with cancer, cerebral palsy, heart disease, disabilities, and those who have HIV (Darwish et al., 2020; Chen et al., 2011; Raina et al., 2004; Bachanas et al., 2001; Sloper and Turner, 1993; Blancer, 1984). There is a paucity of research on the burdens experienced by caregivers of the paediatric CKD patient population, particularly in developing countries (Alshammari et al., 2019; Oyegbile and Brysiewicz, 2017b; Geense et al., 2017; Zhang et al., 2016).

However, to manage their CKD condition, increased physical, emotional, social, and financial dependence is placed by the child on their primary caregiver. *Caregivers* can be identified as an unpaid person, (usually a family member or close friend) who is most closely involved in caring for the patient and helps the patient cope with and manage the chronic illness (Adejumo et al., 2019; Brown and Brown, 2014; Belasco et al., 2006; Chou, 2000; Cantor, 1983). Since a child cannot be expected to manage the complexities of their disease without the help of a competent adult, the primary caregiver has a crucial role in the daily management of their child's disease, for which they are often unprepared (Swallow et al., 2014; Friedman, 2006). They adopt the role of a healthcare provider, such as the skills of a nurse, pharmacist and physician in addition to their already challenging roles as parents (Kari et al., 2014). In addition to the management of the child's treatment, primary caregivers experience difficulties in balancing the needs of the ill child with their other responsibilities such as work, social life and the needs of other family members (Eccleston et al., 2012; Barlow and Ellard, 2006). Thus, like any occupational career, the notion of a 'caregiver career' implies a dynamic process where "the caregiver proceeds through a sequence of stages, necessitating considerable transitions and restructuring of responsibility over time" (Raina et al., 2004: 8). For a caregiver, these stages include preparation for and acquisition of the caregiver role, implementing the tasks and responsibilities and eventually disengagement from the role (Raina et al., 2004: 8). However, the 'caregiver career' differs from an occupational career in several important respects. Becoming an informal caregiver is not typically chosen or planned. In addition, an informal caregiver lacks the rights, privileges and prerogatives that are associated with a formal career. Caregiving is often not a career recognized by society as worthwhile and progression along its pathway is determined by the disease and the functional dependencies it creates (Raina et al., 2004). Finally, unlike an occupational career choice, the caregiving career cannot be entered into and left at one's own will (Raina et al., 2004).

Advances in treatment for paediatric CKD, have resulted in hospital-based care being increasingly replaced by home-based care, provided largely by a family member who takes on the role of primary caregiver in the family (Kepreotes et al., 2010; Murphy, 2008). Paediatric CKD serves as a significant stressor for the primary caregivers from the time of diagnosis, the ongoing treatment processes to the continued prognosis of the disease, often having to deal alone with family struggles without adequate formal and informal support (Ong et al., 2021). Caregiving for children with CKD is distinctive in that it requires indefinite commitment of the caregiver from the child’s diagnosis until death (Parham et al., 2016; Walker et al., 2016; Noble et al., 2013).

To date, there has been no research in South Africa, on the perceptions and lived experiences of the primary caregivers and how they adjust and cope with their burdens in the care of the child with CKD. As the caregiver becomes overwhelmed with feelings of uncertainties; increased vulnerability to several severe physical health challenges emerges and financial concerns, emotional ill-health and psychosocial tensions and conflicts during the prolonged trajectory of illness and treatment become apparent (Singh, 2016; Northhouse et al., 2012; Belasco and Sesso, 2002). These burdens are explained below:

### 2.14.1 Physical burden symptoms experienced by caregivers

Overburdened caregivers of paediatric CKD have problems with poor health and end up falling ill in the long term (Javalkar et al., 2017) because they tend to neglect their own health needs and forego preventive medical visits. The primary caregivers are prone to experience physical ill health owing to poor quality of sleep, exhaustion, poor dietary habits and are usually not involved in physical activities (Viljoen, 2019; Lima, et al., 2018; Celik et al., 2012). The child’s needs and care are more important, even to the detriment of their own (Javalkar et al., 2017; Geense et al., 2017; Tong et al., 2010; Cimete, 2002). Lima et al. (2019), found that 69% of caregivers experienced chronic pain, and 16% had developed hypertension, which they attributed to the stresses and demands of caring for the child undergoing dialysis. Other health problems include back injuries, gastric ulcers, and headaches (Hawken et al., 2018; Lovell et al., 2012). Physical exertion and a lack of respite are commonly reported by dialysis caregivers of children with CKD throughout the world (Wightman et al., 2019; Kiliś-Pstrusińka et al., 2013b; Jacoby et al., 2018; Tong et al., 2010). During the dialysis sessions, caregivers must spend most of their day and energy on the child undergoing dialysis which is an exhausting routine for many (Pourghaznein et al., 2018; Tong et al., 2010; Waissman, 1990). The wait for procedures such as pathology tests, X-rays, biopsies and waiting for medication is time-consuming and exhausting (Tong et al., 2010).

### 2.14.2 Psychological and social burden symptoms experienced by caregivers

Sari et al. (2018), and Ghane et al. (2016), found that caregivers experience significant emotional distress and psychological symptoms, and may feel anger, anxiety, helplessness, social isolation, loss of freedom, and vulnerability. The mental health of caregivers of highly dependent CKD paediatric patients worsens as the patient's condition progresses and depression is the most common disorder amongst these caregivers (Pereira et al., 2017; Fan et al., 2008; Tsai et al., 2006). Jacoby et al. (2018), described the caregiving experience as one of powerlessness and being "suffocated" by fear of complications and powerlessness of being unable to improve the child's or their own condition within the setting of CKD. The chronicity of the illness and the nature of dialysis greatly hindered the education of children with CKD and the caregivers found this to be a major source of sorrow, especially if the educators and schools were not supportive of the child's needs (Cimete, 2002; Dracopoulos and Weatherly, 1983). Uncertainty of the child's outcomes and the fear of impending death of the child were also a major source of stress and anxiety for the caregiver, and which was often triggered by the death of the child's peers with the same disease (Pourghaznein et al., 2018b; Mieto and Bousso, 2014; Tong et al., 2010; Dracopoilos and Weatherly, 1993).

The dual role of parenting and being a medical caregiver causes fatigue, stress, and emotional pain (Tong et al., 2010; de Paula et al., 2008). Caregivers found the various medical processes and treatments that the child had to undergo, and the pain they experienced, as heart-breaking to witness (Mieto and Bousso, 2014; Tong et al., 2010; Waissman, 1990). Geense et al. (2017), and Tong et al. (2010), found that the caregivers were often excluded from the decisions made by the health care professionals. Pourghaznein et al. (2018a), Pourghaznein et al. (2018b), found that the caregivers felt unacknowledged and feared being labelled as troublesome and overprotective, and thus they avoided asking questions for help, which in turn leads to increased burdens and anxiety. These experiences demoralize the caregiver. All these factors may impact the caregiver’s daily functions and readiness to meet the demands of medical care for the child (Price et al., 2016).

Another form of societal pressure that contributed to additional distress was the stigmatization that caregivers experienced, particularly families who had to depend on others for financial aid, and the pressure they experienced to earn an income despite having to care for the chronically ill child (Wightman et al., 2019). The caregivers had to cope with the pain of seeing their child face discrimination, for example, due to the effect of the disease on their growth and appearance (Ong et al., 2021).

Kari et al. (2018), found that the daily care routines for the child with CKD, impacted negatively on the ability of primary caregivers to care for other family members. The primary caregivers are often forced to make trade-offs between caring for the chronically ill child and their other children which creates a source of tension within the family (Wightman et al., 2019; de Paula et al., 2008; Kari, et al., 2018; Sari et al., 2018; Mieto and Bousso, 2014). Lopes et al. (2014), found that the time demanded by clinical care routines, for example, taking care of the fistula and ensuring that medications are taken on time, leave little time for personal needs. Caregivers appreciated specialists who provided information and was honest about the child’s prognosis and nurses who had a good relationship with the child.

Caregivers may face the tasks of navigating different social and health care settings in the search for medical treatment; dealing with bureaucracy; sourcing finances for treatment and searching for educational programmes for information and support (Wariguah, 2022; Wightman et al., 2019; Tong et al., 2010). Additional challenges are particularly prominent in rural areas which lack paediatric CKD treatment centers, creating burden, anxiety and social dysfunction among primary caregivers and the family in the search of treatment centers for their chronically ill child.

### 2.14.3 Economic burdens experienced by caregivers

There are many unanticipated costs in the care of the child with CKD and financial burden of the disease includes more than just the dialysis procedures and medications. The cost of travel, dietary restrictions and other household expenses all added on to the constant strain on family finances (Wightman et al., 2019; Pourghaznein et al., 2018a; Sari et al., 2018; Bello et al., 2018; Kari et al., 2014; Cimete, 2002; Dracopoulos and Weatherly, 1983). Studies throughout the world demonstrate that the primary caregiver for a child on dialysis finds it difficult to work outside the home (Lima et al., 2019; Bello et al., 2018; Iyengar et al., 2018; Pourghaznein et al., 2018a; Jacoby et al., 2018; Sari and Allenidekania, 2018; Medyńska et al., 2017; Geense et al., 2017; Mieto and Bousso, 2014; Laakkonen et al., 2014; Kari et al., 2014; Kiliś-Pstrusińka et al., 2013b; Teh et al., 2011; Hardart and Truog, 2003; Geary, 1998). Caregivers may have to take leave from work to care for their child, impacting job progression and stability and even worse, many lose their only source of income, causing economic hardship (Wightman et al., 2019; Tong et al., 2010; Bello et al., 2018; Sari et al., 2018; Kari et al., 2014; Cimete, 2002).

Some families enter into debt or severely curtail spending elsewhere, or both, causing weakened financial stability within the family (Reddy et al., 2022; Wightman et al., 2019; Pourghaznein et al., 2018b; Bello et al., 2018). Families that experience financial strain are less confident in their ability to take care of a child with CKD (Bignall and Goldstein, 2015). Furthermore, families with low socio-economic status face disparities in health care that compound the stress of dealing with a CKD diagnosis in their child (Hidalgo et al., 2015). The renal healthcare teams should actively advocate for financial aid especially in terms of transport and nutrition (Bignall and Goldstein, 2015).

Caregivers find the new CKD processes to be complex, overwhelming and intrusive. Research into the lived experiences of caregivers found a number of stressors, such as poor physical health, worry about their child’s development and growth, diminished household income, loss of social interactions, strained family relationships, and concern related to complexity of the on-going CKD treatment (Alshammari et al., 2021; Chhetri and Baral, 2020; Adib-Hajbaghery and Ahmadi, 2019; Zhang et al., 2016). The stressors, maladaptive behaviours, and burdens that primary caregivers face can influence their children’s treatment, development, quality of care, and quality of life (Tsai et al., 2006).

## 2.15 Coping strategies and support needs of the caregiver of paediatric CKD patients

Burdens experienced by the caregivers are often overlooked and unmet by the renal healthcare workers attending to the paediatric CKD patient because most renal teams do not fully include the caregivers in their management plan (Adejumo et al., 2019). Hanson et al. (2017), found that primary caregivers do not disclose their concerns to the health care providers, not only because of limited consultation times but also that they felt that the care would be jeopardized. Kuo et al. (2012), and Aldridge (2008), claim that a collaborative partnership between patients, primary caregivers and the renal healthcare providers is central to caring for children with CKD, not only to support the child's HRQoL but to ensure that the primary caregiver burdens are recognized and addressed, and they feel empowered to cope with their caregiving roles.

There is a lack of research on the coping strategies of caregivers, caring for children with CKD within SA. Thus, an important objective of this study is to investigate whether there are screening tools at the treatment centers to assess possible caregiver burdens and concerns and to recommend coping interventions that could be provided to prevent their burnout. The involvement of educational, social, and psychological support is vital to improving the caregivers' ability to handle adversities (Celik et al., (2012: 524). The level of burden, anxiety, and social dysfunction in this population of caregivers is a cause of concern, and it is necessary to implement programmes and interventions that aim to help them better manage childcare and their own quality of life.

Although caregivers feel overwhelmed and many have reported on the high burden and anxiety caused in the care of the child with CKD, some caregivers cope effectively without evidence of negative impacts (Cohen et al., 2002; Garity, 1997). However, despite facing overwhelming challenges, caregivers strived to consistently deliver their caregiving and medical responsibilities (Tong et al., 2010).

## 2.16 Conclusion

This study is a holistic and critical evaluation of the perceptions and the burdens experienced by the primary caregivers of children on dialysis, the coping strategies and the type of support systems they require. There is a need for evidence–based means not only to establish the burdens experienced by caregivers of children with CKD, (particularly in SA) but also to identifying areas where suitable support is needed. Overall, the results of this study may assist policy makers at national and local level develop policies and appropriate and targeted interventions for the holistic management of caregiving for children with CKD in SA.

# 3 CHAPTER THREE
# RESEARCH METHODOLOGY

## 3.1 Study design

The study applied a cross-sectional descriptive research design. This method best suited the research area as it allowed the researcher to investigate the variables causing burdens in the caregiver with minimum bias in the data collection process and to present the results as the trends emerged.

## 3.2 Study location

Although this study aimed to compare caregivers between the private and public renal units, unfortunately the researcher could not access private providers due to limited treatment modalities for CKD in this patient population. Only one private provider, in Durban, provided a single patient and caregiver but this caregiver declined to participate. Thus, this study was conducted at a single-center public hospital, namely, Inkosi Albert Luthuli Central Hospital in KwaZulu Natal, which offers paediatric renal care.

## 3.3 Study population

The population targeted was the caregivers of children with CKD on haemodialysis. Taking into consideration inclusion and exclusion criteria twenty-one caregivers qualified for inclusion in the study. Since the study population is a small number, the researcher targeted all eligible caregivers in the renal unit. Thus, a total of 21 questionnaires were administered and 21 were returned which gave a 100% response rate. The research included caregivers of children with CKD, primarily between stages 2 – 5. The patients' records were accessed to obtain the following data: primary diagnosis of the kidney disease, patient's age at the time of diagnosis, aetiology of CKD, CKD duration, and dialysis treatment duration. Participation in the study was voluntary and written informed consent was obtained from all primary caregivers before participation in the study. The participants were advised that they could withdraw from participation at any time. The recruitment period was from March 2022 to September 2022. The ages of patients ranged from 2 years to 18 years and the caregivers ages ranged from 20 years to fifty-nine years.

## 3.4 Inclusion criteria

- The primary caregiver for the child receiving treatment for CKD was recruited
- The child had to be under 18 years old with confirmed diagnosis for CKD and had to be on haemodialysis (HD) treatment for at least 4 weeks
- Renal healthcare professionals involved in the provision of treatment for the child with CKD
- Only those participants who had signed consent forms participated
- Patients from Inkosi Albert Luthuli Central Hospital were targeted
- The primary caregiver had to be a South African citizen

## 3.5 Exclusion criteria

- Patients who have had a kidney transplant
- The child with CKD will not participate in this study due to the study focusing on the primary caregiver experiences and perspectives in caring for a child with chronic kidney disease.
- The primary caregiver /s who does not give signed consent

## 3.6 Ethical considerations

Approval for this study was obtained from the Institutional Research and Ethics Committee (IREC) of the Durban University of Technology where the researcher is registered as a PhD student. Gatekeeper permission was obtained from the Provincial Department of Health (KZN) and the Head of the Renal Health Facility at the Hospital to conduct this study. Participants were assured that their participation was voluntary and that they could withdraw from the study at any time. Anonymity and confidentiality were always maintained. The researcher explained to the participants the benefits and risks associated with the study. Once the participants expressed interest in participating in this study, they were issued with a letter of information and a consent form. The data was stored on a password protected personal computer and external hard drive accessible only to the researcher. Hard copies of data were stored securely. All data will be stored for five years on completion of the study and thereafter electronic data will be securely deleted and hard copies shredded.

## 3.7 Data collection instruments

The researcher sought to elicit information pertaining to the types of burdens (the major domains) experienced by the caregiver through the completion of two questionnaires. The caregivers provided information individually and had to complete the biographical / demographics details section. The questionnaires pertained to the lived experiences of the caregivers caring for a chronically ill child on dialysis. For convenience, the questionnaires were completed (and clarity provided, if necessary, by the researcher) while the child was on dialysis. To elicit further data from the caregivers and renal staff, two semi-structured questionnaires, developed by the researcher were also completed. These semi-structured questionnaires provided data on the types of support the caregivers needed to cope with their burdens and the staff had to complete a semi-structured questionnaire on the information provided and communication with caregivers. All questionnaires were translated into isiZulu and were available as required.

The study used the following two validated questionnaires:

### 3.7.1 Paediatric Renal - Caregiver Burden Scale (PR-CBS). (Appendix 8)

Parham (2011) was the first researcher to develop a measure of caregiver burden specific to caregivers of children with CKD. The generation of a comprehensive item pool was informed by extensive collaborative research with nephrologists, clinical psychologists, and the caregivers. The resultant questionnaire was piloted with the caregivers and feedback on the usability, readability, and content measure of items, helped to refine the instrument, and thus the PR-CBS was developed.

The PR-CBS is a 51-item, validated scale for measuring caregiver burden in children with CKD, which includes stage 5 chronic kidney disease / kidney failure. It has been validated in various countries such as the US, UK, India and Egypt (Reddy et al., 2022; Bauer et al., 2020; Parham et al., 2016; El-Abbassy et al., 2015; Parham, 2011). Caregivers rated their responses to statements (for example, “Feeling alone in caring for my child”) on a 5-point Likert scale ranging from 1 (never) to 5 (always) to indicate their subjective appraisals of how much of a problem the aspect of caregiving had been over the last month, giving a total score. The 51 statements are further classified into nine sub-domains: physical, financial, social, emotional/psychological, caregiver role/identity, impact on family, impact on child, CKD treatment responsibility, and contact with hospital/medical staff (Parham, 2011).

### 3.7.2 General Health Questionnaire - 12 (GHQ - 12). (Appendix 8)

The study also sought to establish the correlation between anxiety, distress and social dysfunction, thus the caregivers completed the GHQ - 12 (Goldberg and Williams, 1988). In its original version, it had 60 items (GHQ-60). However, with subsequent research it was reduced to 30 items (GHQ - 30), then to 28 items (GHQ - 28) until this iteration with 12 items (GHQ - 12) (Goldberg and Williams, 1988). The GHQ - 12 measure is used to detect nonpsychotic domains such as distress or anxiety in adults (Goldberg and Williams, 1988). The scale elicits whether the respondent has experienced a particular symptom or behavior in the previous two weeks and assesses the mental and physical functioning and overall health-related quality of life (Goldberg and Williams, 1988). There are twelve statements, four per domain and each item is rated on a four-point scale (less than usual: rating 0, no more than usual: rating 1, rather more than usual: rating 2, or much more than usual: rating 3). The higher the rating values, indicates more than usual nonpsychotic symptoms. The validity and reliability of the GHQ-12 was tested in several settings and countries and its application in international research settings, as a multi-dimensional screening tool, is well documented, with the Cronbach's α for GHQ - 12 being 0. 72 (Anjara et al., 2020; Adejumo et al., 2019; El-Metawally et al., 2018; Kiliś-Pstrusińska et al., 2013a; Mann et al., 2011; Sánchez-Lopéz and Dresch, 2008; Werneke et al., 2000). The instrument has been translated into 38 languages since its development, indicating its validity across cultures (Jackson, 2007).

### 3.7.3 Caregiver coping and support needs (Appendix 8).

The researcher included a self-developed, semi-structured questionnaire to elicit information from the caregiver on the types of support received and the practices that they may need to assist them to cope with any burdens experienced

### 3.7.4 Renal staff information sharing and communication with caregivers (Appendix 10)

The researcher used a self-developed questionnaire to ascertain information sharing and communication strategies between the renal staff and the caregivers and possible improvement of areas of support that could be provided to the caregivers.

The use of multiple instruments aimed to elicit a comprehensive range of burdens, anxiety and social dysfunction experienced, and the resources and areas of support needed for the caregivers of children with CKD.

# 4 CHAPTER FOUR

# RESULTS AND ANALYSIS OF THE DATA

## 4.1 Introduction

The data collected from the responses were analysed, with the assistance of a statistician, using SPSS version 28.0. The results are presented as descriptive statistics in the form of graphs, cross tabulations and other figures for both the quantitative data and qualitative data that was collected. Inferential techniques include the use of correlations and chi square test values, which are interpreted using the p-values. The traditional approach to reporting a result requires a statement of statistical significance. A p-value is generated from a test statistic. A significant result is indicated with "$p < 0.05$". Demographic data were analysed using frequency distributions, means and cross tabulations.

Similar to previous studies, the PR-CBS questionnaire was useful to elicit the experiences of caregivers who take care of children with CKD, in this single-center study, and revealed a high prevalence of burdens experienced by these caregivers (Reddy et al., 2022; Bauer et al., 2020; Wightman et al., 2019; Parham et al., 2016; El-Abbassy et al., 2015; Parham, 2011; Tong et al., 2010; Tsai et al., 2006). The majority of caregivers experienced burden in all domains, with the financial domain showing an elevated frequency of burden (mean 4.86; 86% of respondents).

Jacoby et al. (2018), reported that caregivers of children on dialysis put their professional and social identities on hold and Pourghaznein et al. (2018a), found that life became focussed on caring for the ill child, leaving little time for social interaction. This is similar to results in this study, as 71% of respondents felt alone in caring for the child since they did not have support for caregiving from other people and there is further correlation with fifteen (71.4%) participants experiencing loneliness and isolation. Seventeen (81%) stated that they felt overwhelmed to be strong for the child and family and moreover 71,4% stated that they could not switch off from managing the child's condition, causing mental fatigue.

Among the number of primary caregivers, data from 16 of females and 5 male caregivers were analyzed. Seventeen were biological children of the caregivers, one child was adopted and three were stepchildren. There were no grandchildren, orphans, foster children and child-headed households represented in this sample.

The overall burden mean score among caregivers for GHQ - 12 was 10.5 and the SD was 8.67. The PR-CBS instrument revealed an overall burden mean score of 220.24 with a SD of 41.74 and is higher than previously reported (Reddy et al., 2022; Wightman et al., 2019). The results of both instruments show moderate to severe burden of care.

## 4.2 Sample

Taking into consideration inclusion and exclusion criteria twenty-one caregivers qualified for inclusion in the study. Thus, a total of 21 questionnaires were administered and 21 were returned which gave a 100% response rate.

## 4.3 Research instruments

The research instrument consisted of 103 items, with a level of measurement at a nominal or an ordinal level. The findings and analysis of the research instruments were divided into five sections which measured various themes as illustrated below:

- The General Health Questionnaire - 12
- The Paediatric Renal Caregiver Burden Scale

- Caregiver Demographics
- Patient Demographics
- Semi-structured questionnaire: Practices that could assist with Caregiver Burden
- Semi-structured questionnaire: Staff communication and information sharing with caregivers

## 4.4 Reliability Statistics

The two most important aspects of precision are reliability and validity. Reliability is computed by taking several measurements on the same subjects. A reliability coefficient of 0.60 or higher is considered as "acceptable" for a newly developed construct. Although this sample is small (21), the results are reliable due to the specialized groups of participants. In other words, individuals outside of this specialization will not be able to interpret and respond appropriately to these statements. Furthermore, the cohort in this study is sizeable for a single-centre paediatric dialysis unit and represents a more diverse population than other published works. For example, research on this topic by Erez et al. (2022), was conducted with a small sample of 25 caregivers and patients, 60% of whom were white, from a single-centre; Bauer et al. (2020), had mainly white participants - 21 patients on HD and their caregivers; and Kiliś-Pstrusińska et al. (2013a), conducted their research with 41 children with CKD and 40 mothers and 39 fathers, consisting of only Polish participants.

## 4.5 Cronbach's alpha score

The tables below reflect the Cronbach's alpha score for all the items that constituted the questionnaires:

### General Health Questionnaire – 12

Table 6: Cronbach' Alpha score for the GHQ - 12

| | Domain | Number of statements | Cronbach's Alpha |
|---|---|---|---|
| A | Anxiety/depression | 4 | 0.543 |
| B | Distress/mood | 4 | 0.761 |
| C | Social dysfunction/lack of confidence | 4 | 0.771 |
| All items included | | 12 | 0.833 |

Table 7: Cronbach' Alpha score for the PR-CBS

### The Paediatric Renal Caregiver Burden Scale

| | Domain | Number of statements | Cronbach's Alpha |
|---|---|---|---|
| A | Physical | 2 | 0.802 |
| B | Financial | 1 | - * |
| C | Social | 2 | 0.235 |
| D | Emotional/psychological | 9 | 0.925 |
| E | Caregiver role/identity | 4 | 0.868 |
| F | Impact on Family | 8 | 0.794 |
| G | Impact on child | 5 | 0.822 |
| H | CKD treatment responsibility | 12 | 0.916 |
| I | Contact with hospital/medical staff | 8 | 0.928 |
| All items included | | 51 | 0.945 |

*The statistician advised that there is no Cronbach's Alpha for a domain that had only one statement as there needs to be a minimum of two statements for a value to be generated

The reliability scores for overall constructs exceed the recommended Cronbach's alpha value. This indicates a degree of acceptable, consistent scoring for these sections of the research. However, one sub-scale with the minimum number of items (C – Social) had a low Cronbach’s alpha value. This can be attributed to the fact that this domain comprised only two statements in this sub-scale and/or how the participants interpreted these statements.

## 4.6 Factor Analysis

*Why is factor analysis important?*

Factor analysis is a statistical technique whose main goal is data reduction. A typical use of factor analysis is in survey research, where a researcher wishes to represent several questions with a small number of hypothetical factors. The principal component analysis was used as the extraction method, and the rotation method was Varimax with Kaiser Normalization. This is an orthogonal rotation method that minimizes the number of variables that have high loadings on each factor. It simplifies the interpretation of the factors. Factor analysis/loading shows inter-correlations between variables. Items of questions that loaded similarly imply measurement along a similar factor. An examination of the content of items loading at or above 0.5 (and using the higher or highest loading in instances where items cross-loaded at greater than this value) effectively measured along the various components. Factor analysis can be used to establish whether the measures do, in fact, measure the same components. If so, they can then be combined to create a new variable, a factor score variable that contains a score for each respondent on the factor. Factor techniques are applicable to a variety of situations.

The matrix table/s is preceded by a summarised table that reflects the results of KMO and Bartlett's Test. The **KMO and Bartlett's Test** table below shows two tests that indicate the suitability of data for structure detection. The **Kaiser-Meyer-Olkin Measure of Sampling Adequacy** is a statistic that indicates the proportion of variance in the variables that might be caused by underlying factors. High values (close to 1.0) generally indicate that a factor analysis may be useful with the data. If the value is less than 0.50, the results of the factor analysis probably won't be very useful.

**Bartlett's test of sphericity** tests the hypothesis that the correlation matrix is an identity matrix, which would indicate that the variables are unrelated and therefore unsuitable for structure detection. Small values (less than 0.05) of the significance level indicate that a factor analysis may be useful with the data. (https://www.ibm.com/docs/de/spss-statistics/24.0.0?topic=detection-kmo-bartletts-test). Factor analysis is done only for the Likert scale items. Certain components divided into finer components. This is explained below in the rotated component matrix.

## 4.7 KMO and Bartlett's Test

### General Health Questionnaire – 12

Table 8:: KMO and Bartlett's Test for GHQ - 12

| **KMO and Bartlett's Test** | | |
|---|---|---|
| Kaiser-Meyer-Olkin Measure of Sampling Adequacy. | | 0.653 |
| Bartlett's Test of Sphericity | Approx. Chi-Square | 238.904 |
| | Df | 55 |
| | Sig. | 0.000 |

## The Paediatric Renal Caregiver Burden Scale

Table 9: KMO and Bartlett's Test for the Paediatric Renal Caregiver Burden Scale

| | | Kaiser-Meyer-Olkin Measure of Sampling Adequacy. | Bartlett's Test of Sphericity | | |
|---|---|---|---|---|---|
| | | | Approx. Chi-Square | df | Sig. |
| A | Physical | 0.500 | 13.342 | 1 | < 0.001 |
| C | Social | 0.500 | 0.350 | 1 | 0.554 |
| D | Emotional/psychological | 0.500 | 0.496 | 8 | 0.006 |
| E | Caregiver role/identity | 0.683 | 74.521 | 10 | < 0.001 |
| F | Impact on Family | 0.722 | 725.514 | 6 | < 0.001 |
| G | Impact on child | 0.572 | 612.707 | 4 | < 0.001 |
| H | CKD treatment responsibility | 0.872 | 306.499 | 11 | < 0.001 |
| I | Contact with hospital/medical staff | 0.708 | 205.073 | 28 | < 0.001 |

All of the conditions were satisfied for factor analysis, except for the test of Bartlett's Test of Sphericity for C – Social. This is due to the minimum number of items, as identified earlier. The Kaiser-Meyer-Olkin Measure of Sampling Adequacy value should be greater than 0.500 and the Bartlett's Test of Sphericity significant value should be less than 0.05.

## 4.8 Rotated Component Matrix

### General Health Questionnaire – 12

Table 10: Rotated Component Matrix for the General Health Questionnaire – 12.

| | Component | | | |
|---|---|---|---|---|
| | 1 | 2 | 3 | |
| Able to concentrate on what you are doing | 0.224 | 0.922 | -0.004 | C1_A |
| Felt constantly under strain | 0.018 | 0.016 | 0.911 | C5_R_A |
| Been thinking of yourself as a worthless person_R | 0.965 | -0.053 | 0.124 | C11_R_A |
| Lost much sleep over worry | 0.205 | 0.019 | 0.911 | C2_R_B |
| Been able to face up to your problem | 0.731 | 0.392 | -0.354 | C8_B |
| Been feeling unhappy or depressed_R | 0.810 | 0.096 | 0.338 | C9_R_B |
| Been losing confidence in yourself_R | 0.933 | 0.215 | 0.078 | C10_R_B |
| Felt that you are playing useful part in things | 0.661 | 0.609 | -0.103 | C3_C |
| Felt capable of making decisions about things | 0.876 | 0.217 | 0.132 | C4_C |
| Been able to enjoy your normal day-to-day activities | 0.010 | 0.840 | -0.120 | C7_C |
| Been feeling reasonably happy, all things considered | 0.218 | 0.842 | 0.327 | C12_C |
| Felt that you could not overcome your difficulties | | 0.215 | | |

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.

a. Rotation converged in 6 iterations.

Analysis indicates that the most significant result for the Anxiety / Depression Domain (1) is 0.965, reflected in the statement “been thinking of yourself as a worthless person”.

For the Distress / Mood Domain (2) it emerges that the most significant result is 0.933, for the statement “been losing confidence in yourself”.

The statement “felt capable of making decisions about things” with a significant value of 0.876 falls within the Social Dysfunction / Lack of confidence Domain (3).

## The Paediatric Renal Caregiver Burden Scale

Table 11 Rotated Component Matrix for the Paediatric Renal Caregiver Burden Scale.

| A : Physical | Component |
|---|---|
| | 1 |
| Worrying about the effect of caring for my child on my health | 0.927 |
| Feeling exhausted from caring for my child | 0.927 |

Extraction Method: Principal Component Analysis.

a. 1 components extracted.

Sixteen (76.2%) respondents indicated that they felt caring for the ill child affected their health negatively and caused them to feel exhausted. Thirteen respondents (61.9%) disregarded their own health needs as they felt that the child's needs super-ceded their own.

Table 12: Component analysis for the social domain (PR-CBS)

| C: Social | Component |
|---|---|
| | 1 |
| Feeling trapped because of caring for my child | 0.754 |
| Sadness about not socialising as much as I want to because of caring for my child | 0.754 |

Extraction Method: Principal Component Analysis.

a. 1 components extracted.

Analysis indicates that 67%, (14) respondents felt burden due to the lack of socialising as caring for the ill child is not only time consuming, but with CKD being an unpredictable disease, the child cannot be left without adult supervision. This study also revealed that due to the intense and prolonged nature of caregiving, the caregivers experienced a sense of social isolation from friends and family, and the larger community as they are unable to participate fully in spiritual or recreational activities.

Table 13  Component analysis for the emotional/psychological domain (PR-CBS)

| D: Emotional/Psychological | Component | |
|---|---|---|
| | Emotional isolation | Emotional challenges |
| Feeling that I am not able to 'switch off' to my child's condition | 0.808 | 0.565 |
| Worrying about the future | 0.610 | 0.466 |
| Blaming myself for my child's kidney problems | 0.257 | 0.951 |
| Feeling troubled by difficult memories of when my child was first diagnosed or has been very ill in the past | 0.535 | 0.639 |
| Worrying about my child during the night | 0.884 | 0.247 |
| Worrying about my child getting very ill or dying | 0.859 | 0.368 |
| Feeling that other people do not understand my situation | 0.191 | 0.925 |
| Difficult feelings due to the uncertainty of my child's condition | 0.933 | 0.078 |
| Feeling alone in caring for my child | 0.686 | 0.467 |

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.

a. Rotation converged in 3 iterations.

This domain analyses the emotional / psychological burden of the caregiver with the highest score relating to blaming themselves for the child's kidney problems (component analysis of 0.951, 57%, 12 respondents) and the uncertainty of the child's condition (0.933, 81%; 17 respondents).  A sense of isolation is experienced in the high score of 0.925 (62%, 13 respondents) of feeling that other people do not understand their situation.  They feel fearful and anxious about the child especially during the night (0.884, 76%, 16 respondents), either getting very ill or dying (0.859, 76%, 16 respondents).

Table 14:  Component analysis for the caregiver role/identity domain (PR-CBS)

| E: Caregiver Role/Identity | Component |
|---|---|
| | 1 |
| Feeling that my child's condition has taken over life | 0.806 |
| Feeling unable to think about my own needs | 0.937 |
| Sadness that I cannot do things that I used to do because of caring for my child (e.g.. work, leisure activities, hobbies) | 0.681 |
| Worrying about the impact of my child's condition on my other children | 0.845 |
| Sadness that I am not the person that I used to be | 0.838 |

Extraction Method: Principal Component Analysis.

a. 1 components extracted.

The findings indicate a high burden for the domain, Caregiver Role / Identity, as they indicated that the patient was fully dependent on them (0.806; 62%; 13 respondents) and thus they could not pursue their previous individual activities either for work or leisure (0.681; 71.4%; 15 respondents), causing them sadness. Due to the time spent with the caregiving duties, the caregivers lacked sufficient personal time and felt unable to think about their own private needs with a high score of (0.937; 71.4%; 15 respondents).

Table 15: The component analysis for impact on family domain (PR-CBS)

| F: Impact on Family | Component | |
|---|---|---|
| | Role conflict | Overwhelmed |
| Feeling guilty about spending less time with my other child/children/partner | 0.916 | 0.203 |
| Feeling overwhelmed by trying to fit family life around my child’s condition | 0.345 | 0.929 |
| Feeling under pressure to be strong for my child and family | -0.095 | 0.959 |
| Arguing with my partner/family about my child’s care | 0.430 | 0.352 |
| Feeling uncertain about how to manage my child’s emotions and difficult behaviour | 0.345 | 0.929 |
| Sadness that I do not have a ‘normal’ relationship with my child | 0.831 | 0.056 |
| Sadness about the impact of my child’s kidney problems on my relationship with my partner | 0.953 | 0.166 |

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.

a. Rotation converged in 3 iterations.

The roles and responsibilities as a caregiver, affects other relationships negatively (Ong et al., 2021; Wightman, 2020; Kari et al., 2014; Byrd et al., 2011). The caregiver finds difficulty in balancing time, in caring for the ill child and spending time with other children and their partner as indicated by a high burden score (mean of 0.916; 74% respondents) and (mean of 0.953; 76.2% respondents respectively). This indicates that there is severe role conflict. Furthermore, regarding this domain there was high burden and feeling of being overwhelmed with being strong for the ill child, (0.959, 81%, 17 respondents) and difficulty in managing the child’s own emotions (0.929, 71.4%, 15 respondents).

Table 16 Component analysis for the impact on child domain (PR-CBS).

| G: Impact on Child | Component | |
|---|---|---|
| | Loss of control | Fears of child's future |
| Feeling helpless when my child is ill or in pain | 0.972 | 0.054 |
| Sadness about the things that my child misses out on | 0.976 | -0.011 |
| Worrying about how my child is coping | 0.984 | -0.029 |
| Worrying about the disruptions to my child's education | 0.961 | 0.021 |
| Worrying about my child's growth and development | 0.009 | 1.000 |

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.

a. Rotation converged in 3 iterations.

Caregivers experience a loss of control because of the illness on the child's future and scored as one of the highest burdens of all the domains (education: 0.961, 76.2%, 16 respondents); to worrying about the child's growth and development (1.000, 86%, 18 respondents). Seventeen respondents (81%, 0.972) feel helpless when the child is in pain and there is constant worry regarding how the child is coping (16 respondents, 76.2%; mean 0.984). Furthermore, when caregivers thought of the child's future, they struggled with feelings of grief, anxiety; and fear of the child's impending death made the caregivers feel hopeless at times (Ong et al., 2021; Wightman et al., 2019; Pourghaznein et al., 2018a).

Table 17 Component analysis of the CKD treatment responsibilities domain (PR-CBS)

| H: CKD Treatment Responsibilities | Component | | |
|---|---|---|---|
| | Medical Fears | Safety Fears | Coping Fears |
| Worrying if my child has had the correct amount of fluid | 0.453 | 0.116 | 0.867 |
| Feeling preoccupied with checking my child for signs of illness | 0.170 | 0.807 | 0.542 |
| Blaming myself if my child gets ill or has bad test results | 0.382 | 0.697 | 0.560 |
| Worrying about getting medical procedures wrong (e.g. dialysis, injections, tube feeding) or taking measurements incorrectly | 0.944 | 0.064 | 0.005 |
| Feeling overwhelmed by decisions that I have to make about my child’s condition | 0.976 | 0.116 | 0.083 |
| Feeling overwhelmed by changes in my child’s usual treatment | 0.837 | 0.337 | -0.005 |
| Worrying about getting my child’s medicines wrong | 0.758 | 0.432 | -0.011 |
| Feeling overwhelmed by feeding difficulties (eg. lack of appetite, managing diet restrictions, vomiting) of my child | 0.539 | 0.511 | 0.173 |
| Worrying about having to deal with unexpected changes in my child’s condition (eg. unexpected hospital admissions) | 0.809 | 0.146 | 0.286 |
| Feeling that I should be doing more for my child | -0.162 | 0.036 | 0.915 |
| Difficult feelings due to my child taking responsibility in his or her care (eg. worrying if medicines have been taken) | 0.961 | 0.139 | 0.151 |
| Feeling preoccupied with keeping my child safe from illness | 0.111 | 0.878 | -0.132 |

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.

a. Rotation converged in 5 iterations

Regarding this domain, sixteen respondents (76.2%; mean: 0.976), felt overwhelmed about constantly making medical decisions for the child’s condition and also felt burden in ensuring compliance with the child’s medical regimen (81%; mean 0.961). Eighteen (86%) respondents expressed coping fears that they were providing insufficient care for the child.

Table 18 Component analysis of contact with hospital domain (PR-CBS)

| I: Contact with Hospital/Medical Staff | Component | |
|---|---|---|
| | Communication Challenges | Frustrations with Hospital Environment |
| Frustration when dealing with staff that do not know my child | 0.929 | 0.234 |
| Difficult feelings due to having no privacy when at the hospital | 0.809 | 0.440 |
| Worrying that my child may have to be admitted to hospital | 0.930 | 0.239 |
| Feeling unable to 'switch off' when waiting for test results or a telephone call from the hospital | 0.767 | 0.280 |
| Feeling bored when having to spend time at the hospital | 0.166 | 0.910 |
| Holding back when I disagree with medical staff | 0.381 | 0.860 |
| Feeling frustrated when having to spend time at the hospital | 0.438 | 0.775 |
| Worrying that I have not understood medical information | 0.780 | 0.401 |

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.

a. Rotation converged in 3 iterations.

Analysis of this domain indicates that 16 caregivers (76.2%; mean 0.930) worried about the implications when the child was admitted to hospital. Fourteen of respondents (67%; mean: 0.910) felt frustrated and tired with being in the hospital environment while the child was on dialysis or was admitted to hospital.

### General Health Questionnaire - 12

The statements that constituted sub-scale A loaded across 3 components, with the remaining two dimensions loading along 2 components.

### The Paediatric Renal Caregiver Burden Scale

The statements that constituted sections A, C and E loaded perfectly along a single component. This implies that the statements that constituted these sections perfectly measured what it set out to measure.

It is noted that the variables that constituted the remaining sections loaded along 2 or 3 components (sub-themes). This means that respondents identified different trends within the section. Within the section, the splits are colour coded. The researcher provided names for these components, which aided with the analysis.

## 4.9 Caregiver Biographical Data

This section summarises the biographical characteristics of the respondents.

Table 19 Overall gender distribution by age.

| | | | Gender | | Total |
|---|---|---|---|---|---|
| | | | Female | Male | |
| Age (years) | 20 - 29 | Count | 3 | 0 | 3 |
| | | % within Age (years) | 100,0% | 0,0% | 100,0% |
| | | % within Gender | 18,8% | 0,0% | 14,3% |
| | | % of Total | 14,3% | 0,0% | 14,3% |
| | 30 - 39 | Count | 9 | 0 | 9 |
| | | % within Age (years) | 100,0% | 0,0% | 100,0% |
| | | % within Gender | 56,3% | 0,0% | 42,9% |
| | | % of Total | 42,9% | 0,0% | 42,9% |
| | 40 - 49 | Count | 3 | 4 | 7 |
| | | % within Age (years) | 42,9% | 57,1% | 100,0% |
| | | % within Gender | 18,8% | 80,0% | 33,3% |
| | | % of Total | 14,3% | 19,0% | 33,3% |
| | 50 - 59 | Count | 1 | 1 | 2 |
| | | % within Age (years) | 50,0% | 50,0% | 100,0% |
| | | % within Gender | 6,3% | 20,0% | 9,5% |
| | | % of Total | 4,8% | 4,8% | 9,5% |
| Total | | Count | 16 | 5 | 21 |
| | | % within Age (years) | 76,2% | 23,8% | 100,0% |
| | | % within Gender | 100,0% | 100,0% | 100,0% |
| | | % of Total | 76,2% | 23,8% | 100,0% |

This study revealed the primary caregiver is the biological mothers of the patient (81%) and that females (76.2%) are the majority of the primary caregivers who experience multiple burdens, anxieties and social dysfunction. These include, for example, worry about the child’s development and well-being, fears about the progression of the disease, constant vigilance regarding medication regimens and fatigue due to the demands of daily caregiving.

Overall, the ratio of male to female caregivers is approximately 1:3 (23.8%: 76.2%) (p = 0.016). International studies also show similar results as this study (81%), that most primary caregivers for these chronically ill children were female (Bauer et al., 2021; Medyńska et al., 2017; Mieto et al., 2014; Pourghaznein et al., 2018a; Pourghaznein et al., 2018b). Within the age category of 40 to 49 years, 57.1% were male. Within the category of males (only), 80.0% were between the ages of 40 to 49 years. This category of males between the ages of 40 to 49 years formed 19.0% of the total sample. This contrasts with the females, where most of them (56%) were in the age range between 30-39 years.

The age distributions are not statistically different (p = 0.101). The descriptive statistics for age (in years) is shown in Table 20 below:

Table 20: Caregivers age in years

| N | Minimum | Maximum | Mean | Std. Deviation |
|---|---|---|---|---|
| 21 | 25.0 | 55.0 | 38.4 | 8.6 |

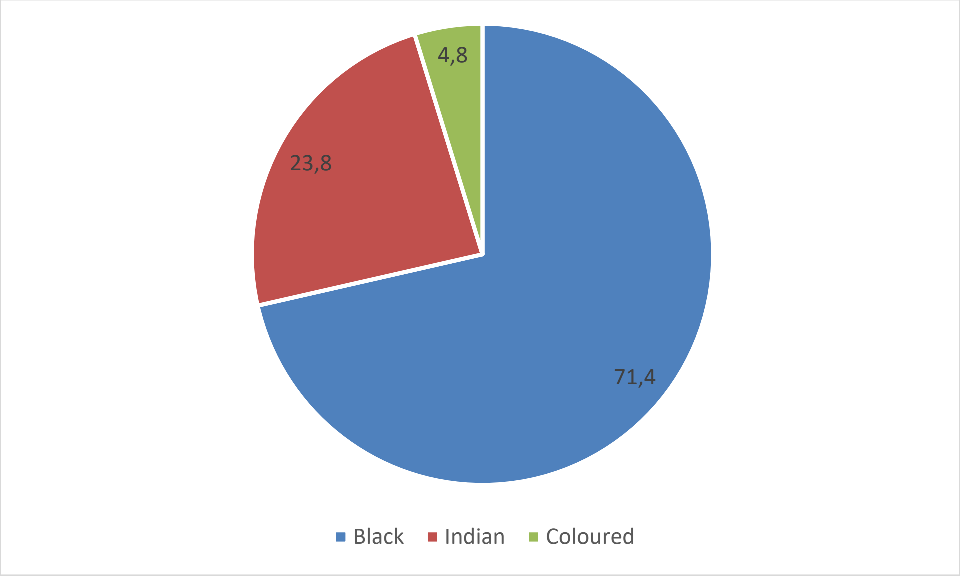


Figure 2 The racial composition of the sample.

There were significantly more Black respondents (71.4%), with Indian respondents forming a little less than a quarter of the sample (23.8%). Coloured respondents formed the smallest sample (4.8%) (p = 0.001), with no White paediatric patients at this renal centre. With reference to Table 21 below, although the numbers are similar for the Black and Coloured population and the study sample, the number for Indian CKD paediatric patients may need to be further investigated as to the high prevalence of CKD for this ethnic group as well as the lack of White paediatric CKD patients in this renal unit.

Table 21 Population data for SA by ethnic group (Davids et al., 2017)

| **Population group** | **Million** | **%** |
|---|---|---|
| Black | 45.65 | 80.8 |
| Coloured (mixed ancestry) | 4.96 | 8.8 |
| White | 4.49 | 8.0 |
| Indian/Asian | 1.41 | 2.5 |
| **Total** | **56.52** | **100** |

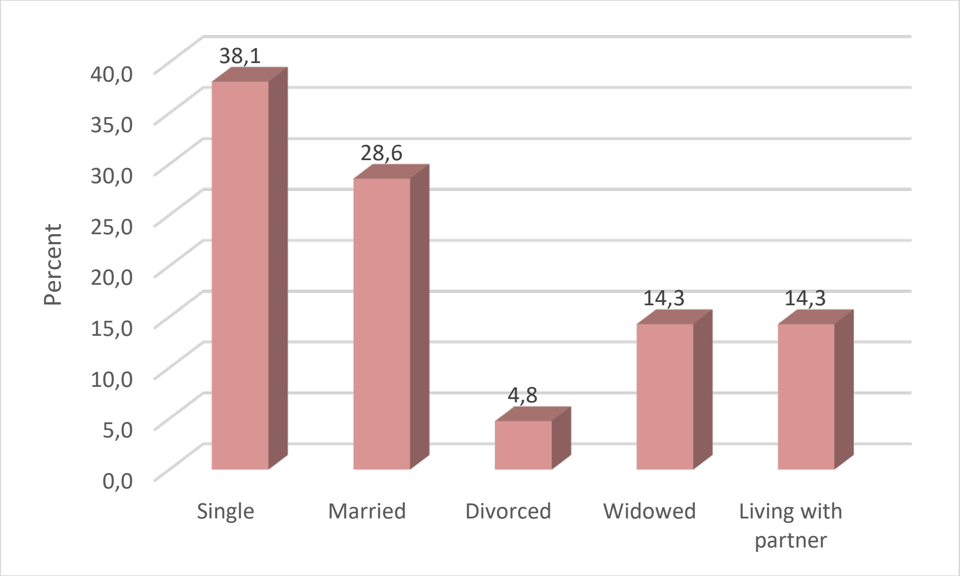


Figure 3 The marital status of the respondents.

There were 8 female caregivers who were single; and there were 2 widows and 1 widower in this group of caregivers and 38% reported to be the sole CKD caregiver. Two-thirds of the sample comprised of single and married respondents (66.7%) (p = 0.119). Notably only 4,8% are divorced caregivers in this group of participants. This is consistent with a longitudinal study performed on caregivers / parents of children with CKD in Finland, in which no significant changes in spousal relationships were observed (Laakkonen et al., 2014). Some studies show that marriage is a source of support for the caregiver (Baek et al., 2018; Wiedebusch et al., 2010). Thus, this could be a factor for the domain "Impact on Family" having a low mean score of 3,80; SD 0.77. No statistically significant differences were found with respect to the caregivers' gender or marital status and burden of care.

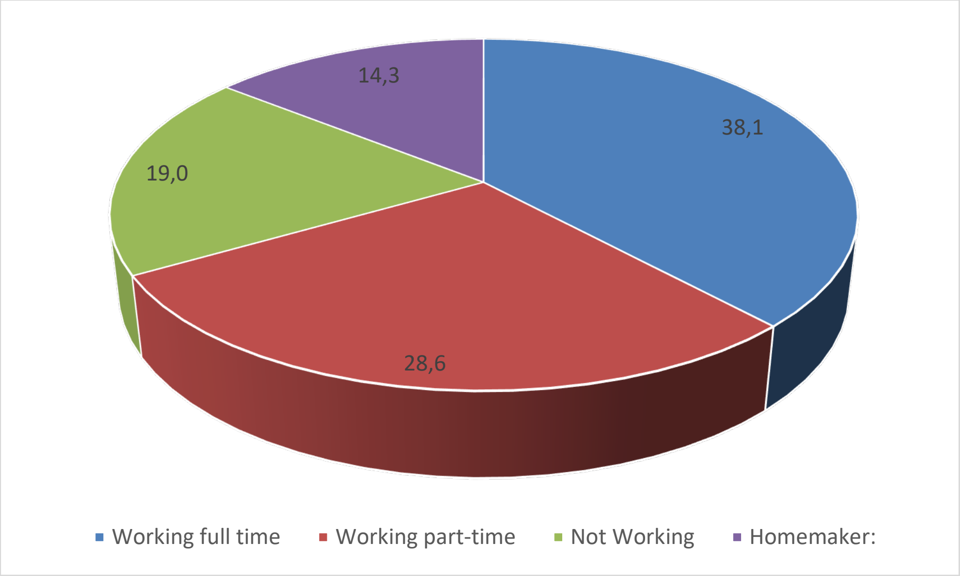


Figure 4  The employment status of the respondents.

Approximately 38% of respondents were employed full-time, with more than 28% having part-time employment.  Smaller numbers were comprised of either homemakers or those who were unemployed (33,3%) (p = 0.422).

Table 22  The education levels of the respondents.

| | Frequency | Percent |
|---|---|---|
| Secondary | 14 | 66.7 |
| Tertiary | 7 | 33.3 |
| Total | 21 | 100.0 |

The majority of respondents (66.7%) had at most a secondary school qualification, with a third (33.3%) having a tertiary qualification (p = 0.127).  This is a useful statistic as it indicates that a fair proportion of the respondents have a higher education qualification. This suggests that the respondents would have understood the questions, and that they could clearly articulate their concerns and burdens.

Table 23: The relationship of the respondents with the patient.

| | Frequency | Percent |
|---|---|---|
| Biological child | 17 | 81.0 |
| Adopted child | 1 | 4.8 |
| Stepchild | 3 | 14.3 |
| Total | 21 | 100.0 |

The majority of the respondents were the biological parents of the patient: 17 (81%; $p < 0.001$). It is noteworthy that there were no child-headed families represented in this sample. All the respondents indicated that they were the primary caregivers of the patient and that the patient lived with them.

Table 24 The duration of caregiving that respondents have been involved in over the years:

| (years) | Frequency | Percent |
|---|---|---|
| 1 - 3 | 5 | 23.8 |
| > 3 | 16 | 76.2 |
| Total | 21 | 100.0 |

Three-quarters of the respondents (76.2%) indicated that they had been taking care of the ill child for more than 3 years ($p = 0.016$).

Table 25: The number of hours of caregiving per week.

| | Frequency | Percent |
|---|---|---|
| 5 - 10 | 2 | 9.5 |
| > 10 | 19 | 90.5 |
| Total | 21 | 100.0 |

Significantly more respondents (90.5%) indicated that they looked after the patient for more than 10 hours per week ($p < 0.001$).

Table 26 The number of paediatric haemodialysis sessions.

| | Frequency | Percent |
|---|---|---|
| ≤ 20 | 5 | 23.8 |
| 20 - 40 | 14 | 66.7 |
| > 40 | 2 | 9.5 |
| Total | 21 | 100.0 |

Significantly more respondents (66.7%) indicated that 20 to 40 sessions were done ($p < 0.001$) per month. Each haemodialysis session is of three-hour duration, undertaken three times per week.

Table 27: The caregiver's place of residence.

| | Frequency | Percent |
|---|---|---|
| Urban: formal | 12 | 57.1 |
| Rural: formal | 1 | 4.8 |
| Rural: informal | 8 | 38.1 |
| Total | 21 | 100.0 |

More than half of the sample indicated that they were based in formal urban areas ($p = 0.012$). However, travel time data to and from the renal unit and transport costs were not investigated and could contribute to financial burden for the caregiver, particularly for the 8 respondents from rural, informal areas.

Table 28: The statistics of the household income per month.

| N | Minimum | Maximum | Mean | Std. Deviation |
|---|---|---|---|---|
| 20 | 1200.0 | 15000.0 | 6672.5 | 3793.7 |

The mean income was R6 672.50.

Table 29 The statistics for the number of people in the household.

| N | Minimum | Maximum | Mean | Std. Deviation |
|---|---|---|---|---|
| 21 | 3.0 | 9.0 | 5.3 | 1.9 |

On average, there were between 5 to 6 people living in the home.

The findings established that the median age among caregivers was 38.4 years, ranging between 20 and 59 years. Majority of the caregivers 16 (76,2%%) were female vs 5 (23,8%) male. Fourteen (66,7%) had secondary education as their highest level of education and more than a third had a tertiary qualification (33,3%). Seventeen (81%) of caregivers were biological parents to the patient, one child was adopted (4,8%) and 3 (14,3%) were stepchildren. Marital status analysis revealed that 28,6% were married, 38,1% were single, and 28,6% were either widows or living with a partner and 38% reported to be the sole CKD caregiver. No statistically significant differences were found with respect to the caregivers' gender or marital status and burden of care.

Thirty nine percent had full-time employment; 33,3% did not receive an income and were either unemployed or homemakers, whilst 29% had part-time employment. The mean monthly income was R6,672,50. The number of people staying with the caregiver ranged from 3-9 with a mean of 5.3, averaging between 5-6 people living at the home. Thus, the income per month was barely adequate for basic family needs. A study by Reddy et al. (2022), indicated that due to severe financial burden, families discontinued treatment for their child, resulting in poor patient outcomes for the child and ethical dilemmas for the health care team. The findings also suggest that (48%) of the caregivers were financing their caregiving expenses through SASSA grants.

## 4.10 Patient demographics

This section presents the summary of the patient (child) demographics.

Table 30: Patient demographics (child)

| | Frequency | Percent | p-value |
|---|---|---|---|
| **Gender** | | | |
| Female | 11 | 52.4 | 0.827 |
| Male | 10 | 47.6 | |
| **Age (years)** | | | |
| 2 – 5 | 9 | 42.9 | |
| 6 – 11 | 9 | 42.9 | 0.180 |
| 12 - 18 | 3 | 14.3 | |
| **Chronic Kidney Disease Stage** | | | |
| 2 | 7 | 33.3 | |
| 3 | 4 | 19.0 | |
| 4 | 1 | 4.8 | 0.119 |
| 5 | 2 | 9.5 | |
| 6 | 7 | 33.3 | |
| **CKD Treatment** | | | |
| hemodialysis | 21 | 100.0 | - |
| **Aetiology:** | | | |
| CKD: Yes | 21 | 100.0 | - |
| **Specify:** | | | |
| Nephrotic Syndrome | 9 | 42.9 | |
| CAKUT | 6 | 28.6 | |
| HUS | 2 | 9.5 | |
| Glomerulonephritis | 1 | 4.8 | |

| | | | |
|---|---|---|---|
| Other | 3 | 14.3 | |
| **Other Information:** | | | |
| albumniuria | 4 | 19.0 | |
| hematuria | 4 | 19.0 | |
| hyperlipidimia | 6 | 28.6 | |
| oedema | 7 | 33.3 | |
| **Congenital kidney malformation** | | | |
| Yes | 6 | 28.6 | - |
| **Time since diagnosis (years)** | | | |
| 0 – 1 | 4 | 19.0 | < 0.001 |
| 2 – 5 | 15 | 71.4 | |
| 6 – 10 | 1 | 4.8 | |
| > 10 | 1 | 4.8 | |

Most children (81%) were growing up in family-centred environment; and more than half of the patients (57%) lived in an urban formal setting. The characteristics of the children with CKD are presented in Table 30. Most children (81%) lived with their biological parents; only 8 (38,1%) lived with one parent, their mother. There were 11 girls and 10 boys in this study. The ages ranged from 2-5 years (42,9%); 6-11 year (42, %) and 12-18 years (14,3%), respectively, with a mean age of 10.59 years. Ten (47,6%) of the patients were male, and the data reflects a low incidence of congenital anomalies of the kidneys and the urinary tract (CAKUT) in the male patients (28,6%), unlike in other studies (Wariguah, 2022; Bhimma et al., 2008; Harambat et al., 2012). More than 40% the children had nephrotic syndrome (42.9%) with oedema being present in 33% of the children. The highest cohort of children in this study, who had been diagnosed with CKD, for 2-5 years, was 71.4%, and all the children (100%) were on haemodialysis treatment. Similar to a study by Baek et al., (2018), there was no significant relationship between the gender of male children (10) vs female children (11), p = 0.827. However, previous studies show that there is a higher proportion of male children with CKD (Bauer et al., 2020; Darwish et al., 2020; Adib-Hajbaghery and Ahmadi, 2019; Harambat et al., 2012). All children at compulsory school age (6 years+; *n* = 12; 57,1%) carried on with their education. Unfortunately, the children were unable to consistently attend school due to the dialysis sessions being more than three to four hours per session and three times per week. The caregivers stated that all the children received some educational assistance from them, at some stage, especially if the child missed school due to the severity of their condition and on the days of dialysis and hospitalisation. These circumstances also contribute to high burden and anxiety in caregivers.

## 4.11 Section analysis

The section that follows analyses the scoring patterns of the respondents per variable per section. The results are first presented using mean scores for the variables that constitute each section. The mean score calculations considered the reverse scored statements in the calculations. Results are then further analysed according to the importance of the statements.

### 4.11.1 General Health Questionnaire - 12

The study sought to establish the correlation between anxiety, distress and social dysfunction, thus the caregivers completed the GHQ - 12 (Goldberg and Williams, 1988). Psychological health is a major component contributing to overall well-being. The World Health Organization (WHO) defined mental health “as a state of well-being in which every person realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to contribute to her or his community” (WHO, 1999: 2001). The GHQ - 12 measure is used to detect nonpsychotic domains. The analysis that follows provides details of the anxiety, distress and social dysfunction experienced by this cohort of caregivers.

The table below summarises the scoring patterns for the overall sub-dimensions of the construct.

Table 31: Scoring for all the sub-dimensions for GHQ - 12

| | | **Count** | **Mean** | **Standard Deviation** | **Median** | **Maximum** | **Minimum** |
|---|---|---|---|---|---|---|---|
| C_A | Anxiety/depression | 21 | 0.95 | 0.63 | 0.75 | 2.25 | 0.00 |
| C_B | Distress/mood | 21 | 0.85 | 0.94 | 0.75 | 2.25 | 0.00 |
| C_C | Social dysfunction/lack of confidence | 21 | 0.71 | 0.94 | 0.00 | 2.50 | 0.00 |
| C_Average | C_Average | 21 | 0.84 | 0.72 | 0.50 | 2.08 | 0.00 |
| C_Total | C_Total | 21 | 10.05 | 8.67 | 6.00 | 25.00 | 0.00 |

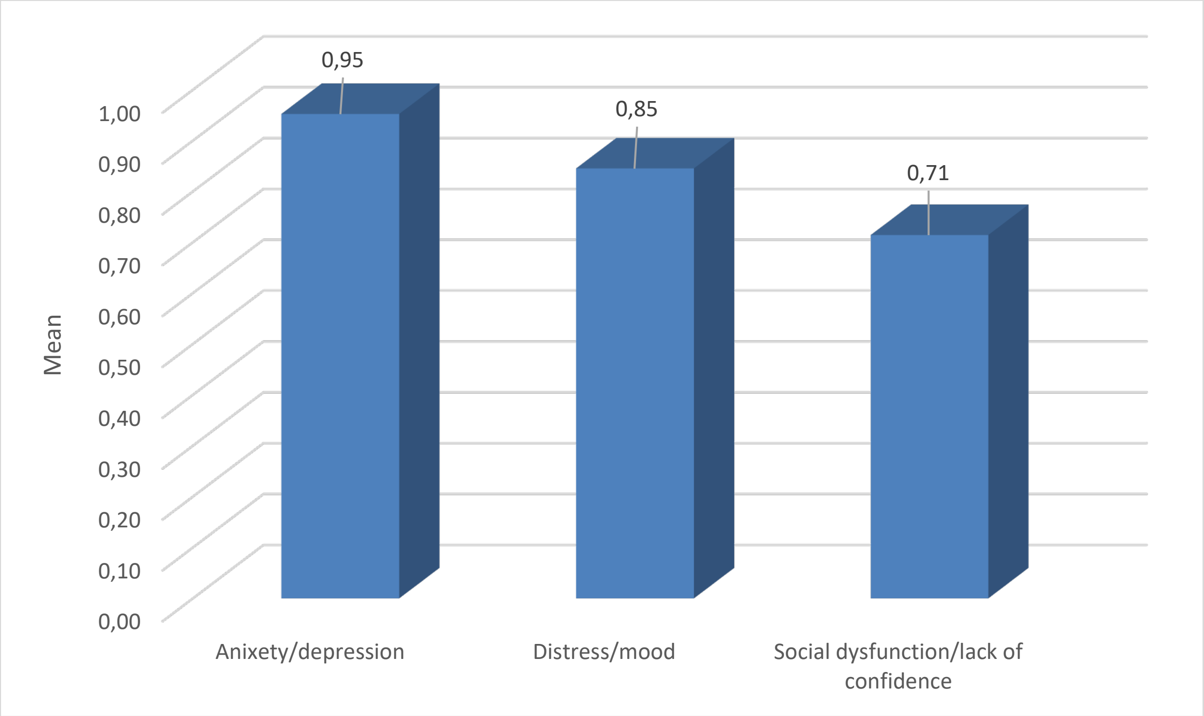


Figure 5: Mean scores for the domains for GHQ - 12

The following patterns are observed:

- The mean scores for all sub-dimensions fall below 1 (in this study, a result of > 0.5 was coded as “moderate to severe burden”). This implies that there is a general consistency across the dimensions

- It is also notes that “Social dysfunction / lack of confidence” domain showed the smallest deviation (0.71), from the minimum rating score of zero (coded as “Less than usual”). The higher the values per statement indicate more psychological symptoms such as anxiety.

From Figure 5 above it is evident that overall Domain A (Anxiety and Depression) was the most significant (mean: 0.95) regarding the inability to carry out normal day-to-day functiotioning by the caregiver. It is worth noting the statement “felt constantly under strain” had a mean value of 2.43 which scored the highest as compared to Domain C (Social Dysfunction and Lack of Confidence) which had a mean of 0.71.

To determine whether the scoring patterns were significantly different per dimension, a binomial test was done with a cut-off at 1.50 (the middle score). The null hypothesis claims that similar numbers of respondents scored below 1.50 as there were those who scored more than 1.50. The results are shown in the table below:

Table 32: Binomial test results: GHQ - 12

| | Exact Sig. (2-tailed) |
|---|---|
| C_A | 0.001 |
| C_B | 0.189 |
| C_C | 0.007 |
| C_Average | 0.007 |

The highlighted significant values (p-values) are less than 0.05 (the level of significance), it implies that the distributions were not similar. That is, there was a difference in the number of responds who scored more than 1.50 compared to less than 1.50 and it needs to be shown statistically.

Table 33: Analysis of statement 1: GHQ - 12

**Able to concentrate on what you are doing(1)**

| Anxiety /depression Domain | | No | Percent | Mean 0.52 |
|---|---|---|---|---|
| Valid | Less than usual | 17 | 81.0 | |
| | Rather more than usual | 1 | 4.8 | |
| | Much more than usual | 3 | 14.3 | |
| | Total | 21 | 100.0 | |

Lima et al. (2019), found that caring for a child with CKD is an intense experience, with negative consequences, due to the uncertainties about the future and the very specialized care these children require. A significantly high percentage (81%) of the participants responded that they are unable to concentrate. Furthermore, when caregivers thought of the child's future, they struggled with feelings of uncertainty and anxiety, and fear of the child's impending death made the caregivers feel hopeless (Ong et al., 2021; Whiteman et al., 2019; Pourghaznein et al., 2018a).

Table 34 Analysis of statement 2: GHQ - 12

**Lost much sleep over worry**

| Distress/mood Domain | | Frequency | Percent | Mean 2.71 |
|---|---|---|---|---|
| Valid | Less than usual | 1 | 4.8 | |
| | No more than usual | 1 | 4.8 | |
| | Rather more than usual | 1 | 4.8 | |
| | Much more than usual | 18 | 85.7 | |
| | Total | 21 | 100.0 | |

The high percentage of 85,7% is a strong indication of distress in the respondents. Caregivers, particularly early in the diagnosis, or when there are bad test results and / or unexpected hospitalisations of the child, are constantly fearful and the endless worry may cause a lack of sleep which ultimately impacts their physical health. The primary caregiver faces uncertainty about their ability to cope with their new CKD treatment processes, for example, managing the medication regimen and preparing a special diet for the ill child. They risk becoming overburdened and developing symptoms of anxiety and distress as they believe that the child's needs and care are more important, even to the detriment of their own health (Javalkar et al., 2017; Geense et al., 2017; Tong et al., 2008; Cimete, 2002).

Table 35 Analysis of statement 3: GHQ - 12

**Felt that you are playing a useful part in things**

| Social dysfunction/lack of confidence Domain | | Frequency | Percent | Mean 0.86 |
|---|---|---|---|---|
| Valid | Less than usual | 15 | 71.4 | |
| | Much more than usual | 6 | 28.6 | |
| | Total | 21 | 100.0 | |

Many caregivers feel overwhelmed and lack confidence with their new roles and abilities about making medical decisions which causes burden, for example, in ensuring compliance with the child's medication regimen dietary requirements, liquid intake, and recognising the side effects of the medication (Geense et al., 2017; Tong et al., 2008). Since the caregivers are seldom part of medical decision-making with the renal team, the caregivers feel that they are not playing a helpful role in caring for the child with CKD.

Table 36: Analysis of statement 4: GHQ - 12

**Felt capable of making decision about things**

| Social dysfunction/lack of confidence Domain | | Frequency | Percent | Mean1.19 |
|---|---|---|---|---|
| Valid | Less than usual | 12 | 57.1 | |
| | No more than usual | 1 | 4.8 | |
| | Much more than usual | 8 | 38.1 | |
| | Total | 21 | 100.0 | |

This statement indicates that there is a moderate lack of confidence in the respondents with a mean of 1.19. Twelve (57.1%) of the respondents expressed that their social function and confidence levels were “less than usual” whilst 38% stated that they were able to make decisions. This could be related to the fact that 33% of respondents had a tertiary qualification. A study by Lima et al. (2019), and Medway et al. (2015), found that a higher education promotes caregiver confidence in the management of the child’s illness. However, twelve of the respondents indicated that they felt unable to make decisions. This could be attributed to several reasons, for example, lack of communication and consultation with the renal team and feeling overwhelmed due to the intensive nature of taking care of a child with CKD.

Table 37 Analysis of statement 5: GHQ - 12

**Felt constantly under strain**

| Anxiety /depression Domain | | Frequency | Percent | Mean 0.2.43 |
|---|---|---|---|---|
| Valid | Less than usual | 3 | 14.3 | |
| | No more than usual | 1 | 4.8 | |
| | Rather more than usual | 1 | 4.8 | |
| | Much more than usual | 16 | 76.2 | |
| | Total | 21 | 100.0 | |

The GHQ - 12 questionnaire revealed that participants experienced severe anxiety and depression with a mean of 0.95 for this domain. Regarding this statement, a high number of respondents (16; a mean of 2.43), indicated that they felt constantly under strain which contributes to the high anxiety / depression experienced in this domain (mean 0.95). This could be due to several factors, chief among these are:

- Financial challenges due to the cost of travel, dietary restrictions, and other household expenses all of which contributes to the constant strain on family finances (Ong et al., 2021; Wightman et al., 2019; Pourghaznein et al., 2018b; Sari et al., 2018; Cimete, 2002; Dracopoulos and Weatherly, 1983). Anxiety and depression in this cohort of respondents is heightened by the fact that 62,3% did not have a stable monthly income: 33,3% did not receive an income at all and were either unemployed or homemakers, whilst only 29% had part-time employment.
- Due to the considerable amount of time spent on the child's medical needs and treatment regimens, some studies found that the well-being of partners and other children were often neglected by caregivers (Ong, et al., 2021; Wightman, 2020; Kari et al., 2014). This role conflict further adds to the strain and anxiety experienced by the caregiver.

Table 38: Analysis of statement 6: GHQ - 12

**Felt that you could not overcome your difficulties**

| Anxiety /depression Domain | | Frequency | Percent | Mean 1,95 |
|---|---|---|---|---|
| Valid | Less than usual | 6 | 28.6 | |
| | No more than usual | 1 | 4.8 | |
| | Rather more than usual | 2 | 9.5 | |
| | Much more than usual | 12 | 57.1 | |
| | Total | 21 | 100.0 | |

Caring for a child with CKD is very complex, which necessitates that the caregiver receives information and preparation for their new roles, particularly from the renal team. Twelve (57%) of the caregivers stated that they are unable to overcome their difficulties. The caregiver usually assumes functions for which he / she is not prepared, and thus ends up having his / her health impaired through extended periods of high anxiety (Legg et al., 2013; van Exel et al., 2008). Caregivers feel disempowered (Fisher, 2001) due to lack of information about the disease itself, treatment procedures and side effects, how to manage the child's emotional and psychological behavioural problems. These are only a few examples that increase the burden, anxiety and social dysfunction in the caregiver and makes them feel that they are unable to overcome their challenges.

Table 39 Analysis of statement 7: GHQ - 12

**Been able to enjoy your normal day-to-day activities**

| Social dysfunction/lack of confidence | | Frequency | Percent | Mean 0.19 |
|---|---|---|---|---|
| Valid | Less than usual | 19 | 90.5 | |
| | No more than usual | 1 | 4.8 | |
| | Much more than usual | 1 | 4.8 | |
| | Total | 21 | 100.0 | |

Fifteen participants stated that they spent as much as 71,4% of the time in taking care of the ill child, leaving little time to attend to personal needs such as going to the gym and fulfilling their own plans. Tong et al. (2010), found that the lives of the caregiver revolve around the dialysis sessions, consuming their thoughts, time and energy, causing fatigue, all of which leaves little time and energy to pursue personal activities that previously gave them fulfilment. In this study fifteen (71.4%) participants experienced loneliness and isolation. Thus, this is reflected in the significantly high number of respondents (90.5%) who are unable to enjoy normal day-to-day activities.

Table 40 Analysis of statement 8: GHQ - 12

**Been able to face up to your problem**

| Distress/mood Domain | | Frequency | Percent | Mean 1.24 |
|---|---|---|---|---|
| Valid | Less than usual | 12 | 57.1 | |
| | Rather more than usual | 1 | 4.8 | |
| | Much more than usual | 8 | 38.1 | |
| | Total | 21 | 100.0 | |

Tong et al., 2010, stated that during the initial diagnosis primary caregivers experienced shock, disbelief, devastation, confusion, and fear of losing the child. Some even denied their reality (Mieto et al., 2014). During the child's hospitalisation, the invasive procedures traumatised the caregivers and made them feel distressed and helpless (Tong et al., 2010). In this study, all the caregivers expressed the need for more information and communication from the renal professional team which would further assist with their coping and alleviation of anxiety and distress.

Table 41 Analysis of statement 9: GHQ - 12

**Been feeling unhappy or depressed**

| Distress/mood Domain | | Frequency | Percent | Mean 2.00 |
|---|---|---|---|---|
| Valid | Less than usual | 5 | 23.8 | |
| | Rather more than usual | 3 | 14.3 | |
| | Much more than usual | 13 | 61.9 | |
| | Total | 21 | 100.0 | |

Various factors could contribute to 61.9% of respondents revealing that they were unhappy or depressed. This could include, for example, the caregivers concern about the appearance, development and future prospects of the child; their inability to cope with the physical, emotional and social challenges that the child faces due to their illness; financial difficulties due to the cost of care associated with the disease; the limitations of their own social lives imposed on them by the disease. The caregiver needs to carry out complex medical and dietary regimens, deal with severe side-effects of the dialysis procedure, face unexpected hospitalisations and still has to maintain day-to-day tasks and career activities, all of which adds to their strain and anxiety. Above all, the uncertainty and the CKD progression causes fear of the loss of the child causing caregiver distress and grief.

Table 42 Analysis of statement 10: GHQ - 12

**Been losing confidence in yourself**

| Distress/mood | | Frequency | Percent |
|---|---|---|---|
| Valid | Less than usual | 3 | 61.9 |
| | No more than usual | 1 | 4.8 |
| | Rather more than usual | 4 | 19.0 |
| | Much more than usual | 13 | 14.3 |
| | Total | 21 | 100.0 |

The caregiver experienced a lack of confidence due to unexpected events for which they were not prepared, for example, when the child suddenly starts to vomit, or is hospitalised unexpectedly. The caregiver then blames themselves for the child’s illness (Tong et al., 2010; Heaton et al., 2005; Carnevale et al., 2006). Caregivers provide complex care to the child with CKD, for which they may not be prepared. This is reflected by almost 62% of the respondents stating that they lacked confidence in their caregiving roles and responsibilities, which is exacerbated by a lack of communication and information from the renal team.

Table 43 Analysis of statement 11: GHQ - 12

**Been thinking of yourself as a worthless person**

| Anxiety /depression Domain | | Frequency | Percent | Mean 2.24 |
|---|---|---|---|---|
| Valid | Less than usual | 3 | 14.3 | |
| | No more than usual | 1 | 4.8 | |
| | Rather more than usual | 3 | 14.3 | |
| | Much more than usual | 14 | 66.7 | |
| | Total | 21 | 100.0 | |

Data from the WHO (2017), estimate that approximately 4.4% of the world population suffers from depression and 3.6% from anxiety disorders. The results for this statement show that 66.7% of respondents think of themselves as worthless, contributing to a high anxiety and depression level (mean of 2.24); similar to previous studies that revealed that there is a high prevalence of moderate to severe depression symptoms (18.4%) and anxiety (47%) in caregivers of chronic patients when compared to the general population (Costa et al., 2016, in Lima et al., 2019; Lima et al., 2016). Jacoby et al (2018), described the caregiver as feeling powerless to improve the child's or their own wellbeing in the setting of CKD, increasing their feeling of being worthless.

Table 44 Analysis of statement 12: GHQ - 12

**Been feeling reasonably happy, all things considered**

| Social dysfunction/lack of confidence Domain | | Frequency | Percent | Mean 0.62 |
|---|---|---|---|---|
| Valid | Less than usual | 16 | 76.2 | |
| | No more than usual | 1 | 4.8 | |
| | Much more than usual | 4 | 19.0 | |
| | Total | 21 | 100.0 | |

Caregivers experience anxiety, psychosocial dysfunction, financial burden, and physical deprivation due to the intensive, exhausting and challenging roles and responsibilities of taking care of a child with CKD. Social isolation was described using the metaphor of prison – the “mother’s life imprisoned by the dialysis machine” (Mieto and Bousso, 2014), which is reflected in this study, were 76.2% of caregivers indicated that “feeling reasonably happy, all things considered” was “less than usual”.

#### 4.11.2 Paediatric Renal Caregiver Burden Scale

Children by their very nature are unable to take care of themselves particularly with a serious illness such as CKD. The use of the PR-CBS quantitiatively characterised the level of pervasivness the illness represents, which is simiar to findings by Wightman et al. (2019), and Parham et al. (2016). In this study, the PR-CBS findings established that caregivers experienced high levels of burden across all domains, ranging from the highest (Financial ) being a severe burden with a mean score of 4,86 to moderate burden (Social), with a mean of 3,29.

Table 45 The scoring codes for PB-CBS

| | Code |
|---|---|
| Never | 1 |
| Rarely | 2 |
| Sometimes | 3 |
| Often | 4 |
| Always | 5 |

Table 46: Summary of the scoring patterns for the overall sub-dimensions of the PR-CBS.

| | | **Count** | **Mean** | **Standard Deviation** | **Median** | **Maximum** | **Minimum** |
|---|---|---|---|---|---|---|---|
| D_A | Physical | 21 | 4.45 | 1.12 | 5.00 | 5.00 | 1.00 |
| D_B | Financial | 21 | 4.86 | 0.36 | 5.00 | 5.00 | 4.00 |
| D_C | Social | 21 | 3.29 | 1.28 | 3.00 | 5.00 | 1.00 |
| D_D | Emotional/psychological | 21 | 4.44 | 0.87 | 5.00 | 5.00 | 1.67 |
| D_E | Caregiver role/identity | 21 | 4.37 | 0.96 | 4.80 | 5.00 | 1.00 |
| D_F | Impact on Family | 21 | 3.80 | 0.77 | 4.29 | 4.29 | 1.67 |
| D_G | Impact on child | 21 | 4.70 | 0.60 | 5.00 | 5.00 | 2.60 |
| D_H | CKD treatment responsibility | 21 | 4.46 | 0.83 | 5.00 | 5.00 | 1.75 |
| D_I | Contact with hospital/medical staff | 21 | 4.34 | 1.02 | 4.88 | 5.00 | 1.13 |
| D_Average | D_Average | 21 | 4.30 | 0.74 | 4.65 | 4.92 | 1.87 |
| D_A_Total | Physical | 21 | 8.90 | 2.23 | 10.00 | 10.00 | 2.00 |
| D_B_Total | Financial | 21 | 4.86 | 0.36 | 5.00 | 5.00 | 4.00 |
| D_C_Total | Social | 21 | 6.57 | 2.56 | 6.00 | 10.00 | 2.00 |
| D_D_Total | Emotional/psychological | 21 | 40.00 | 7.86 | 45.00 | 45.00 | 15.00 |
| D_E_Total | Caregiver role/identity | 21 | 21.67 | 4.89 | 24.00 | 25.00 | 5.00 |
| D_F_Total | Impact on Family | 21 | 26.38 | 5.81 | 30.00 | 30.00 | 10.00 |
| D_G_Total | Impact on child | 21 | 23.48 | 3.01 | 25.00 | 25.00 | 13.00 |
| D_H_Total | CKD treatment responsibility | 21 | 53.57 | 9.94 | 60.00 | 60.00 | 21.00 |
| D_I_Total | Contact with hospital/medical staff | 21 | 34.71 | 8.19 | 39.00 | 40.00 | 9.00 |
| D_Total | D_Total | 21 | 220.14 | 41.74 | 242.00 | 250.00 | 82.00 |

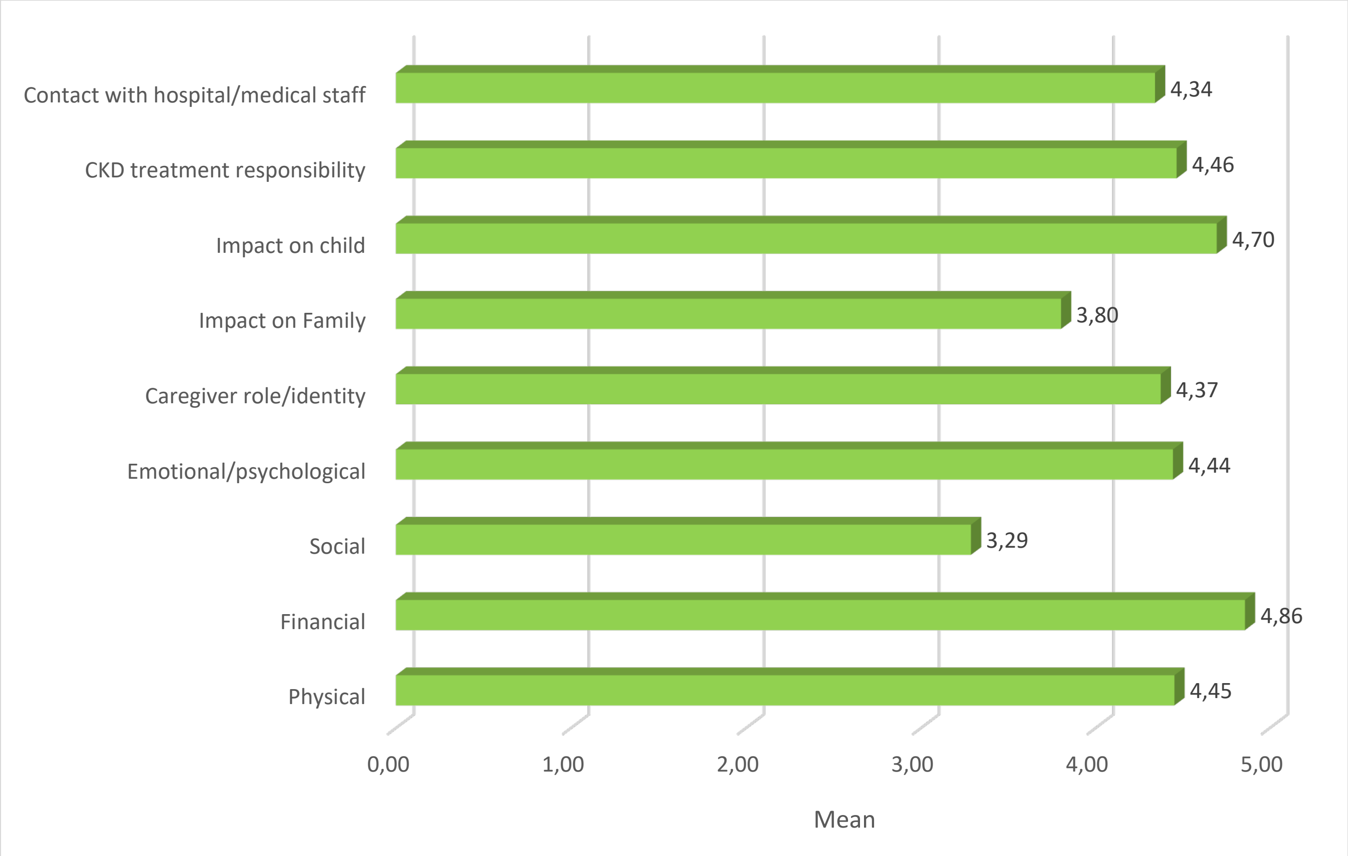


Figure 6  The mean scores for the domains for the PR-CBS

The following patterns, using the PR-CBS, are observed for caregivers of children on HD:

- The mean scores, for all domains, fall closer to 4 and 5 (which corresponds to high burden frequency occurrences). In other words, in all instances, except for Social (mean of 3,29), the means approximate greater frequency occurrences. This implies that there are higher levels of burden across all domains, with Impact on Family having a low mean score of 3,80; SD 0,77 and Social having the lowest mean score of all the domains.
- The domains of Financial (mean of 4,86; SD 0,77) and Impact on Child (mean of 4,70; SD 0,60) reflect the highest burden scores.
- CKD Responsibility (mean of 4,45); Physical burden (mean of 4,45) and Emontional/Psychological (mean of 4,44) are also notably high.

Table 47 The mean binomial score for PR-CBS

| | | Exact Sig. (2-tailed) (p-value) |
|---|---|---|
| D_A | Physical | <0.001 |
| D_B | Financial | < 0.001 |
| D_C | Social | 0.383 |
| D_D | Emotional/psychological | < 0.001 |
| D_E | Caregiver role/identity | < 0.001 |
| D_F | Impact on Family | 0.007 |
| D_G | Impact on child | < 0.001 |
| D_H | CKD treatment responsibility | < 0.001 |
| D_I | Contact with hospital/medical staff | 0.001 |
| D_Average | | < 0.001 |

The mean binomial score was used as a comparative measure and was 3.0. The results are shown below. It is noted that all of the p-values, except Social, are significant (< 0.050). Hence, the level of higher frequency occurrences of burden was significant. Together with the intense caregiving all the different roles interplay to produce caregiver burden. However, Geense et al. (2017), found that balancing their personal needs are seldom prioritized by the caregiver as the child's treatment needs are considered paramount.

The tables below show the burdens as experienced by the participants and analysis is based on grouping the statements according to the PR-CBS domains:

Table 48: Analysis of statement 1: PR-CBS

**Physical: worrying about the effect of caring for my child on my health (1)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 1 | 4.8 |
| | Sometimes | 1 | 4.8 |
| | Often | 3 | 14.3 |
| | Always | 16 | 76.2 |
| | Total | 21 | 100.0 |

Table 49 Analysis of statement 48: PR-CBS

**Physical: Feeling exhausted from caring for my child (48)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 3 | 14.3 |
| | Often | 2 | 9.5 |
| | Always | 16 | 76.2 |
| | Total | 21 | 100.0 |

The above two statements and tables above pertaining to the *Physical* domain reflect significantly high physical burden (76,2%) and mental fatigue experienced by 16 (76.2%) caregivers in this study. As a result of strenuous routines and treatment schedules, caregivers experience exhaustion and lack of energy (Ong et al., 2021; Wightman, 2020). Participants in this study (71.4%) indicated a lack of time in taking care of their own health due to the child's illness.

Fifteen participants stated that they spent as much as 71,4% of the time in taking care of the ill child, leaving no time to attend to personal needs such as going to the gym and fulfilling their own plans.

Caregivers of children with CKD have problems with poor health habits and end up falling ill in the long term (Javalkar et al., 2017) because they tend to neglect their own health needs and forego preventive medical visits. Wightman (2020), found that the caregiver's physical exhaustion led to the development of hypertension and diabetes in the caregiver. Tong et al., (2010), found that the lives of the caregiver revolve around the dialysis sessions, consuming their thoughts, time and energy, causing fatigue. Oyegbile (2017), and Noble et al. (2013), comment that there is an overall deterioration of the caregiver's physical health, leading to the increased morbidity of pre-existing illness or increased susceptibility to new stress related ill-health and mortality.

Table 50: Analysis of statement 8: PR-CBS

**Financial: Worrying about money due to the costs of my child's care (8)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Often | 3 | 14.3 |
| | Always | 18 | 85.7 |
| | Total | 21 | 100.0 |

The responses from the caregiver for this domain, *Financial Burden*, was significantly high (85,7%). Dialysis is extremely expensive and is conservatively estimated to cost approximately ZAR450 000 per annum per patient in the public health sector (Chothia (2023). Public health care facilities use a sliding scale, where the fees are charged dependent on income. Indigent patients are able to access services free of charge (Naicker, 2013; Leatt et al., 2006). Financial burden in this cohort of respondents is heightened by the fact that 62,3% did not have a stable monthly income: 33,3% did not receive an income at all and were either unemployed or homemakers, whilst 29% had part-time employment. The cost of travel, dietary restrictions and other household expenses all added on to the constant strain on family finances (Reddy et al., 2022;

Wightman et al., 2019; Pourghaznein et al., 2018a; Sari et al., 2018; Cimete, 2002; Dracopoulos and Weatherly, 1983). The caregivers also spend significant time off work to accompany the child to appointments and may face unemployment due to the caregiving needs of the patient (Wightman (2020).

Table 51 Analysis of statement 4: PR-CBS

**Social: Feeling trapped because of caring for my child (4)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 3 | 14.3 |
| | Rarely | 1 | 4.8 |
| | Often | 3 | 14.3 |
| | Always | 14 | 66.7 |
| | Total | 21 | 100.0 |

Table 52 Analysis of statement 21: PR-CBS

**Social: Sadness about not socialising as much as I want to because of caring for my child (21)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 13 | 61.9 |
| | Often | 2 | 9.5 |
| | Always | 6 | 28.6 |
| | Total | 21 | 100.0 |

The responses of the caregivers for the domain regarding *Social* is reflected in two of the above-mentioned statements and is related to the fact that caregiving imposes restrictions and affects all aspects of life of the caregiver, including the disruption (Jacoby et al., 2018; de Paula et al., 2008; Bauer and Sousa-Poza, 2015). This study also revealed that due to the intense, unexpected and prolonged nature of caregiving, the caregivers experienced a sense of social isolation from friends and family and the larger community, for example, they are unable to participate fully in spiritual activities or recreational activities. In this study, fourteen (66,7%) respondents felt the burden of social isolation. Jacoby et al. (2018), reported that caregivers of children on dialysis meant that they put their professional and social identities on hold. Ong et al. (2021), also found that caregivers had to cope with the pain of seeing their child face discrimination due to their illness.

Table 53 Analysis of statement 2 PR-CBS

**Table 53**
**Emotional/psychological: Feeling that I am not able to 'switch off' due to my child's condition (2)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 1 | 4.8 |
| | Sometimes | 2 | 9.5 |
| | Often | 3 | 14.3 |
| | Always | 15 | 71.4 |
| | Total | 21 | 100.0 |

Table 54 Analysis of statement 3: PR-CBS

Table 54:

**Emotional/psychological: Worrying about the future (3)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Rarely | 1 | 4.8 |
| | Sometimes | 1 | 4.8 |
| | Often | 3 | 14.3 |
| | Always | 16 | 76.2 |
| | Total | 21 | 100.0 |

## Table 55 Analysis of statement 6:  PR-CBS

Table 55:

**Emotional/psychological: Blaming myself for my child's kidney problems (6)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 4 | 19.0 |
| | Sometimes | 1 | 4.8 |
| | Often | 4 | 19.0 |
| | Always | 12 | 57.1 |
| | Total | 21 | 100.0 |

## Table 56 Analysis of statement 16 PR CBS

**Emotional/psychological: Feeling troubled by difficult memories of when my child was first diagnosed or has been very ill in the past (11)**

| Table 56<br>Frequency | Percent | Percent |
|---|---|---|
| 1 | 4.8 | 4.8 |
| 1 | 4.8 | 4.8 |
| 3 | 14.3 | 14.3 |
| 16 | 76.2 | 76.2 |
| 21 | 100.0 | 100.0 |

## Table 57 Analysis of statement 12:  PR-CBS

Table 57:  Analysis of statement 12:  PR-CBS

**Emotional/psychological: Worrying about my child during the night (12)**

| | Frequency | Percent |
|---|---|---|
| Never | 1 | 4.8 |
| Often | 4 | 19.0 |
| Always | 16 | 76.2 |
| Total | 21 | 100.0 |

## Table 58 Analysis of statement 15:  PR-CBS

Table 58:  Analysis of statement 15:  PR-CBS

**Emotional/psychological: Worrying about my child getting very ill or dying (15)**

| | Frequency | Percent |
|---|---|---|
| Never | 1 | 4.8 |
| Sometimes | 1 | 4.8 |
| Often | 3 | 14.3 |
| Always | 16 | 76.2 |
| Total | 21 | 100.0 |

## Table 59 Analysis of statement 16:  PR-CBS

Table 59:

**Emotional/psychological: Feeling that other people do not understand my situation (16)**

| | Frequency | Percent |
|---|---|---|
| Never | 4 | 19.0 |
| Rarely | 1 | 4.8 |
| Often | 3 | 14.3 |
| Always | 13 | 61.9 |
| Total | 21 | 100.0 |

## Table 60 Analysis of statement 19:  PR-CBS

Table 60

**Emotional/psychological: Difficult feelings due to the uncertainty of my child’s condition (19)**

| | Frequency | Percent |
|---|---|---|
| Sometimes | 1 | 4.8 |
| Often | 3 | 14.3 |
| Always | 17 | 81.0 |
| Total | 21 | 100.0 |

Table 61 Analysis of statement 27:  PR-CBS

Table 61:

**Emotional/psychological: Feeling alone in caring for my child (27).**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 2 | 9.5 |
| | Often | 4 | 19.0 |
| | Always | 15 | 71.4 |
| | Total | 21 | 100.0 |

The above-mentioned results from the group of nine statements in the *Emotional / Psychological* domain, indicates significant burden and anxiety experienced by the caregiver.  Wightman (2020), and Wightman et al. (2019), found that caregivers felt powerless in response to the intense changes to their lives.  The new and overwhelming routines provoked anxiety and distress as they sought to adapt to their new roles caring for the child with CKD (Wightman, 2020; Wightman et al., 2019; Kari et al, 2014).

Table 62 Analysis of statement 13:  PR-CBS

Table 62:

**Caregiver Role/Identity: Feeling that my child's condition has taken over my life (13)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 3 | 14.3 |
| | Sometimes | 1 | 4.8 |
| | Often | 4 | 19.0 |
| | Always | 13 | 61.9 |
| | Total | 21 | 100.0 |

## Table 63 Analysis of statement 20: PR-CBS

Table 63: Analysis of statement 20: PR-CBS

**Caregiver Role/Identity: Feeling unable to think about my own needs (20)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 1 | 4.8 |
| | Often | 5 | 23.8 |
| | Always | 15 | 71.4 |
| | Total | 21 | 100.0 |

## Table 64 Analysis of statement 26: PR-CBS

Table 64: Analysis of statement 26: PR-CBS

**Caregiver Role/Identity: Sadness that I cannot do things that I used to do because of caring for my child (e.g. work, leisure activities, hobbies) (26)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 2 | 9.5 |
| | Rarely | 1 | 4.8 |
| | Often | 3 | 14.3 |
| | Always | 15 | 71.4 |
| | Total | 21 | 100.0 |

## Table 65 Analysis of statement 14: PR-CBS

Table 65: Analysis of statement 14: PR-CBS

**Caregiver Role/Identity: Worrying about the impact of my child's condition on my other children (14)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 2 | 9.5 |
| | Sometimes | 1 | 4.8 |
| | Often | 3 | 14.3 |
| | Always | 14 | 66.7 |
| | Total | 20 | 95.2 |
| Missing | System | 1 | 4.8 |
| Total | | 21 | 100.0 |

Table 66 Analysis of statement 35:  PR-CBS

Table 66:  Analysis of statement 35:  PR-CBS

**Caregiver Role/Identity: Sadness that I am not the person that I used to be (35)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 1 | 4.8 |
| | Rarely | 1 | 4.8 |
| | Often | 4 | 19.0 |
| | Always | 15 | 71.4 |
| | Total | 21 | 100.0 |

The cluster of results in this domain, *Caregiver Role and Identity*, comprises of the five above-mentioned statements and yielded significantly high results of caregiver burden (mean 4.37).  In most circumstances caregiving exceeds the physical, financial, and psychological resources of the caregiver and thus they are often unable to meet their own needs (Wightman, 2020).  In addition to the management of their child’s treatment, caregivers experience difficulties in balancing the needs of their child with their other responsibilities such as work, social life and the needs of other family members, thus heightening their burden (Eccleston et al., 2012; Barlow and Ellard, 2006).  Wightman et al. (2019), and Pourghaznein et al. (2018a), reported that over a period, caregivers developed patience, gained proficiency in managing their child’s illness and treatment, and sought spirituality.  Reframing their experience was critical in adapting to their new situation, gaining insight, developing resilience, and becoming advocates for their children (Wightman et al., 2019).  Wightman et al. (2019), reported that caregivers formed communities amongst themselves, and made new friendships because they spent time with each other during the children’s dialysis session (Wightman et al., 2019; Medyńska et al., 2017).

## Table 67 Analysis of statement 18: PR-CBS

Table 67: Analysis of statement 18: PR-CBS

**Impact on Family: Feeling guilty about spending less time with my other child/children/partner (18)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 2 | 9.5 |
| | Often | 3 | 14.3 |
| | Always | 14 | 66.7 |
| | Total | 19 | 90.5 |
| Missing | System | 2 | 9.5 |
| Total | | 21 | 100.0 |

## Table 68 Analysis of statement 22: PR-CBS

**Impact on Family: Feeling overwhelmed by trying to fit family life around my child's condition (22)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 1 | 4.8 |
| | Rarely | 1 | 4.8 |
| | Often | 4 | 19.0 |
| | Always | 15 | 71.4 |
| | Total | 21 | 100.0 |

## Table 69 Analysis of statement 25: PR-CBS

Table 69: Analysis of statement 25: PR-CBS

**Impact on Family: Feeling under pressure to be strong for my child and family (25)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Sometimes | 1 | 4.8 |
| | Often | 3 | 14.3 |
| | Always | 17 | 81.0 |
| | Total | 21 | 100.0 |

## Table 70 Analysis of statement 32:  PR-CBS

Table 70:  Analysis of statement 32:  PR-CBS

**Impact on Family:  Arguing with my partner/family about my child's care (32)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 1 | 4.8 |
| | Rarely | 1 | 4.8 |
| | Often | 4 | 19.0 |
| | Always | 13 | 61.9 |
| | Total | 19 | 90.5 |
| Missing | System | 2 | 9.5 |
| Total | | 21 | 100.0 |

## Table 71 Analysis of statement 34:  PR-CBS

Table 71:  Analysis of statement 34:  PR-CBS

**Impact on Family: Feeling uncertain about how to manage my child's emotions and difficult behaviour (34)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 2 | 9.5 |
| | Often | 4 | 19.0 |
| | Always | 15 | 71.4 |
| | Total | 21 | 100.0 |

## Table 72 Analysis of statement 38:  PR-CBS

Table 72:  Analysis of statement 38:  PR-CBS

**Impact on Family: Sadness that I do not have a 'normal' relationship with my child (38)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 3 | 14.3 |
| | Sometimes | 1 | 4.8 |
| | Often | 3 | 14.3 |
| | Always | 14 | 66.7 |
| | Total | 21 | 100.0 |

Table 73 Analysis of statement 51: PR-CBS

Table 73: Analysis of statement 51: PR-CBS

**Impact on Family: Sadness about the impact of my child's kidney problems on my relationship with my partner -51**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 1 | 4.8 |
| | Rarely | 1 | 4.8 |
| | Often | 3 | 14.3 |
| | Always | 16 | 76.2 |
| | Total | 21 | 100.0 |

### Impact on family:

The seven statements above pertaining to the domain, *Impact on Family*, shows how the caregiving tasks and activities contribute to role conflict resulting in a high burden for the caregiver. Primary caregivers experience burden in relationship with their partner and / or the other children due to the considerable amount of time spent on the child's medical needs and treatment regimens. Consequently, some studies found that the well-being of partners and other children were often neglected by caregivers (Ong, et al., 2021; Wightman, 2020; Kari et al., 2014). This burden increases as and when the child's illness changes such as unexpected hospitalisation, experiencing severe pain or vomiting after a dialysis session. Additional burden is placed on the caregiver, indicated by the high percentage (81%), of responses for them to be strong for the child to handle his / her illness. Caring for a child on dialysis is a source of tension within the family and negatively impacted the ability of the caregivers to care for other family members and disrupted family cohesion (Sari et al., 2018; Pourghaznein et al., 2018a; Medway et al., 2015; Kari et al., 2014; Neul, 2012; Wiedebusch et al., 2010; de Paula et al., 2008).

## Table 74 Analysis of statement 9:  PR-CBS

Table 74:  Analysis of statement 9:  PR-CBS

**Impact on Child:  Feeling helpless when my child is ill or in pain (9)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Sometimes | 1 | 4.8 |
| | Often | 3 | 14.3 |
| | Always | 17 | 81.0 |
| | Total | 21 | 100.0 |

## Table 75 Analysis of statement 30:  PR-CBS

Table 75:  Analysis of statement 30:  PR-CBS

**Impact on Child:  Sadness about the things that my child misses out on (30)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 1 | 4.8 |
| | Often | 3 | 14.3 |
| | Always | 17 | 81.0 |
| | Total | 21 | 100.0 |

## Table 76 Analysis of statement 33:  PR-CBS

Table 76:  Analysis of statement 33:  PR-CBS

**Impact on Child:  Worrying about how my child is coping (33)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 1 | 4.8 |
| | Often | 4 | 19.0 |
| | Always | 16 | 76.2 |
| | Total | 21 | 100.0 |

Table 77 Analysis of statement 36:  PR-CBS

Table 77:  Analysis of statement 36:  PR-CBS

**Impact on Child:  Worrying about the disruptions to my child's education (36)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Sometimes | 1 | 4.8 |
| | Often | 4 | 19.0 |
| | Always | 16 | 76.2 |
| | Total | 21 | 100.0 |

Table 78 Analysis of statement 45:  PR-CBS

Table 78:  Analysis of statement 45:  PR-CBS

**Impact on Child:  Worrying about my child's growth and development (45)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 1 | 4.8 |
| | Often | 2 | 9.5 |
| | Always | 18 | 85.7 |
| | Total | 21 | 100.0 |

Analysis of the five statements for this domain, *Impact on Child*, reveals that the caregiver experiences continuous worry over the deterioration of the child's health, grief over what the child's life could have been and guilt when trying to make medical decisions regarding their child's care (Pourghaznein et al., 2018a; Wightman, 2019; Kari et al., 2014). Furthermore, when caregivers thought of the child's future, they struggled with feelings of uncertainty and anxiety, and fear of the child's impending death made the caregivers feel hopeless at times (Ong et al., 2021; Whiteman et al., 2019; Pourghaznein et al., 2018a).

## Table 79 Analysis of statement 5:  PR-CBS

Table 79:  Analysis of statement 5:  PR-CBS

**CKD Treatment Responsibilities:  Worrying if my child has had the correct amount of fluid (5)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 2 | 9.5 |
| | Often | 3 | 14.3 |
| | Always | 16 | 76.2 |
| | Total | 21 | 100.0 |

## Table 80 Analysis of statement 50:  PR-CBS

Table 80:  Analysis of statement 50:  PR-CBS

**CKD Treatment Responsibilities:  Feeling preoccupied with checking my child for signs of illness (50)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 4 | 19.0 |
| | Often | 3 | 14.3 |
| | Always | 14 | 66.7 |
| | Total | 21 | 100.0 |

## Table 81 Analysis of statement 17:  PR-CBS

Table 81:  Analysis of statement 17:  PR-CBS

**CKD Treatment Responsibilities:  Blaming myself if my child gets ill or has bad test results (17)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 2 | 9.5 |
| | Rarely | 2 | 9.5 |
| | Sometimes | 1 | 4.8 |
| | Often | 4 | 19.0 |
| | Always | 12 | 57.1 |
| | Total | 21 | 100.0 |

## Table 82 Analysis of statement 39: PR-CBS

Table 82: Analysis of statement 39: PR-CBS

**CKD Treatment Responsibilities: Worrying about getting medical procedures wrong (e.g. dialysis, injections, tube feeding) or taking measurements incorrectly (39)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 2 | 9.5 |
| | Often | 5 | 23.8 |
| | Always | 14 | 66.7 |
| | Total | 21 | 100.0 |

## Table 83 Analysis of statement 29: PR-CBS

Table 83: Analysis of statement 29: PR-CBS

**CKD Treatment Responsibilities: Feeling overwhelmed by decisions that I have to make about my child's condition**
**-29**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 1 | 4.8 |
| | Rarely | 1 | 4.8 |
| | Often | 3 | 14.3 |
| | Always | 16 | 76.2 |
| | Total | 21 | 100.0 |

## Table 84 Analysis of statement 37: PR-CBS

Table 84: Analysis of statement 37: PR-CBS

**CKD Treatment Responsibilities: Feeling overwhelmed by changes in my child's usual treatment (37)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Sometimes | 2 | 9.5 |
| | Often | 4 | 19.0 |
| | Always | 15 | 71.4 |
| | Total | 21 | 100.0 |

## Table 85 Analysis of statement 39:  PR-CBS

Table 85:  Analysis of statement 39:  PR-CBS

**CKD Treatment Responsibilities:  Worrying about getting my child's medicines wrong (39)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 3 | 14.3 |
| | Often | 3 | 14.3 |
| | Always | 15 | 71.4 |
| | Total | 21 | 100.0 |

## Table 86 Analysis of statement 42:  PR-CBS

Table 86:  Analysis of statement 42:  PR-CBS

**CKD Treatment Responsibilities:  Feeling overwhelmed by feeding difficulties (e.g.  lack of appetite, managing diet restrictions, vomiting) of my child (42)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 2 | 9.5 |
| | Often | 2 | 9.5 |
| | Always | 17 | 81.0 |
| | Total | 21 | 100.0 |

## Table 87 Analysis of statement 43:  PR-CBS

Table 87:  Analysis of statement 43:  PR-CBS

**CKD Treatment Responsibilities:  Worrying about having to deal with unexpected changes in my child's condition (eg.  unexpected hospital admissions) (43)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 1 | 4.8 |
| | Often | 2 | 9.5 |
| | Always | 18 | 85.7 |
| | Total | 21 | 100.0 |

## Table 88 Analysis of statement 46:  PR-CBS

Table 88:  Analysis of statement 46:  PR-CBS

**CKD Treatment Responsibilities:   Feeling that I should be doing more for my child**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 1 | 4.8 |
| | Often | 2 | 9.5 |
| | Always | 18 | 85.7 |
| | Total | 21 | 100.0 |

## Table 89 Analysis of statement 46: PR-CBS

Table 89: Analysis of statement 46: PR-CBS

**CKD Treatment Responsibilities: Difficult feelings due to my child taking responsibility in his or her care (eg. worrying if medicines have been taken) (46)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 1 | 4.8 |
| | Sometimes | 1 | 4.8 |
| | Often | 2 | 9.5 |
| | Always | 17 | 81.0 |
| | Total | 21 | 100.0 |

## Table 90 Analysis of statement 50: PR-CBS

Table 90: Analysis of statement 50: PR-CBS

**CKD Treatment Responsibilities: Feeling preoccupied with keeping my child safe from illness (50)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 1 | 4.8 |
| | Often | 5 | 23.8 |
| | Always | 15 | 71.4 |
| | Total | 21 | 100.0 |

The above cluster of data emerging from twelve statements regarding the domain, *CKD Treatment Responsibilities,* indicates severe burden. Primary caregivers of the child diagnosed with CKD are seldom part of the decision-making of the renal team regarding for example, the treatment plan and prognosis. Due to a lack of evidence-based information from the renal team, it is no wonder that many caregivers feel overwhelmed with their new roles and making medical decisions which causes high burdens and anxiety, for example, in ensuring compliance with the child's medication regimen, dietary requirements, liquid intake, and possibilities of side effects of the medication on the child. Compliance with fluid, diet and medication are often met with strong resistance by the child (Wee et al., 2022).

## Table 91 Analysis of statement 10:  PR-CBS

Table 91:  Analysis of statement 10:  PR-CBS

**Contact with Hospital/Medical Staff:   Frustration when dealing with staff that do not know my child (10)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 2 | 9.5 |
| | Often | 5 | 23.8 |
| | Always | 14 | 66.7 |
| | Total | 21 | 100.0 |

## Table 92 Analysis of statement 23:  PR-CBS

Table 92:  Analysis of statement 23:  PR-CBS

**Contact with Hospital/Medical Staff:   Difficult feelings due to having no privacy when at the hospital (23)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 1 | 4.8 |
| | Rarely | 1 | 4.8 |
| | Sometimes | 1 | 4.8 |
| | Often | 5 | 23.8 |
| | Always | 13 | 61.9 |
| | Total | 21 | 100.0 |

## Table 93 Analysis of statement 28:  PR-CB

Table 93:  Analysis of statement 28:  PR-CBS

**Contact with Hospital/Medical Staff:   Worrying that my child may have to be admitted to hospital (28)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 1 | 4.8 |
| | Sometimes | 1 | 4.8 |
| | Often | 3 | 14.3 |
| | Always | 16 | 76.2 |
| | Total | 21 | 100.0 |

## Table 94 Analysis of statement 31: PR-CBS

Table 94: Analysis of statement 31: PR-CBS

**Contact with Hospital/Medical Staff: Feeling unable to 'switch off' when waiting for test results or a telephone call from the hospital (31)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 1 | 4.8 |
| | Often | 3 | 14.3 |
| | Always | 17 | 81.0 |
| | Total | 21 | 100.0 |

## Table 95 Analysis of statement 40: PR-CBS

Table 95: Analysis of statement 40: PR-CBS

**Contact with Hospital/Medical Staff: Feeling bored when having to spend time at the hospital (40)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 3 | 14.3 |
| | Rarely | 2 | 9.5 |
| | Often | 2 | 9.5 |
| | Always | 14 | 66.7 |
| | Total | 21 | 100.0 |

## Table 96 Analysis of statement 41: PR-CBS

Table 96: Analysis of statement 41: PR-CBS

**Contact with Hospital/Medical Staff: Holding back when I disagree with medical staff (41)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 2 | 9.5 |
| | Rarely | 3 | 14.3 |
| | Often | 3 | 14.3 |
| | Always | 13 | 61.9 |
| | Total | 21 | 100.0 |

## Table 97 Analysis of statement 44: PR-CBS

Table 97: Analysis of statement 44: PR-CBS

**Contact with Hospital/Medical Staff: Feeling frustrated when having to spend time at the hospital (44)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 3 | 14.3 |
| | Sometimes | 1 | 4.8 |
| | Often | 2 | 9.5 |
| | Always | 15 | 71.4 |
| | Total | 21 | 100.0 |

## Table 98 Analysis of statement 47: PR-CBS

Table 98: Analysis of statement 47: PR-CBS

**Contact with Hospital/Medical Staff: Worrying that I have not understood medical information (47)**

| | | Frequency | Percent |
|---|---|---|---|
| Valid | Never | 1 | 4.8 |
| | Rarely | 2 | 9.5 |
| | Often | 2 | 9.5 |
| | Always | 16 | 76.2 |
| | Total | 21 | 100.0 |

The results reflected in the eight above-mentioned statements from this domain, *Contact with Hospital / Medical Staff*, indicates significant burden (average percentage of caregivers' responses as "always" is 70,25%), regarding the hospital environment and contact with renal staff. Caregivers feel excluded from decision making regarding the care of the child. The lack of effective communication with the renal care team causes them coping fears that they are providing insufficient care for the patient. Wightman et al. (2019), found that caregivers felt guilt when making certain medical decisions or making mistakes that may lead to complications in the child's care. Furthermore, caregivers struggled to find information independently and found incorrect or overly negative information online.

A caregiver-centred approach will do much to mitigate burden that the primary caregiver experiences (Wightman, 2020; Kiliś-Pstrusińska et al., 2013a). The renal nurses spend hours with the child during dialysis sessions and can play a pivotal role in providing evidence-based information to caregivers. A communication and information sharing strategy is key to raising caregivers' awareness of treatment responsibilities and possible challenges associated with paediatric CKD caregiving, particularly at the early stages of the child's illness. Information is critical in aiding the caregiver make decisions about medical routines that best fit their needs, the family's needs, and will enable better care to the child (Wee et al., 2022; Pourghaznein et al., 2018a). However, similar to findings from Ong et al. (2021), this cohort of caregivers also found a lack of formal support from healthcare staff as reflected by 76.2% of caregivers stating that they did not understand the medical information from staff and that there was little opportunity to get clarity.

### 4.11.3 Findings and interpretation of results from the caregiver semi-structured questionnaire: Practices that could assist to alleviate Caregiver Burden

This section of the study analyses the information gathered regarding the current and future support needs of participants, which could contribute to alleviating caregiver burden. Owing to the serious nature of the disease and the incapacity of children to undertake the complex treatment protocols, paediatric CKD patients need comprehensive support from their caregivers, which contributes to the caregivers experiencing physical, psychosocial and financial burden.

It is not only the availability of dialysis for the child who has CKD but in order for the patient to derive benefit from the treatment regimen, he / she has to be compliant with the full spectrum of medical processes and dietary needs. For this to happen, the role of the caregiver is paramount. The relationship between the caregiver and patient can best be seen as a symbiotic one in that the support afforded to the caregiver to cope with and ameliorate caregiver burden is necessary for healthy outcomes for both the patient and the caregiver.

The following Table indicates the scoring codes used in this study:

Table 99 The scoring codes for the PR-CBS

Table 99: The scoring codes for the PR-CBS

| | Code |
|---|---|
| Strongly disagree | 1 |
| Disagree | 2 |
| Neutral | 3 |
| Agree | 4 |
| Strongly agree | 5 |

Table 100: Summary of the scoring patterns for support needs indicated by the caregivers.

| | | **Count** | **Mean** | **Standard Deviation** | **Median** | **Maximum** | **Minimum** | **Binomial p-value (cut-off = 3.00)** |
|---|---|---|---|---|---|---|---|---|
| E1 | Dedicated times for self-care (e.g. for exercise) | 21 | 4.90 | 0.30 | 5.00 | 5.00 | 4.00 | < 0.001 |
| E2 | Continuous education and information from the treatment centre (e.g. managing the disease as it progresses) | 21 | 4.95 | 0.22 | 5.00 | 5.00 | 4.00 | < 0.001 |
| E3 | Family or friend support (e.g. physical or emotional) | 21 | 4.67 | 0.91 | 5.00 | 5.00 | 1.00 | < 0.001 |
| E4 | Financial support from friends, family or government grant | 21 | 4.38 | 1.43 | 5.00 | 5.00 | 1.00 | 0.001 |
| E5 | Support group for caregivers of children with CKD | 21 | 5.00 | 0.00 | 5.00 | 5.00 | 5.00 | < 0.001 |
| E6 | Faith-based or spiritual practices | 21 | 4.71 | 0.78 | 5.00 | 5.00 | 2.00 | < 0.001 |
| E7 | Other practices that I use to cope with my caregiving burden. | 21 | 4.86 | 0.48 | 5.00 | 5.00 | 3.00 | < 0.001 |

A similar finding to a study by Swallow et al. (2014), found that all (100%) of the respondents, in this study, (mean score: 5,00) felt that a social network with other caregivers would be helpful to manage the burdens, as they understood the particular circumstances. Caregivers of children on dialysis meant that they put their professional and social identities on hold and their lives became focussed on caring for the ill child, leaving little time for social interaction or recreational activities (Jacoby et al., 2018; Pourghaznein et al., 2018a). Similarly, in this study fifteen (71.4%) participants experienced loneliness and isolation, increasing burden, anxiety and social dysfunction. The renal nurses could play a key role in linking caregivers to paediatric CKD caregiver support groups.

Caregivers should accept offers of help from family and friends even for non-CKD treatment tasks, such as doing household tasks. They should delegate to friends and family that they trust (and after some demonstration) for undertaking some of their CKD-related duties and/or transport to the renal unit. A high mean score of 4,90, p =<0.001 shows that this should provide dedicated self-time for them to undertake much needed gym visits or other personal activities. Psychologists / social workers at the renal unit, can play a role in advising the caregiver of how to delegate tasks to achieve dedicated time for self-activities.

A significant high mean score of 4.95 indicates that most caregivers would appreciate sufficient details to understand the disease, treatment options, CKD treatment processes, and resources available for them. This will enable them to make informed decisions (Geense et al., 2017) and would do much to mitigate fears, uncertainties, confusion, and anxiety. Government and / or private partnerships could develop information booklets available in various languages and formats, and links to useful internet sites to address gaps, misinformation and misunderstandings that create burden in caregivers. The staff at the renal unit could then disseminate such literature and enter into further discussions during scheduled information sharing sessions.

Similar to the results in this study, (Wightman et al., 2019) found that caregiver burdens are likely highest among caregivers of young children on dialysis (84% in this study; mean age of 10.59 years), and among those with the fewest available external resources and support. Financial burden in this cohort of respondents, with a mean income per month of R6,672.50, is heightened by the fact that 62,3% did not have a stable monthly income: more than thirty percent (33,3%) did not receive an income at all and were either unemployed or homemakers, whilst 29% had part-time employment). The cost of travel, dietary restrictions and other household expenses all contributes to the constant strain on family finances (Wightman et al., 2019; Pourghaznein et al., 2018; Sari et al., 2018; Cimete, 2002; Dracopoulos and Weatherly, 1983). A mean of 4.38 of respondents indicated that funding from government, or financial support from family and friends would contribute to alleviating financial burden of the cost of providing CKD care for the ill child. Modi et al. (2021), found that compared to children with other chronic diseases, the financial burden of children with CKD was reportedly greater as they were hospitalised 12 times more often and incurred higher medical costs.

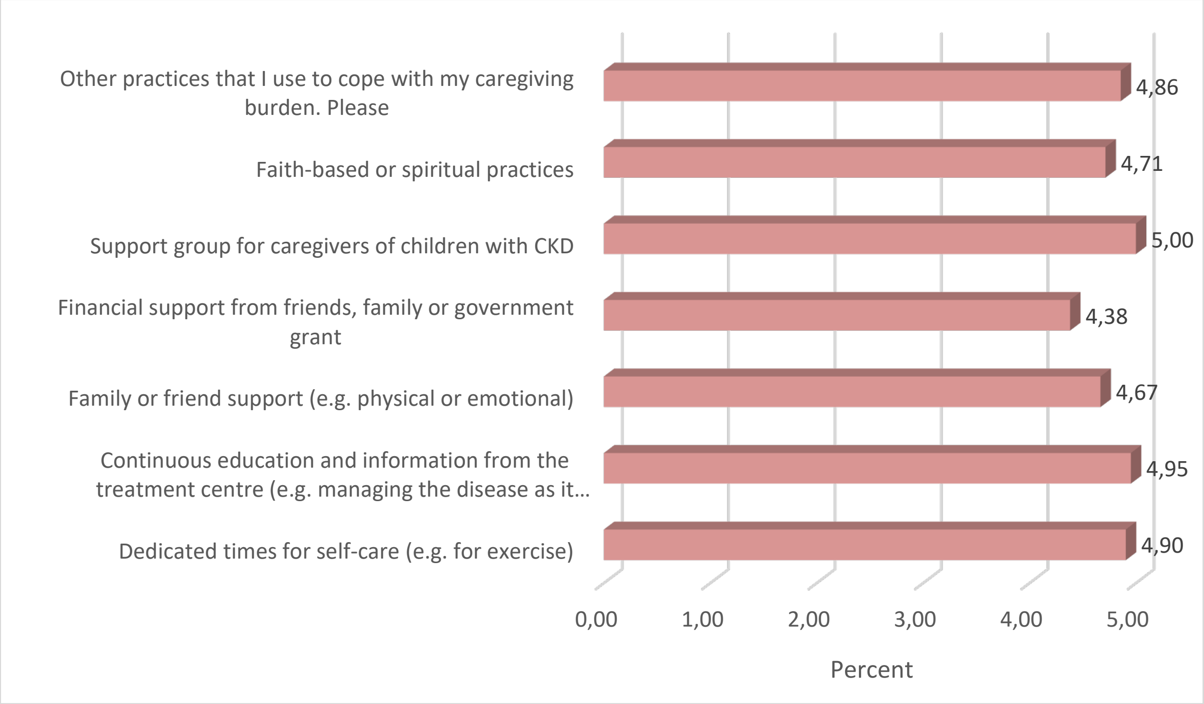


Figure 7: The mean scores for the types of interventions needed by paticipants

The mean scores are all significantly closer to 5 (high level of agreement). This implies that all of the strategies could assist with easing the burden of looking after the patient. In general, caregivers expressed that external support was insufficient to counter the overwhelming demands of caregiving to meet their information, physical, psychosocial, and emotional needs.

#### 4.11.3.1 Categories of support to alleviate caregiver burden

Several researchers have suggested that support needs of the caregivers in the following broad categories: emotional, informational, spiritual, and practical (Geense et al., 2017; Wong et al., 2014; Hudson and Aranda, 2013; Epiphaniou et al., 2012).

4.11.3.1.1 Emotional needs: namely, psychological support and coping skills from the nurses, nephrologists, and social workers. High levels of social support correlated with higher positive outcomes, less distress and better health in caregivers (Pakenham and Bursnall, 2006; Haley et al., 1996). Bauer et al. (2020), found that educational programmes and programmes such as stress management, were associated with better self-management. El-Abbassy et al. (2015), demonstrated improvements of the PR-CBS score among 50 caregivers of children on HD in Egypt, after an intensive 10-week intervention focused on developing coping strategies.

4.11.3.1.2 Practical support needs: for some caregivers, the costs associated with dialysis for the child could cause debt and / or poverty for the family (Reddy et al., 2022; Wightman et al., 2019). In developing countries such as South Africa, which is resource-scarce, it is not feasible to fully meet the needs of the caregiver in this patient population. Financial support from government, family members or friends is reflected in the significantly high mean of 4,38 and would do much to alleviate burden in this domain. Family caregivers in Australia, for example, might receive support in the form of caregiver’s allowance, emotional information and psychological support (Family Caregiver Alliance, 2011; Australian Government, 2010). In the USA, Medicare also provides home health care to patients requiring dialysis services (Cruz, 2016). These types of assistance provide substantial relief to primary caregivers who will then not have to pay out of pocket costs associated with health care needs of the ill child. In this study, the cost of the dialysis and medication is provided by the government for indigent patients and is based on a sliding scale for those who have an income. In Nigeria, for example, family caregivers bear all the costs associated with caregiving for CKD patients without any form of assistance from the government (Oyegbile, 2017; Arogundade, 2013). However, to mitigate burden, nephrologists should advocate to government, as a start, to provide funding for psychologists, social workers and respite support for caregivers (Wightman et al., 2019). The mean of 4,67 stating that friends or family can provide physical or emotional support is consistent with other studies, where caregivers felt that practical help, even doing household chores, would give them time for much-needed respite (Medway et al., 2015).

4.11.3.1.3 Informational needs: Nephrologists must educate primary caregivers and fully engage them in informed, shared decision making about the child's treatment regimen (Wightman et al., 2019). Caregivers consistently request for more information, for example, about the child's disease status, treatment, prognosis, and available resources. In addition, caregivers felt that the renal team could give more information on, for example, infectious complications, how to prepare meals for the child's restricted diet and anticipated costs of dialysis and possible sources of funding. Parents also wanted information pertaining to complications of dialysis and managing their child's psychological and behavioural problems (Tong et al., 2010). This can easily be provided in the form of information sheets, and ongoing dialogue with the caregiver and the renal-care team. Ideally information should be provided in different languages and in easy to understand visual, verbal and hardcopy formats for reference later on by the caregiver.

4.11.3.1.4 Social support: Erez et al. (2022); and Tong et al. (2010), found some caregivers gained external sources of emotional support from other dialysis caregivers and online paediatric caregiver support groups. Support groups reduce the caregivers' sense of isolation, and they benefit by learning coping skills from each other, for example, skills related to nutrition and medical management (Cimete, 2002). Support groups help caregivers cope with difficulties encountered during all stages of the child's illness (Tong et al., 2010). Specifically, caregivers noted that opportunities to share information and their experiences within their social network positively influenced their adjustment and outcomes (Kita and Ito, 2013; McCausland and Cavanaugh, 2001). Methods to reduce caregiver burden include intervention programmes to increase disease awareness, psycho-educational programmes, and communication skills were also found to be beneficial (Javalkar et al. (2017; Tong et al., 2010). 100% of the respondents felt that a social network with other caregivers / parents of children with CKD would be helpful to manage the stress and burden as they understood the unique circumstances; this is a similar finding to a study by Swallow et al. (2014). The renal nurses could play a key role in linking caregivers to paediatric CKD caregiver support groups.

4.11.3.1.5 Spiritual and religiosity can be considered as an avenue to provide support and respite for caregivers. Wightman et al. (2019), Bravin et al. (2019), Pourghaznein et al. (2018b), found that religiosity and spirituality restore hope and assists with coping, minimizing depression associated with caregiving. Attending church services and upholding religious practices and values allowed caregivers to maintain a life separate from caregiving, which they considered important (Thornton and Hopp, 2011).

It is evident that a multi-dimensional approach be adopted as the effectiveness of strategies may vary depending on the situation and the burdens encountered.

#### 4.11.3.2 Biographical Impacts on the sub-dimensions

An independent samples test was done with Kruskal Wallis 1-way Anova to determine whether there was a statistically significant relationship between the biographical factors and the mean sub-dimension scores. The null hypothesis states that there is no difference in the mean values across the categorical options. The alternate hypothesis indicates that there is a difference.

Table 101 A summary of the results of the chi square tests PR-CBS.

**D_B across Gender**

**Independent-Samples Kruskal-Wallis Test Summary**

| | |
|---|---|
| Total N | 21 |
| Test Statistic | 10,667[a,b] |
| Degree Of Freedom | 1 |
| Asymptotic Sig.(2-sided test) | 0.001 |

a. The test statistic is adjusted for ties.

b. Multiple comparisons are not performed because there are less than three test fields.

The p-value between "D_B (Financial)" and "Gender" is 0.001. This means that there is a significant difference in the way males and females interpreted financial burden. An examination of the mean scores indicates that females felt higher financial burden (mean = 5.00) compared to males (mean = 4.40).

All p-values more than 0.05 did not have a significant difference.

#### 4.11.3.3 Correlations

Bivariate correlation was also performed on the data where the positive values indicated a direct proportional relationship between the variables and a negative value indicated an inverse relationship. All significant relationships are indicated by a * or **. The results indicate the following patterns:

For example, the correlation value between "C_B (Distress/mood)" and "C-C (Social dysfunction/lack of confidence)" is 0.786 and is directly related proportionally. Results indicate that the greater the levels of distress experienced by respondents, the more dysfunctional respondents would be, and vice versa.

Negative values imply an inverse relationship. That is, the variables have an opposite effect on each other. That is, as one increases, the other decreases. For example, the correlation value between "C_A (Anxiety/depression)" and "D_A (Physical)" is -0.585. That is, the less the physical burden experienced, the respondent's anxiety levels decrease. The correlation value between "C_B" (Distress/Mood) and "D_B" (Financial) is -0.627 indicating that the greater financial challenges increases the distress of the caregiver. When caregivers interact with the renal healthcare team "D_I" (Contact with hospital/medical staff) and "C_B" (Distress/mood) a significant correlation value is -0.715 indicating severe distress.

From the findings the caregivers clearly identified areas of interventions that could support them to alleviate burden. In addition, this cohort suggested coping strategies that would be useful to them to address their anxiety and burdens. However, further quantitative studies need to be undertaken in this area. Participants stated that there was a general lack of communication, continuous education, and information from the renal unit (mean: 4,95). Limited information was provided after the initial diagnosis was made and this related mainlynto the administrative aspects of managing the disease such as number of dialysis sessions, type of diet, and liquid intake. There was no mention regarding the topic of caregiver burden or availability of psychologists or social workers that they could speak with about the burden, anxiety and social dysfunction they experienced. Most caregivers would appreciate sufficient details to understand the disease, treatment options as the disease progresses and resources that could assist them in their caregiver roles. This will enable them to make informed decisions (Geense et al., 2017).

It is vital that the renal team (nephrologists, renal-care nurses, social workers, dieticians and psychologists), include primary caregivers in all medical decision-making about the child's treatment plan, prognosis, and development and these caregiver-centred discussions should describe the practical demands that will be placed on the caregiver (Wightman, 2020). Caregiver burden must be incorporated in the child's treatment regimen and information should be evidence-based and as much as possible be tailored for each family's particular situation. There should be open and transparent dialogue to prevent the caregiver feeling overwhelmed with the plethora of new caregiving roles and responsibilities.

### 4.11.4 Findings and interpretation of results from the staff semi- structured questionnaire: Staff communication methods and information sharing with the caregivers

#### 4.11.4.1 Introduction

This section presents the results and discusses the findings obtained from the semi-structured questionnaires for staff input for this study. This was used to elicit feedback from the renal staff as to the type of communication and informational support provided and / or available to the caregivers. The semi-structured questionnaire was the primary tool that was used to collect data and was distributed to 10 renal staff members in the unit. The data collected from the responses was analysed with SPSS version 28.0. The results will present the descriptive statistics in the form of frequency tables and cross tabulations for the quantitative data that was collected. Inferential techniques include the use of chi square test values, which are interpreted using the p-values. The traditional approach to reporting a result requires a statement of statistical significance. A p-value is generated from a test statistic. A significant result is indicated with "$p < 0.05$".

Owing to the complex nature of CKD in paediatric patients, the role of the paediatric renal team (Nephrologists, nurses, dieticians, social workers, and psychologists) is vital to manage their condition. Chronic kidney disease in children is associated with complications that require nursing interventions in both the inpatient and outpatient settings. The renal team need to implement acute and preventive care strategies owing to the progressive nature of the disease and the complexity of the treatment regimen. They need to equip families for the challenges of managing the child’s long-term care by educating them about the importance of and complying with prescribed medications, diet and follow-up sessions. Planning for the child’s future therapies, providing guidance on immunisation and growth development, are important roles for the renal nurses in management of the child's chronic illness (Miller and MacDonald, 2006).

The role of the social worker assists with family adapting to and coping with having a child with CKD, they monitor the child's school performance and provide assistance if the child or caregivers have any concerns. The renal dietician plays an integral role in managing the child's CKD by providing nutrition education to the patients and caregivers. It is vital that the child's liquid, phosphorus, sodium and potassium intake be monitored; the dietician also provides guidance regarding phosphate binders and increasing calorie intake, the importance of reading labels, advice on school lunches and meal preparation. The dietician optimises dietary intake and nutritional status by assessing body composition, growth and patient data to modify the nutritional plan of care for the child as the need arise.

#### 4.11.4.2 The sample

In total, 10 questionnaires were despatched and 10 were returned which gave a 100% response rate.

#### 4.11.4.3 The research instrument

The research instrument consisted of 18 items, with a level of measurement at a nominal level.

#### 4.11.4.4 Analysis

Responses for the staff semi-structured questionnaire were statistically analyzed to show what communication and informational support / strategies are available. In addition, consideration of possible improvements by the renal staff to mitigate the burdens experienced by the primary caregiver is suggested.

The results of the semi-structured questionnaire and analysis are indicated below:

Table 102 The occupation of the staff

| | Frequency | Percent |
|---|---|---|
| Clinical Technologist | 6 | 60.0 |
| Registered Nurse | 4 | 40.0 |
| Total | 10 | 100.0 |

There was no significant difference in the composition ($p = 0.527$), with the ratio of Clinical Technologists to Nurses being 3: 2 (60.0%: 40.0%). Nurses and Clinical Technologists provide inpatient care for children with CKD. They play an important role in the treatment of acute complications as well as in the implementation of strategies for lifelong management of CKD and its comorbidities (Miller and MacDonald, 2004). It is important for the nursing staff to ensure that the family understands that CKD is a chronic, lifelong condition, regardless of the treatment selected for the child.

Table 103 Formal instrument to assess the caregiver attributes.

| | No | | Yes | | Chi Square p-value |
|---|---|---|---|---|---|
| | Frequency | Percent | Frequency | Percent | |
| Knowledge | 8 | 80.0 | 2 | 20.0 | 0.058 |
| Skills | 8 | 80.0 | 2 | 20.0 | 0.058 |
| Attitudes | 8 | 80.0 | 2 | 20.0 | 0.058 |

In all categories, 8 of the 10 respondents indicated that instruments to assess knowledge, skills and attitudes for their new roles as caregivers, were not available (p = 0.058). However, as indicated in the previous section 4.11.3 above, all caregivers indicated that there was little to no communication and ongoing information pertaining to the child's illness nor was any information provided about possible burdens that they could experience or resources to help alleviate them.

The manner of how caregivers were advised about the caregiving tasks of the child with CKD is shown in the Table 104 below.

Table 104: Educational strategies used by staff for advising caregivers

| | No | | Yes | | Chi Square p-value |
|---|---|---|---|---|---|
| | Frequency | Percent | Frequency | Percent | |
| Verbal, informal sessions | 0 | 0.0 | 10 | 100.0 | - |
| Written information | 7 | 70.0 | 3 | 30.0 | 0.206 |
| None | 10 | 100.0 | 0 | 0.0 | - |
| Other | 10 | 100.0 | 0 | 0.0 | - |

All of the respondents indicated that advice was done verbally, with 30.0% being given as written information. Education of risk factors that worsen the progression of CKD is provided to caregivers by the renal staff. Dietary restrictions are an important part of comprehensive management of CKD patients, and the caregivers are encouraged to manage the liquid intake to improve the quality of healthy lifestyles among CKD patients. Geense et al. (2017), found that caregivers who were not fully informed about the child's condition, by the health professionals, searched on the Internet for additional information and often this is overwhelming, incomprehensible or unreliable.

Table 105 below, indicates the manner of communication fostered to address any concerns of the caregiver (outside the scheduled dialysis sessions).

Table 105: Communication strategies used by staff for caregivers

| | No | | Yes | | Chi Square p-value |
|---|---|---|---|---|---|
| | Frequency | Percent | Frequency | Percent | |
| Make an appointment to address issue/s | 1 | 0.0 | 9 | 100.0 | 0.011 |
| Telephonically | 6 | 70.0 | 4 | 30.0 | 0.206 |
| Electronically | 10 | 100.0 | 0 | 0.0 | - |
| None | 10 | 100.0 | 0 | 0.0 | - |
| Other | 10 | 100.0 | 0 | 0.0 | - |

To discuss any aspect regarding the child's illness, significantly more renal staff used appointments (90.0%), whilst 30.0% of the respondents indicated that these were done telephonically.

Caregivers who expressed trust in the medical team viewed their time spent in the medical environment as a time of respite, support, understanding and friendship. Conversely, caregivers who reported distrusting the medical team were unable to accept support from the dialysis staff and described their experiences in the medical environment as stressful and isolating. (Wightman et al., 2019). Unfortunately, this latter statement was experienced by more than two thirds of the caregivers in this study. More than sixty percent (66.7%) felt frustrated when dealing with the staff; 62% revealed that there was no privacy at the hospital to address concerns with staff and or when disagreeing with staff; and most worrying is that 76.2% worried that they did not understand the medical information when they left the hospital. This lack of open communication and evidence-based information sharing increased the burden experienced by the caregiver.

The renal nurses spend many hours with the child during the dialysis sessions and thus could play a pivotal role in teaching caregivers how to manage and troubleshoot challenges that arise (Pourghaznein et al., 2018a; Fraser et al., 2015). The identified areas of burden are especially significant as they provide a signpost for the renal nurses to provide appropriate, timely information for caregivers who are new to the CKD roles and responsibilities. Nurses need to provide evidence-based information to caregivers which will enable them to make decisions that best fit their needs, cope better with certain challenges and provide better care for the patient.

The responses to “Are there interventions/counselling within the Renal Unit that assists the caregiver manage their caregiver burdens to improve overall patient outcomes?” are shown in Table 106 below:

Table 106 Intervention strategies used by staff to assist caregivers

| | Frequency | Percent |
|---|---|---|
| No | 8 | 80.0 |
| Yes | 2 | 20.0 |
| Total | 10 | 100.0 |

Although all respondents were from the same renal unit, only 2 of the 10 respondents were aware of indicated that there were some interventions in place. These interventions were identified as follows:

Health Education, catheter and fistula care, the availability of social worker (n = 1), and dietician (n = 2).

In terms of suggested strategies that can provide interventions to assist the caregiver manage their burdens to improve overall patient outcomes, all 10 respondents indicated that education about the disease, the affects it can have on the child and on the caregiver, and psychological support should be provided to caregivers. Regarding emotional support needs, many studies noted the importance of the supportive role of the dialysis team, particularly the nurses and social workers (Wightman et al., 2019; Kari et al., 2014; Tong et al., 2010). However, in this study, only two staff had knowledge of some of the interventions that could help the caregiver. The role of the social worker is crucial, for example, to follow up when dialysis sessions are missed and to provide emotional support for both the patient and caregiver.

This study, like previous studies (Saban et al., 2016; Kari et al., 2014; Tong et al., 2010; Aldridge, 2008; Tsai et al., 2006), show that processes for how the caregiver are informed about the disease diagnosis, how they are counselled about the options for treatment modalities and / or the entire treatment regimen, is inadequate or lacking. Caregivers in this study (100%) revealed that they were informed verbally about the diagnosis: and only the dialysis process, diet and liquid restrictions were discussed. Receiving a CKD diagnosis for a child and initiating dialysis treatment is a shocking experience (Wightman et al., 2019), yet there is no formal assessment of caregiver burden at the renal unit used in this study, nor a formal session to prepare them for their new roles and responsibilities.

A multi-professional team should be provided in a comprehensive tertiary renal centre. The KDIGO clinical practice guidelines “Care of the patient with progressive CKD” suggested that the multidisciplinary team should include, and the patients and caregivers should have access to, dietary counselling, education and counselling about different RRT modalities, transplant options, vascular access surgery, and ethical, psychological and social care (KDIGO,2013). However, similar to this study, Sari et al. (2018), found that this recommendation was not fully implemented owing to over-worked healthcare professionals and economic considerations which may provide challenges to implementing the KDIGO recommendations.

#### 4.11.4.5 Cross tabulations

A Chi square test of independence was performed to determine whether there was a statistically significant relationship between the variables (rows vs columns).

The null hypothesis states that there is no association between the two. The alternate hypothesis indicates that there is an association.

The table summarises the results of the chi square tests.

For example: The p-value between “Knowledge” and “Occupation” is 1.000. This means that there is no significant relationship between the variables highlighted in yellow. That is, the different occupations of the renal staff did not play a significant role in terms of their CKD knowledge and skills.

Table 107: Knowledge of staff at the Renal Unit

| | | | Occupation | | Total |
|---|---|---|---|---|---|
| | | | Clinical Technologist | Registered Nurse | |
| Knowledge | No | Count | 5 | 3 | 8 |
| | | % within Occupation | 83.3% | 75.0% | 80.0% |
| | Yes | Count | 1 | 1 | 2 |
| | | % within Occupation | 16.7% | 25.0% | 20.0% |
| Total | | Count | 6 | 4 | 10 |
| | | % within Occupation | 100.0% | 100.0% | 100.0% |

There is no significant difference in the scoring patterns between clinical technologists and nurses with respect to their CKD knowledge. It is important for the nursing staff to ensure that the family understands that CKD is a chronic, lifelong condition regardless of the treatment selected. Nurses equip families for the challenges of managing the child's long-term care by educating them about the importance of understanding and complying with prescribed medications and frequent physician/hospital visits.

Interaction with renal staff, in this study, revealed a mean of 4.34; SD-1.02, indicating that this area needs urgent improvement. Caregivers reported that there was a lack of formal communication and information systems in place. Caregivers indicated that they expected and would appreciate more detailed information about the child and the progression of the disease and the future of the child, information on resources such as financial, social workers / counselling and peer support groups, for example. Caregivers have found that the renal staff do have good interaction with the child and provide good CKD dialysis care. However, caregivers suggest that the renal staff should share information with them and provide opportunities for queries to be discussed. Nurses are at the forefront of renal care of these patients and can play a pivotal role in advocating for a caregiver-centered approach because they play a critical role in the child's life and compliance with the treatment (Leung, 2022; Angelo et al 2014).

## 4.12 Commentary on the use of the four instruments

### 4.12.1 PR-CBS and GHQ - 12

In this study the PR-CBS findings established that caregivers experienced high levels of burden across all domains, ranging from the highest (Financial ) being a severe burden with a mean score of 4,86 and SD 0.36; to moderate burden (Social), with a mean of 3,29, similar to results in a study by Raina et al. (2004). This study demonstrates the usefulness of PR-CBS as a quantitative tool to capture caregiver burden. In this study the mean PR-CBS score revealed a moderate to very severe burden on all domains associated with care, with a total mean burden score of 220.14; SD=41.74.

The use of the GHQ-12 enhanced the findings of the PR-CBS and gave better insight into the caregiver experience. The prevalence of moderate to severe in the three domains of anxiety, distress and social dysfunction, in this study, is similar to research results from El-Metwally et al. (2018), and Kiliś-Pstrusińska et al. (2013a).

Analysis in the present study using the GHQ-12 scale found that with a mean of 0.71, caregivers had moderate burden in the Social Domain, with SD being 1.28; a mean of 0.85 showed that they had severe burden in the Distress / Mood Domain and a mean of 0.95 indicates a very severe and high burden in the Anxiety / Depression Domain.

There was no significant correlation between GHQ-12 and PR-CBS and caregivers' age, education, and marital status and frequency of burden. The correlation between the two instruments and distance between place of residence and associated travel costs and the renal center was not investigated.

Over 85.7% of primary caregivers in this study received a GHQ - 12 mean score of 0.95 indicating the occurrence of very high anxiety and depression. The results of this study are similar to other research that show in general, higher scores of burden, anxiety and social dysfunction are found in female caregivers, and mothers as caregivers of children with CKD achieve low physical, emotional and daily functioning (Bauer et al., 2020; Wiedebusch, et al., 2010). The results may signal anxiety, depression and loss of confidence as a reaction to difficulties and the inability to fulfill their own goals and objectives. This indicates the strong need for psychological care for the caregivers (Wee et al., 2022; Wightman et al., 2019).

A statically significant correlation was found between the two instruments and gender. The total mean burden score for the PR-CBS for females was significantly higher than that for males (11.30; SD = 6.11 vs 7.83; SD = 4.70; p = 0.005). This is confirmed by the total mean burden score declared by females for GHQ – 12, which was also significantly higher than that declared by males (6.58; SD = 2.83 vs 3.75; SD = 1.80; p = 0.03).

Nijboer et al. (1999), found that caregiving included both positive and pessimistic aspects of providing care. In relation to this view, some caregivers felt that the knowledge and experience gained over time, due to the number of years of caregiving to the child with CKD (greater than 3 years, in this study), enabled them to make informed decisions and perform their roles with proficiency (Wightman et al., 2019; Pourghaznein et al., 2018a); and thus to a certain extent were able to reduce their fears, uncertainties, and anxiety.

Furthermore, Wightman et al. (2019), established that caregiving provided opportunities for building relationships and closer bonds between the sick child, the family and caregivers, and Nicholas (2017), found that families gathered strength and found comfort in being optimistic about their situation and their child's future). Wightman et al. (2020), found that caregivers recognised the benefits of dialysis treatment of the child continuing life within a loving family, far outweigh the heavy burden created in many areas of their lives.

### 4.12.2 Questionnaires pertaining to caregiver needs and staff information and communication:

To the researcher's knowledge, this is the first time that such instruments were used to elicit perspectives from the primary caregiver and the renal team about the caregiving experiences. Undoubtedly, the pediatric renal team has a key role in presenting the initial diagnosis to the caregiver and family; informing them about the treatment regimen pertaining to medication and dialysis; and special dietary needs for the child. All the caregivers in this study acknowledged that this information was verbally given to them.

All the caregivers in this study indicated that they were not informed about the burden, anxiety and social dysfunction that they might experience, and they were not fully prepared for their roles, nor were they given ongoing information about the child's condition or unexpected illnesses that could occur in the child. An increase in the awareness and knowledge of the burden and anxiety experienced by the caregiver would assist renal staff to suggest appropriate coping and support strategies for the caregiver. Financial challenges are the leading cause of burden in this cohort of participants and caregivers would appreciate information on availability of financial resources to support their caregiving roles. This is similar to findings by research of Reddy et al., (2022); Wightman et al., (2019); Bello et al., 2018; Medway et al.,( 2015).

Determining which caregiving activities contribute the most to the burden experienced by the primary caregiver, could help the renal team, including social workers, to provide more suitable support for the caregivers.  Studies demonstrated that caregivers who perceive their social support to be high, experienced decreased levels of burden (Adejumo et al., 2019; Hoang et al., 2018).  Since caregivers experience social isolation, social support programmes have been reported to help caregivers develop coping strategies, reduce the sense of isolation and these groups acted as a powerful tool to improve self-efficacy amongst the caregivers and could thus assist in reducing the burden of caregiving (Adejumo et al., 2019; Kuhn et al., 2003).  The renal healthcare team could play a role in linking caregivers to paediatric CKD caregiver support groups.

Nurses need to acknowledge that ignorance of the disease and its progression exists and may cause fear and uncertainties for the caregiver (Eslami et al., 2016; Sajjdi et al., 2015; Sandy et al., 2013).  Caregivers (mean 4.95, SD = 0.22) expressed the need for more information to increase their knowledge of the child's CKD.  Nurses should educate family caregivers, for example, the different needs that emerge as the disease progresses, provide information on available support groups, teach coping skills to enable caregiver to manage their burden and increase the caregiver competencies (Hudson et al., 2013).

Caregivers play a vital role in reducing costs and resources on the healthcare system by caring for the patients at home.  Therefore, it is essential to take care of caregivers to reduce the long-term negative effects of caregiver burden.  Nephrologists and the renal team should see the caregivers as an important part of the management of the child with CKD.  Therefore, they should include them in the management plans of the paediatric patient.  As mentioned previously, caregiving is complex and multidimensional, and the results from this section of the study provided a signpost for key interventions to improve the quality of life of the caregiver and the overall outcomes of the child.

## 4.13 Conclusion

This study revealed the primary caregiver are the biological mothers of the patient (81%) and that females (76.2%) are the majority of the primary caregivers who experience multiple burdens, anxieties and social dysfunction. These include, for example, worry about the child's development and well-being, fears about the progression of the disease, constant vigilance regarding medication regimens and fatigue due to the demands of daily caregiving which contributes to burdens and anxiety in caregivers.

The findings indicate that a multi-dimensional approach is needed to mitigate caregiver burden. The use of a holistic tool for the periodic assessment of caregiver burden; a communication model between the renal team and caregiver; and a support / coping strategy is necessary to remediate the burden, anxiety and social dysfunction experienced by the caregiver and will contribute to positive outcomes for both the caregiver and the child with CKD.

# 5 CHAPTER FIVE
# DISCUSSION

## 5.1 Introduction

The present study investigated the burden of care amongst caregivers of children with CKD in a single-center paediatric renal unit, located in KZN. The results from this study regarding the lived experiences among caregivers of children with CKD, are consistent with those described in literature: for example, the psychological and emotional challenges (Kiliś-Pstrusińka, et al., 2013a; Parham, 2011; Swallow et al., 2011; de Paula et al., 2008; Tong et al., 2011; Tsai et al., 2006); the burdens related to the child's treatment (Swallow et al., 2011; Tong et al., 2010; Abrahao et al., 2010; Tong et al., 2008; Cimete, 2002); the financial consequences (Chotia, 2023; Erez et al., 2022; Wightman et al., 2019; Bello et al., 2018; Sari et al., 2018); and physical deterioration (Lima et al., 2019; Wightman et al., 2019; Pourghaznein et al., 2018a; de Paula et al., 2008). Furthermore, this study echoed previous studies of lack of coping / support mechanisms for caregivers (Erez et al., 2022; Lima et al., 2019; Geense et al., 2017; Aldridge, 2008).

## 5.2 Discussion of findings

The study findings revealed that, similar to other studies (Wee et al., 2022; Oyegbile and Brysiewicz, 2017a; Lomba et al., 2014; Aldridge, 2008), the majority of primary caregivers were females (76,2%). This could be due to several factors, for example, it could reflect societal and cultural demands on females, particularly in Africa, to be the primary caregiver (Adejumo et al., 2019).

Eighty one percent were biological parents of the patients and lived in the same residence with the patients. A study among Swedish family caregivers of patients living with chronic illness highlighted that "illness is perceived as being a family affair, and that whatever happened to one happened to all, thus increasing the understanding and acceptance of behavioural responses accompanying the disease" (Årestedt et al., 2014).

The mean age of caregivers was 38.4 years with majority (76,1%) of participants aged between 30 years to 49 years old. These findings are comparable to a study conducted in Iran by Adib-Hajbaghery and Ahmadi (2019), who found that more than half of the caregivers (51.5%) were aged between 30 to 50 years. Similarly, Adejumo et al (2019), in a study conducted in Nigeria also revealed that the average age of caregivers was 43 years.

Like other studies, caregivers, mainly females, (76,2%), in this study experienced the most financial burden (Erez et al., 2022; Reddy et al., 2022; Wightman et al., 2019; Sari et al., 2018; Bello et al., 2018). This study revealed that none of the caregivers were paid for their services. This is a similar finding to a study by Adejumo et al. (2019), in which 98,2% of caregivers were not paid for their caregiving services. In addition, regular dialysis sessions mean that the caregivers must ensure that they are available to take the child for the thrice per week, three hourly dialysis sessions. Thus, the caregiver may be limited in being employed as the child is fully dependent on them for compliance with CKD protocols. This is consistent with previous studies (Wightman et al., 2019; Bello et al., 2018; Jacoby et al., 2018; Medway et al., 2015; Kari et al., 2014; Mieto and Bousso, 2014).

Wightman (2019), expressed the view that it is the youngest children on dialysis, who cause the highest burden experienced by caregivers, and the burden is usually among caregivers who have the fewest available external resources and support. The results for this study show similar results with most paediatric patients on HD with the average age here, being 10.59 years, suggesting a cause for high burden in the caregiver.

The paediatric patients age ranged from 2 years to 18 years. These findings differ from those in a study in Iran which found that more than a third of the patients (39%) were aged from 6 to 12 years (Adib-Hajbaghery and Ahmadi, 2019). This could be attributed to several factors such as collection of data pertaining to children with CKD, the distribution of children with CKD in that particular country (compared to this single centre-based study) or the definition of CKD in children. Regarding this study, most of the patients were aged less than 12 years and further revealed that 47,6% of patients were male. This is unlike research by Adib-Hajbaghery and Ahmadi (2019), who found that, in Iran, 60,3% of children with CKD were male and Darwish et al. (2020), who found, that in Egypt, 67,2% of CKD paediatric patients were male.

Darwish et al. (2020), found that 57,6% of children with CKD had a primary level of education, a factor influenced by the average of 11 years in their study, a similar comparison to the average age of 10.59 years in this current, single-centre, KZN-based study. The positive observation in this study, is that all children of school-going age, attended school (52,38%). Education is an important factor in preparing children for participation in adult life (Groothoff et al., 2005). However, more than 60% of the children required additional educational help which is provided by the caregiver and which may constitute additional burden (Kiliś-Pstrusińka, et al., 2013a).

Studies have found that marriage is a source of support to the caregiver and spouses relied on each other for emotional support to overcome hardships (Wightman et al., 2019; Baek et al., 2018; Laakkonen et al., 2014; Wiedebusch et al., 2010) and divorce rates were not significantly high, which is consistent in this study as 28,6% of the respondents are married vs 4,8% who were divorced. However, it must be acknowledged that other studies found that married caregivers experienced frequent burden; marital relationships were found to be a source of stress and intimate relationships were changed by the caregiver role, resulting in high divorce rates among the caregivers (Bauer et al., 2020; Tong et al., 2010; de Paula et al., 2008; Fielding and Brown, 1999).

The burden perceived by the caregivers in this empirical investigation revealed no notable association with variables such as residence, age and gender of the child, and the age and gender of the caregivers. However, caregiver burden was higher when the child had a lack of appetite (81%), when there is a bad test result (76,1%) and when sudden changes occurred as in hospitalization of the child (85,7%). This is consistent with studies conducted by Udoh et al. (2021), and Hu et al. (2016), that identified significant relationship between the caregivers' perception of burden and sudden changes during the duration of illness. Furthermore, in this study, high levels of perceived burden were observed in the following areas:

- Due to strenuous caregiving tasks 72,6% of respondents reported physical burden with 69% experiencing chronic pain and 76,2% stated that they were "unable to switch off" leading to mental fatigue.
- Caregivers provide complex medical care to children with CKD. Notably, in taking responsibility for the care of the ill child, the following aspects emerged as increasing their levels of burden: they experienced fear of unexpected hospitalization (85% - always a burden); being vigilant in selecting the correct doses of medications (71,4% - always a burden), and not making mistakes in medical procedures, (66,7% - always a burden).
- Extended time devoted to the child's care and being limited by the child's affairs was reported by 71,4% of participants. The same percentage of respondents 71,4% experienced loneliness and social isolation and stated an inability to fulfil their own plans and needs.

More than seventy percent (71.4%) of the cohort of children in this study had been suffering from CKD for 2-5 years, and 9,6% between 6 - >10 years of having CKD; with the concomitant number of years of caregiving. More than sixty six percent of the caregivers (66,7%) stated that 20 – 40 HD sessions are completed per month. Thus, the study showed a strong correlation between the duration of the disease and burden of care. More than 90,5% of the caregivers indicated that their caregiving responsibilities such as providing transportation to treatment centres, helping with daily activities, assisting with education activities, dietary requirements and medication administration, and providing acute and / or chronic symptom management (Suri et al., 2011; Tong et al., 2010; Einollahi et al., 2009; Tong et al., 2010; Aldridge, 2008; Tsai et al., 2006), accounted for more than 10 hours per week ($p < 0.001$). Fifteen participants stated that they spent as much as 71,4% of their time in taking care of the ill child, leaving no time to attend to personal needs such as going to the gym and fulfilling their own plans. It is no wonder then, that caregivers of CKD paediatric patients experienced moderate to severe levels of caregiver burden resulting from physical, psychological, and social life changes (Mashayekhi et al., 2015; Bayoumi, 2015; Tong et al., 2010; Aldridge, 2008; Tsai et al., 2006).

Caring for children with CKD has substantial adverse psychological effects on their caregivers. There should be a high index of suspicion for anxiety/depression in these caregivers, as is evident, in this study, from the result of the GHQ – 12 score, which showed a mean of 0,95 for the anxiety/depression domain. Similarly, Lima et al., (2019), found depression among 36,8% and anxiety among 46,5% of caregivers of children with CKD, both rates significantly higher than population norms.

Pinquart and Sörensen (2003), suggest that providing care is a stressful undertaking that can result in the erosion of the caregivers' physical well-being. Despite the high burden experienced by caregivers, many caregivers / parents choose dialysis treatment in part because they recognize the benefits to the ill child’s life within a loving family. However, scant attention is paid to caregiver burden in the paediatric CKD patient population (Alshammari et al., 2019; Oyegbile and Brysiewicz, 2017b; Zhang et al., 2016). Together with the increase in paediatric CKD cases and the increased focus on home therapies, the caregiver burden is becoming a serious concern in renal care. Caregivers gradually develop coping mechanisms for dealing with difficulties and burdens associated with their duties. Despite the coping mechanisms learnt, the caregiver still experiences fears about the illness progression and the future of the child. Caregivers experiencing doubt about their competencies to provide care are likely to benefit from support interventions that enable them to continue with their own lives while providing care to their sick relatives (Noble et al., 2013; Sautter et al., 2014). Studies revealed that caregivers with adequate support interventions experienced less burden (Collins and Swartz, 2011). Caregivers also only establish new friendships with other sick children’s caregivers/parents. This is beneficial in exchanging experiences and is a form of support; however, it also indicates the affected caregivers’ isolation (Kiliś-Pstrusińska et al., 2013a). Peer / caregiver support groups are an avenue for caregivers to engage with others who understand their situation and help reverse social isolation.

Caregivers need more guidance and information on the symptoms of adverse side effects of treatment, anticipated costs of dialysis, including sources for financial assistance, and practical tips to improve their child’s medication intake. Caregivers often have a struggle with adherence to medication intake as the child finds the taste unpleasant (Erez et al., 2022; Geense et al., 2017). Only two staff were aware of availability of social workers and caregivers themselves stated that they were unaware of access to social workers but all indicated the need for such support. The caregiver’s perception of burden and ability to provide care is related to the caregiver’s preparedness for caregiving. Preparedness is viewed as an emotional and anticipatory preparation of the caregiver’s readiness to provide care (Wilborn-Lee, 2015; Schumacher et al., 2008). This is where the health care team can assist the caregivers by providing information on possible burden and stress and where to seek assistance to help the caregiver cope. There is a strong indication for involvement of social workers to help the caregiver cope with their roles. Kiliś-Pstrusińska et al. (2013a), similarly suggest that continuous psycho-social care for caregivers should be provided. The current study has elicited through the use of a qualitative questionnaire, the practical, personal and support needs (information sharing, religious coping, counselling) of the caregiver.

## 5.3 Conclusion

This is a first study in SA to measure caregiver burden specific to children with CKD. Despite competing for resources in a severely under-resourced health sector, together with direct input from the primary caregivers and renal health care professionals, it is hoped that this study will enhance the understanding of caregiver burden in the paediatric CKD population and stimulate further research.

# 6 CHAPTER SIX
# LIMITATIONS OF THE STUDY, RECOMMENDATIONS AND CONCLUSION

## 6.1 Limitations of this study

The unique nature of the area investigated resulted in a small sample size and hence the findings of this study may not be generalized.

The study findings are specific to a single-center public hospital that provided paediatric renal care and therefore the findings cannot be generalized to the rest of the country.

## 6.2 Recommendations

At a macro-level NDoH needs to invest in providing more human and other resources and facilities for renal care (Jardine and Davids, 2020). It is imperative that consensus be reached about the definition of CKD in children to assist with early detection of CKD in children. Late presentations are potentially avoidable and are associated with poorer patient outcomes and may increase caregiver burden and anxiety (Udayaraj et al., 2011). Furthermore, Moosa et al. (2016), recommend that timely referrals of children with CKD will improve assessment of patients, and improve preparation for RRT and obviate the need for acute dialysis. It is noted that the health sector within the country is resource scarce and to conduct empirical-based studies on this topic and to implement strategies to sustain or improve the quality of life of the caregiver will require significant resources from NDoH.

A registry that disaggregates paediatric CKD patients from adult cases will allow for planning, for example, training of paediatric renal staff, infrastructure and other vital resources. Similarly, a database that captures prevalence of paediatric CKD patients before RRT if initiated will also provide information for policy and planning frameworks.

As there is no evidence-based research on this topic in the country, a similar multi-center study for broader comparison and generalization of findings may be necessary. For example, studies of caregivers of paediatric CKD, at both public and private health clinics within SA need to be conducted.

Caregivers should be informed of the expected burdens that they may encounter as the child's primary caregiver, as disregarding these factors complicates the dialysis treatment process and the optimal care of the ill child. The demands dialysis treatment place on caregivers in such serious illness, like paediatric CKD, require nephrologists to include families in the treatment plans to better prepare them for the caregiving roles and responsibilities (Wightman et al., 2019).

The healthcare team should communicate clearly with the caregiver about the condition of the child and the level of care needed. Caregivers want information to reduce their anxiety, fears and concerns. The health authorities should consider the provision of individual and group counselling sessions to help caregivers cope in areas which they experience overwhelming burden.

It is acknowledged that the health sector in SA is severely under-resourced which can hinder clinicians' efforts to providing support services. Adejumo et al. (2019), suggest that a formal caregiver network be developed that will include social workers and clinical psychologists. Ong et al. (2021), recommends that counselling by a health care professional will allow the caregivers to balance their caregiving responsibilities and their own needs to prevent and / or manage stress, physical ill-health and other impairments.

The results of the study strongly recommend that owing to the protracted nature of the disease, caregivers of children with CKD should be assessed for severe burden. This will assist with developing and providing targeted intervention to mitigate anxiety, stress and burden which will ultimately improve the outcomes for the caregivers and the children with CKD.

## 6.3 Conclusion

At the completion of this study, it was evident that the primary caregivers of paediatric CKD patients in KwaZulu Natal experienced moderate to severe burden in all domains of care, being similar with those reported internationally (Bauer et al., 2020; Wightman et al., 2019). Despite experiencing anxiety, social dysfunction and burdens and channeling limited financial resources toward the care of the sick child, the caregiver continued with their caregiving roles and responsibilities. However, this arrangement can only be sustained for a limited time without ultimately causing burdens in the caregiver and negatively impacting the child’s treatment. Using quantitative, validated tools such as the PR-CBS is a good start in measuring caregiver burden; eliciting valuable data for the renal health care team to identify those areas of severe burden in order to provide appropriate support to alleviate caregiver burden. A multi-dimensional approach is needed to mitigate caregiver burden. The development of a holistic tool for the periodic assessment of caregiver burden; a communication model between the renal team and caregiver; and a support / coping strategy is necessary to remediate the burdens experienced by the caregiver and will contribute to positive outcomes for both the ill child and the caregiver.

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# APPENDICES

## Appendix 1- Letter of Information Caregivers

### LETTER OF INFORMATION CAREGIVERS

**Title of the Research Study**: Primary caregiver experiences and perspectives on caring for a child with Chronic Kidney Disease within a South African context.

**Principal Investigator/s/researcher:** Shamanie Govender (Masters in Health Sciences)

Co-Investigator/s/supervisor/s: Professor J K Adam (Doctoral Degree), Professor T. Mgutshini (Doctoral Degree)

Brief Introduction and Purpose of the Study:

Good Day. My name is Shamanie Govender and I am registering for Doctoral degree at the Durban University of Technology. I am currently employed in the Department of Biomedical and Clinical Technology. However, I have previously worked in a renal unit and am aware that children with CKD are dependent on the primary caregiver to manage their condition. This includes many aspects, for example, dietary requirements, transportation to dialysis sessions and administering their medication. The primary focus of this study is to explore the caregiver perceptions and experiences, during their caregiver functions, for example, on their physical health, and emotional and psychological health, and possible financial burdens experienced. The primary caregiver from both private and public dialysis facilities will be compared with regard to, for example, the support, they receive to adjust and care for the chronically ill child, while still maintaining their own quality of health. Strategies that the caregiver uses to manage their stressors will also be probed since the quality of their health determines that the child receives optimal care. I would greatly appreciate it if you would take part in my research. More importantly the research is intended to identify strategies and make recommendations to assist the caregiver to have little to no burden in their roles and functions as a caregiver and in doing so to improve the overall quality of life for both the caregiver and the child with CKD.

Outline of the procedures:

Caregivers in the renal facilities will be asked to complete the structured questionnaire. This will be completed while you are waiting for the child to complete the dialysis treatment or at a time convenient to you. The demographic details of the children with CKD will be noted for research and analytical purposes only. Staff members in the renal unit will be required to participate in a focus group discussion. All information will be strictly confidential and anonymity will be guaranteed. All questionnaires and information will be securely stored. Participation is voluntary.

Risks or Discomforts to the Participant:

There will be no risks to the participants during the completion of the questionnaire. The caregivers can withdraw at any time from the study, should they experience any discomfort or distress.

Benefits:

1. There is currently no research of the experiences and perspectives of the primary caregiver, on caring for a child with Chronic Kidney Disease, within a South African context.
2. The research is intended to identify strategies and make recommendations to develop a support treatment framework that improves and empowers the overall quality of life for both the caregiver and the child with CKD.

Reason/s why the Participant May Be Withdrawn from the Study:

Your participation in this research is completely voluntary and without prejudice. You may withdraw at any time and this will not affect the dialysis treatment of the child or your future support and care of the child. Participants who experience distress or discomfort prior or during the completion of the study will be excluded from the study.

Remuneration:

You will not be paid for completing the questionnaire. Participation is voluntary.

Costs of the Study:

You will not be asked to cover any cost relating to the study.

Confidentiality:

All the information collected will be kept confidential. You will be allocated a number and all your details will be recorded under that number. This means that anyone who looks at my records will not be able to trace it to you. This is done to protect your privacy. In addition, a statement of confidentiality will be signed by both my supervisors and me.

Research-related Injury: There will be no research –related injury as there will be no alterations made to your continued support of the child during the dialysis treatment.

Persons to Contact in the Event of Any Problems or Queries:

Please contact the researcher (0730627083),my supervisor (0313733093), or the Institutional Research Ethics Administrator on 031 373 2375. Complaints can be reported to the Director: Research and Postgraduate Support Dr L Linganiso on 031 373 2577 or researchdirector@dut.ac.za.

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TECHNOLOGY
INSTITUTIONAL
RESEARCH
ETHICS
COMMITTEE

## CONSENT

**Statement of Agreement to Participate in the Research Study:**

- I hereby confirm that I have been informed by the researcher, Miss Shamanie Govender, about the nature, conduct, benefits and risks of this study - Research Ethics Clearance Number: __________,
- I have also received, read and understood the above written information (Participant Letter of Information) regarding the study.
- I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and diagnosis will be anonymously processed into a study report.
- In view of the requirements of research, I agree that the data collected during this study can be processed in a computerized system by the researcher.
- I may, at any stage, without prejudice, withdraw my consent and participation in the study.
- I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.
- I understand that significant new findings developed during the course of this research which may relate to my participation will be made available to me.

______________________ ___________ ______ ________________

**Full Name of Participant** **Date** **Time** **Signature / Right Thumbprint**

I, Miss Shamanie Govender, herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

____________________ ____________ ______________________

**Full Name of Researcher** **Date** **Signature**

____________________ ____________ ______________________

**Full Name of Witness (If applicable)** **Date** **Signature**

__________________ __________ ____________________

**Full Name of Legal Guardian (If applicable) Date** **Signature**

## Appendix 2 Letter of Information Caregivers-IsiZulu

### INCWADI YOLWAZI YEZIGULI

**Isihloko sesifundo socwaningo**: Isipiliyoni somnakekeli kanye nemibono yokunakekela ingane enesifo esingapheliyo sezinso (CKD) ngaphakathi kwesimo seNingizimu Afrika.

**Umphenyi omkhulu/ uMcwaningi:** Shamanie Govender (Masters in Health Sciences)

**Umphenyi obambisene/umphathi/abaphath**i: uProfesa J K Adams (Doctoral Degree), uProfesa T. Mgutshibi (Doctoral Degree).

Isingeniso esifushane nenjongo yokufunda:

Usuku oluhle. Igama lami nguShamanie Govender**,** ngibhalisele iziqu zobudokotela eNyuvesi yeseThekwini Yezobuchwepheshe. Njengamanje ngiqashwe eMnyangweni weBiomedical and Clinical Technology eNyuvesi yochwepheshe yaseThekwini. Kodwake, phambilini ngike ngasebenza ophikweni lwezinso futhi ngiyazi ukuthi izingane ezineCKD zincike kumnakekeli oyinhloko ukuphatha isimo sabo. Lokhu kufaka izici eziningi, ngokwesibonelo, izidingo zokudla, ukuthuthwa ngezikhathi ze-dialysis nokuphathwa kwemithi yabo. Ukugxila okuyinhloko kwalolu cwaningo ukuhlola imibono neziphiliyoni zabanakekeli bezingane zeCKD, ngesikhathi semisebenzi yabo yokunakekela lezingane, ngokwesibonelo, impilo yabo yomzimba, nasemphefumulweni ngokomzwelo nangokwengqondo, kanye nemithwalo yemali engaba khona. Umnakekeli oyinhloko ovela kuzo zombili izindawo, ezimele nezikahulumeni zokuxilonga umzimba, uzoqhathaniswa maqondana nalokhu, isibonelo, ukwesekwa abakutholayo ukulungisa nokunakekela ingane enesifo esingalapheki, ngenkathi nabo besagcina impilo yabo ezingeni eliphakeme. Amasu asetshenziswa umnakekeli ukuphatha izingcindezi zabo, nalokhu kuzobhekwa ngoba ukuphatha kahle impilo yabo kukhombisa ukuthi ingane ithola ukunakekelwa okuhle nayo. Ngingakuthokozela kakhulu uma ungabamba iqhaza ocwaningweni lwami. Okubaluleke kakhulu ngalolucwaningo ukuthi lihlose ukukhombisa amasu nokwenza izincomo zokusiza umnakekeli ukuthi abe nomuthwalo omuncane noma angabi nayo ezindimeni nasemisebenzini yakhe njengomnakekeli futhi ngokwenza njalo ukuthuthukisa izinga lempilo kubo bonke abanakekeli bezingane ezine-CKD.

**Uhlaka lwezinqubo:**

Abanakekeli abasezikhungweni zezinso bazocelwa ukuba bagcwalise uhlu lwemibuzo oluhleliwe. Lokhu kuzophothulwa ngenkathi ulinde ingane ukuthi iqedele ukwelashwa nge-dialysis noma ngesikhathi esivumelana nawe.Imininingwane yezingane ezine-CKD izokwaziswa ngocwaningo nangezinhloso zokuhlaziya kuphela.Abasebenzi base phikweni lwezinso kuzodingeka ukuthi babambe iqhaza engxoxweni yokugxila yeqembu. Yonke imininingwane izoba yimfihlo futhi igama lakho lizosetshenziswa ngokungaziwa. Yonke imibuzo nemininingwane izogcinwa ngokuphephile. Ubamba iqhaza ngokuzithandela.

**Izingozi noma ukungahambisani noku'mbambiqhaza:**

Ngeke kube khona ubungozi kubahlanganyeli ngesikhathi sokugcwaliswa kohlu lwemibuzo. Abanakekeli bangahoxa noma inini ocwaningweni, uma kwenzeka behlangabezana nokungaphatheki kahle noma ukucindezeleka\ usizi.

**Izinzuzo:**

1. Okwamanje akukho cwaningo olwenziwe mayelana nesplliliyoni futhi nemibono yalabo abanakekela izingane ezinesifo sezinso (CKD), ngokwesimo saseNingizimu Afrika.
2. Ngalolucwaningo kuhloswe ukukhomba amasu nokwenza izincomo zokwakha uhlaka lokwelashwa olusekelayo, oluthuthukisayo futhi lunike amandla, futhi kubhekwe nekhwalithi yempilo yomnakekeli wengane ene-CKD.

**Izizathu zokuthi kungani umbambiqhaza angahoxiswa ocwaningweni:**

Ukubamba kwakho iqhaza kulolu cwaningo ukuzithandela ngokuphelele futhi akunabandlululo. Ungahoxa nganoma yisiphi isikhathi futhi lokhu ngeke kuthinte ukwelashwa kwengane kwidialysis, noma ukwesekwa nokunakekelwa kwengane yakho ngesikhathi esizayo. Ababambiqhaza ababhekana nosizi noma ukungaphatheki kahle ngaphambi kesikhathi sokuphothulwa kocwaningo, bazokhishwa ocwaningweni.

**Umholo**:

Ngeke ukhokhelwe ngokugcwalisa uhlu lwemibuzo. Ubamba iqhaza kungokuzithandela.

**Izindleko Zesifundo**:

Ngeke ucelwe ukuthi ukhokhele noma yiziphi izindleko eziphathelane nalolucwaningo.

**Imfihlo**:

Yonke imininingwane eqoqiwe izogcinwa iyimfihlo. Uzonikezwa inombolo la yonke imininingwane yakho izorekhodwa ngaphansi kwaleyo nombolo. Lokhu kusho ukuthi noma ngubani obheka amarekhodi ami ngeke akwazi ukukulandela ifinyelele kuwena. Lokhu kwenzelwa ukuvikela izimfihlo zakho. Ngaphezu kwalokho, isitatimende semfihlo sizosayinwa yimi nabaphathi bami.

**Ukulimala okuhlobene nocwaningo**:

Ngeke kube khona ukulimala okuhlobene nocwaningo ngoba ngeke kube khona ushintsho olwenziwe ekusekeleni kwakho, okuqhubekayo, kwengane ngesikhathi sokwelapha i-dialysis.

**Abantu ongaxhumana nabo uma kuvela noma iziphi izinkinga noma imibuzo**:

Sicela uxhumane nomcwaningi Shamanie (0730627083), uMphathi (031 373 3093) noma i-Institutional Research Ethics Administrator ku-0313732375. Izikhalazo zingabikwa kuMqondisi: Research and Postgraduate Support, uSolwazi\uDr L.Ninganiso – 0313732577, noma ubhalelele u researchdirector@dut.ac.za.

## UKUVUMA

**Isivumelwano sokuba ingxenye yocwaningo:**

- Ngiyavuma ukuthi ngitsheliwe uMcwaningi Mrs Shamanie Govender ngohlobo, ukuziphatha, inzuzo kanye nezingozi zalolugwaningo Research Ethics Clearance number ………….
- Futhi ngithole incazelo ebanzi, ngafunda, ngaqonda ngokubhaliwe kwincazelo ehlangene nalolu cwaningo (Participant letter of information).
- Ngiyazi ukuthi imiphumela yalolucwaningo, efaka phakathi imininingwane ekhombisa ubulili, iminyaka, usuku lokuzalwa, iziqalo zamagama ami, nokuthi imiphumela yokuxilongwa izosetsheziswa ngokungaziwa kumbiko walolucwaningo.
- Ngokuhambelana kwezidingo zalolucwaningo, ngiyavuma ukuthi ukuqoqwa kwemininingwane kungasetsheziswa kuhlelo lwekhompyutha nguMcwaningi.
- Ngigahle, nangasiphi isigaba, ngaphandle kokubadlulula ngikhiphe isivumelwano nokubamb'iqhaza kulolucwaningo.
- Ngilitholile ithuba eliningi lokubuza imibuzo ngalolucwaningo. Futhi ngiyamemezela ngokukhululela ukuthi ngizoba yixhenye yalolucwaningo.
- Ngiyaqonda ukuthi okuphawulekayo, okusha okutholiwe, okuthuthukisayo kulolucwaningo, okungahlanganisa nokuba yingxenye yalolucwaningo kuzotholakala kimi.

| | | | |
|---|---|---|---|
| ____________________ | ____________ | ________ | ______________ |
| **Igama eligcwele lalowo isigxivizo obambe iqhaza.** | **Usuku** | **Isikhathi** | **Isignesha\ sesandla sokudla.** |

Mina, Miss Shamanie Govender, ngiyavuma ukuthi lowo obambe iqhaza utsheliwe kabanzi ngohlobo, ukuziphatha, inzuzo kanye nezingozi zalolugwaningo.

____________________ ____________ ______________________

**Igama Eligcwele omcwaningi** **Usuku** **Signesha**

____________________ ____________ ______________________

**Igama eligcwele lofakazi (Uma ekhona)** **Usuku**
**Signesha**

__________________ ___________ ____________________

**Igama eligcwele lomnakekeli**
**osemthethweni (Uma ekhona)** **Usuku** **Signesha**

## Appendix 3 Letter of Information Staff

### LETTER OF INFORMATION
### Staff

**Title of the Research Study**: Primary caregiver experiences and perspectives on caring for a child with Chronic Kidney Disease within a South African context.

**Principal Investigator/s/researcher:** Shamanie Govender (Masters in Health Sciences)

Co-Investigator/s/supervisor/s: Prof J K Adam (Doctoral Degree), Professor T. Mgutshini (Doctoral Degree)

Brief Introduction and Purpose of the Study:

Good Day. My name is Shamanie Govender and I am registering for Doctoral degree at the Durban University of Technology. I am currently employed in the Department of Biomedical and Clinical Technology. However, I have previously worked in a renal unit and am aware that children with CKD are dependent on the primary caregiver to manage their condition. This includes many aspects, for example, dietary requirements, transportation to dialysis sessions and administering their medication. The primary focus of this study is to explore the caregiver perceptions and experiences, during their caregiver functions, for example, on their physical health, and emotional and psychological health, and possible financial burdens experienced. The primary caregiver from both private and public dialysis facilities will be compared with regard to, for example, the support, they receive to adjust and care for the chronically ill child, while still maintaining their own quality of health. Strategies that the caregiver uses to manage their stressors will also be probed since the quality of their health determines that the child receives optimal care. I would greatly appreciate it if you would take part in my research. More importantly the research is intended to identify strategies and make recommendations to develop a support treatment framework that improves and empowers the overall quality of life for both the caregiver and the child with CKD.

Outline of the procedures:

Caregivers in the renal facilities will be asked to complete the structured questionnaire. This will be completed while you are waiting for the child to complete the dialysis treatment or at a time convenient to you. The demographic details of the children with CKD will be noted for research and analytical purposes only. Staff members in the renal unit will be invited to participate in a focus group discussion that will last approximately 45 minutes. Several dates and times will be suggested and will be finalized to ensure the required number of staff participate. All information will be strictly confidential and anonymity will be guaranteed. All information will be securely stored. Participation is voluntary.

Risks or Discomforts to the Participant:

There will be no risks to the participants during the staff focus group interview and the participants can withdraw at any time from the study.

Benefits:

1. There is currently no research of the experiences and perspectives of the primary caregiver, on caring for a child with Chronic Kidney Disease, within a South African context.
2. The research is intended to identify strategies and make recommendations to develop a support treatment framework that improves and empowers the overall quality of life for both the caregiver and the child with CKD.

Reason/s why the Participant May Be Withdrawn from the Study:

Your participation in this research is completely voluntary and without prejudice. You may withdraw at any time.

Remuneration:

You will not be paid for completing the questionnaire. Participation is voluntary.

Costs of the Study:

You will not be asked to cover any cost relating to the study.

Confidentiality:

All the information collected will be kept confidential. You will be allocated a number and all your details will be recorded under that number. This means that anyone who looks at my records will not be able to trace it to you. This is done to protect your privacy. In addition, a statement of confidentiality will be signed by both my supervisors and me.

Research-related Injury: There will be no research –related injury.

Persons to Contact in the Event of Any Problems or Queries:

Please contact the researcher (0730627083),my supervisor (0313733093), or the Institutional Research Ethics Administrator on 031 373 2375. Complaints can be reported to the Director: Research and Postgraduate Support Dr L Linganiso on 031 373 2577 or researchdirector@dut.ac.za.

**CONSENT**

**Statement of Agreement to Participate in the Research Study:**

- I hereby confirm that I have been informed by the researcher, Miss Shamanie Govender, about the nature, conduct, benefits and risks of this study - Research Ethics Clearance Number: __________,
- I have also received, read and understood the above written information (Participant Letter of Information) regarding the study.
- I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and diagnosis will be anonymously processed into a study report.
- In view of the requirements of research, I agree that the data collected during this study can be processed in a computerised system by the researcher.
- I may, at any stage, without prejudice, withdraw my consent and participation in the study.
- I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.
- I understand that significant new findings developed during the course of this research which may relate to my participation will be made available to me.

| ______________________ | ___________ | _______ | ________________ |
|---|---|---|---|
| **Full Name of Participant** | **Date** | **Time** | **Signature / Right Thumbprint** |

I, Miss Shamanie Govender, herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

____________________ ____________ ______________________

**Full Name of Researcher** **Date** **Signature**

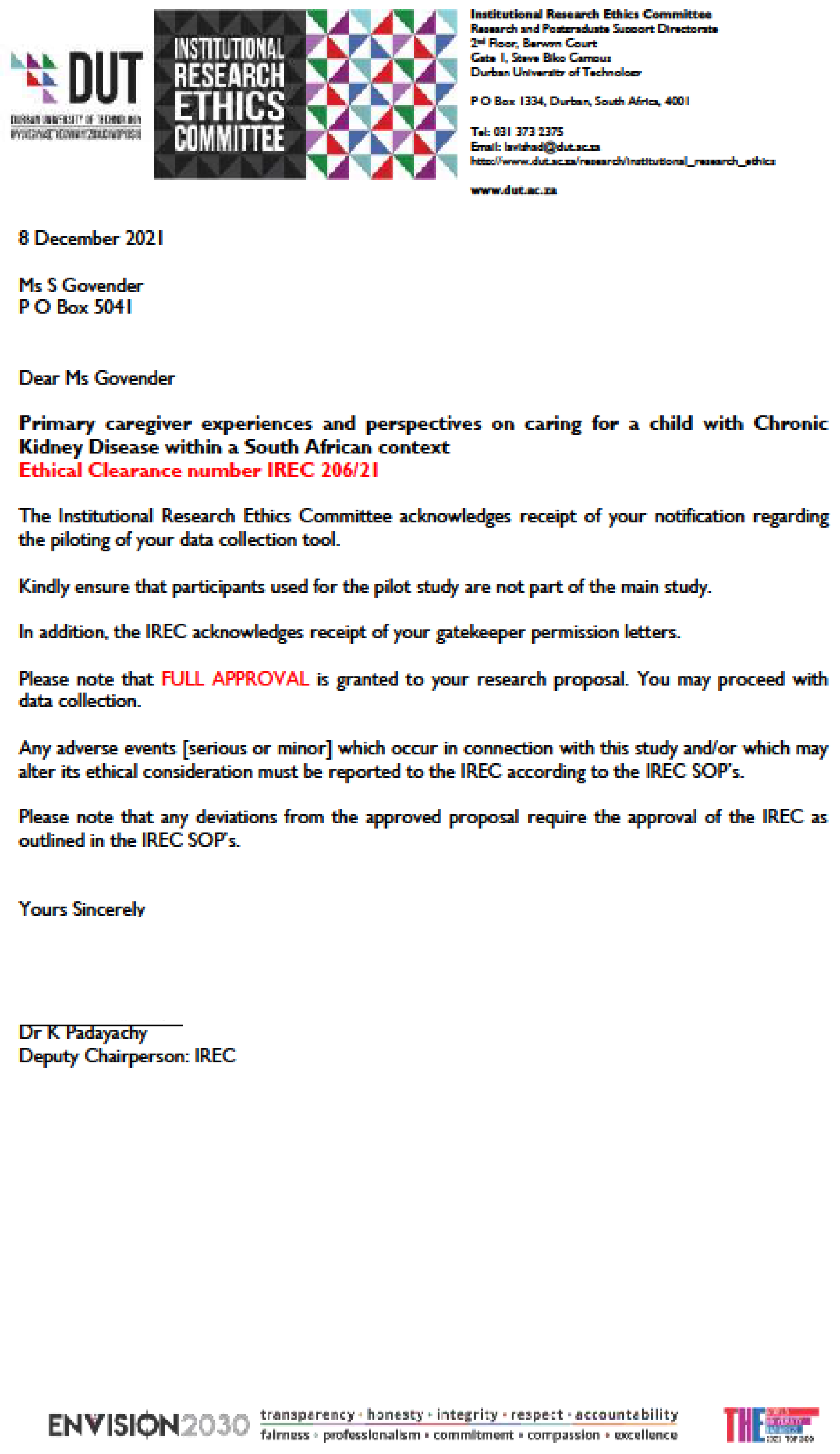
____________________ ____________ ______________________

**Full Name of Witness (If applicable)** **Date** **Signature**

__________________ ___________ ____________________

**Full Name of Legal Guardian (If applicable) Date** **Signature**

# Appendix 4 IREC Letter



INSTITUTIONAL RESEARCH ETHICS COMMITTEE

**Institutional Research Ethics Committee**
Research and Postgraduate Support Directorate
2nd Floor, Berwyn Court
Gate 1, Steve Biko Campus
Durban University of Technology

P O Box 1334, Durban, South Africa, 4001

Tel: 031 373 2375
Email: lavishad@dut.ac.za
http://www.dut.ac.za/research/institutional_research_ethics

www.dut.ac.za

8 December 2021

Ms S Govender
P O Box 5041

Dear Ms Govender

**Primary caregiver experiences and perspectives on caring for a child with Chronic Kidney Disease within a South African context**
**Ethical Clearance number IREC 206/21**

The Institutional Research Ethics Committee acknowledges receipt of your notification regarding the piloting of your data collection tool.

Kindly ensure that participants used for the pilot study are not part of the main study.

In addition, the IREC acknowledges receipt of your gatekeeper permission letters.

Please note that FULL APPROVAL is granted to your research proposal. You may proceed with data collection.

Any adverse events [serious or minor] which occur in connection with this study and/or which may alter its ethical consideration must be reported to the IREC according to the IREC SOP's.

Please note that any deviations from the approved proposal require the approval of the IREC as outlined in the IREC SOP's.

Yours Sincerely

Dr K Padayachy
Deputy Chairperson: IREC

ENVISION2030 transparency · honesty · integrity · respect · accountability
fairness · professionalism · commitment · compassion · excellence

## Appendix 5 Gatekeeper Permission Letter

6 September 2021

330 Langalibalele Street, Pietermaritzburg.

### Request for Permission to Conduct Research

Dear Dr Lutge,

My name is Shamanie Govender and I have registered for Doctoral Degree at the Durban University of Technology. I am currently employed in the Department of Biomedical and Clinical Technology. The research I wish to conduct involves the primary caregiver experiences and perspectives on caring for a child with Chronic Kidney Disease within a South African context.

I am hereby seeking your consent to conduct the research (primarily administration of questionnaires, individual and group interviews) among health care workers and primary caregivers in public hospitals and clinics in KZN.

I have provided you with a copy of the study protocol which includes copies of the data collection tools and consent forms to be used in the research process, as well as a copy of the approval letter which I received from the Institutional Research Ethics Committee (IREC).

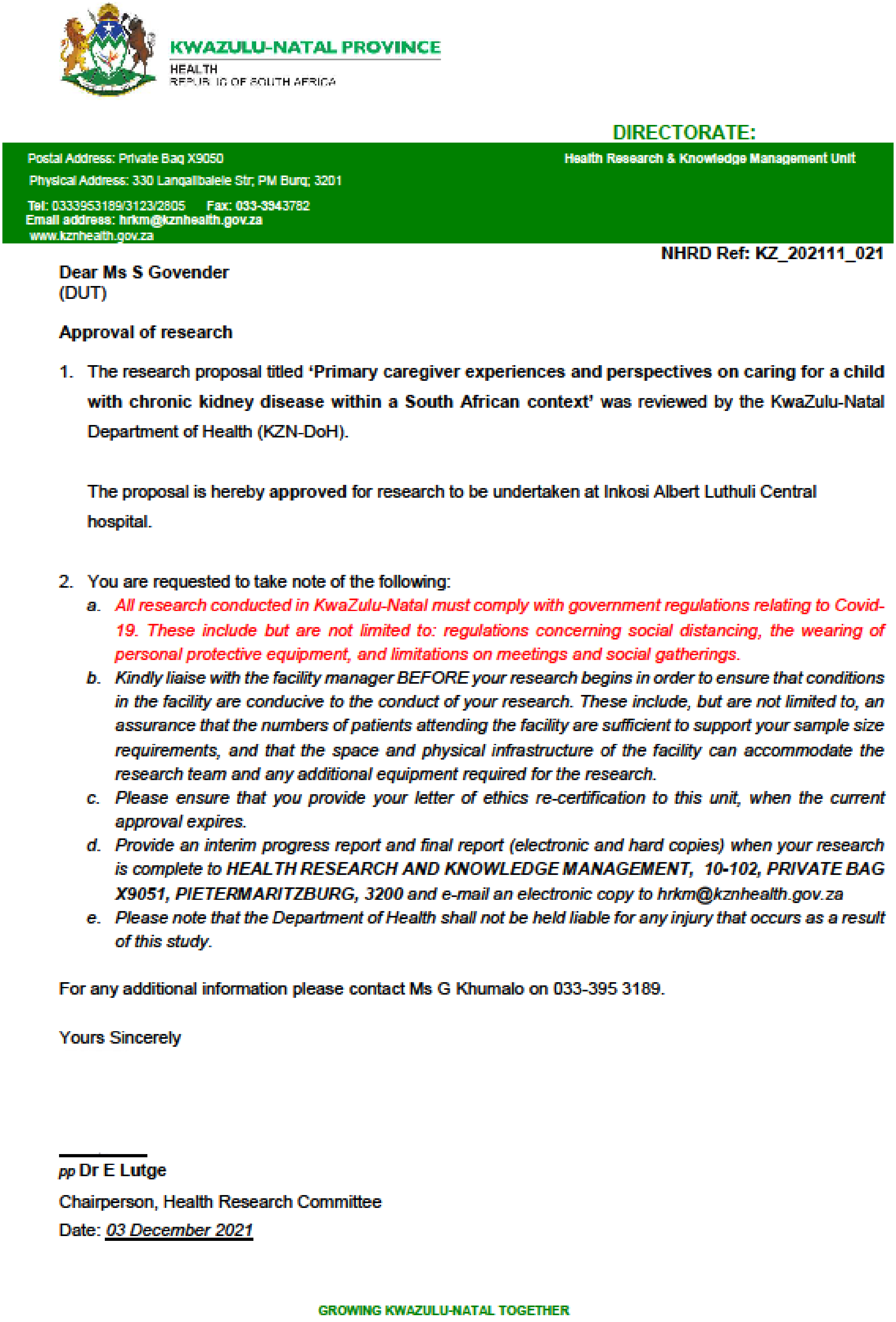
If you require any further information, please do not hesitate to contact me on **0730627083 or via email to ShamanieG@dut.ac.za.** Thank you for your time and consideration in this matter.

Yours sincerely,

Ms Shamanie Govender

Durban University of Technology

# Appendix 6 Department of Health Approval Letter



**KWAZULU-NATAL PROVINCE**
HEALTH
REPUBLIC OF SOUTH AFRICA

**DIRECTORATE:**
**Health Research & Knowledge Management Unit**

Postal Address: Private Bag X9050
Physical Address: 330 Langalibalele Str; PM Burg; 3201
**Tel:** 0333953189/3123/2805 **Fax: 033-3943782**
**Email address: hrkm@kznhealth.gov.za**
www.kznhealth.gov.za

**NHRD Ref: KZ_202111_021**

**Dear Ms S Govender**
(DUT)

**Approval of research**

1. The research proposal titled **'Primary caregiver experiences and perspectives on caring for a child with chronic kidney disease within a South African context'** was reviewed by the KwaZulu-Natal Department of Health (KZN-DoH).

   The proposal is hereby **approved** for research to be undertaken at Inkosi Albert Luthuli Central hospital.

2. You are requested to take note of the following:
   a. *All research conducted in KwaZulu-Natal must comply with government regulations relating to Covid-19. These include but are not limited to: regulations concerning social distancing, the wearing of personal protective equipment, and limitations on meetings and social gatherings.*
   b. *Kindly liaise with the facility manager BEFORE your research begins in order to ensure that conditions in the facility are conducive to the conduct of your research. These include, but are not limited to, an assurance that the numbers of patients attending the facility are sufficient to support your sample size requirements, and that the space and physical infrastructure of the facility can accommodate the research team and any additional equipment required for the research.*
   c. *Please ensure that you provide your letter of ethics re-certification to this unit, when the current approval expires.*
   d. *Provide an interim progress report and final report (electronic and hard copies) when your research is complete to HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200 and e-mail an electronic copy to hrkm@kznhealth.gov.za*
   e. *Please note that the Department of Health shall not be held liable for any injury that occurs as a result of this study.*

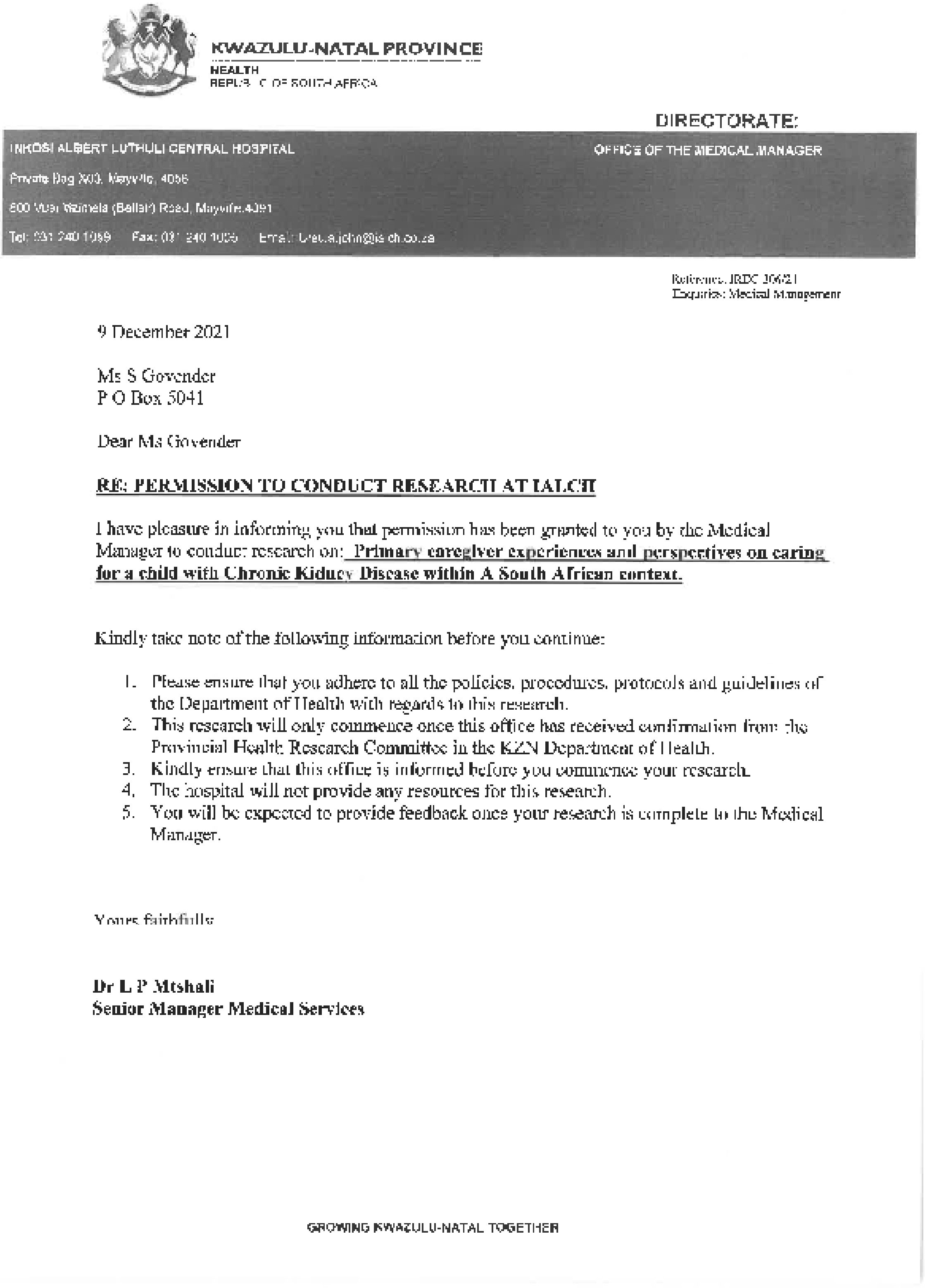
For any additional information please contact Ms G Khumalo on 033-395 3189.

Yours Sincerely

*pp* **Dr E Lutge**
Chairperson, Health Research Committee
Date: *03 December 2021*

**GROWING KWAZULU-NATAL TOGETHER**

# Appendix 7 IALCH Approval Letter



KWAZULU-NATAL PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

DIRECTORATE:

INKOSI ALBERT LUTHULI CENTRAL HOSPITAL
Private Bag X03, Mayville, 4058
800 Vusi Mzimela (Bellair) Road, Mayville 4091
Tel: 031 240 1059 Fax: 031 240 1055 Email: Greta.john@ialch.co.za

OFFICE OF THE MEDICAL MANAGER

Reference: IRDC 206/21
Enquiries: Medical Management

9 December 2021

Ms S Govender
P O Box 5041

Dear Ms Govender

**RE: PERMISSION TO CONDUCT RESEARCH AT IALCH**

I have pleasure in informing you that permission has been granted to you by the Medical Manager to conduct research on: **Primary caregiver experiences and perspectives on caring for a child with Chronic Kidney Disease within A South African context.**

Kindly take note of the following information before you continue:

1. Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
2. This research will only commence once this office has received confirmation from the Provincial Health Research Committee in the KZN Department of Health.
3. Kindly ensure that this office is informed before you commence your research.
4. The hospital will not provide any resources for this research.
5. You will be expected to provide feedback once your research is complete to the Medical Manager.

Yours faithfully

**Dr L P Mtshali**
**Senior Manager Medical Services**

GROWING KWAZULU-NATAL TOGETHER

## Appendix 8 Caregiver Questionnaire

**CAREGIVER QUESTIONNAIRE** **Study Code:**

**This questionnaire has been designed to tell me more about your experiences and perceptions as a caregiver of the child with Chronic Kidney Disease**

**Caregiver Demographics:**

Name and surname: (Respondents will remain anonymous and will be assigned a code)

______________________________________________________________

Gender: Female ☐ Male ☐

Age: ____________

Ethnicity: White ☐ Black ☐ Indian ☐ Coloured ☐ Other ☐

Marital Status:
- Single ☐
- Married ☐
- Divorced ☐
- Widowed ☐
- Living with partner ☐
- Separated ☐

Working status:
- Working full time: ☐
- Working part-time: ☐
- Not Working: ☐
- Homemaker: ☐
- Retired: ☐

Education:
- Primary: ☐
- Secondary: ☐
- Tertiary: ☐

Relationship with patient: Biological child ☐
Adopted child ☐
Foster child ☐
Step-child ☐
Grandchild ☐
Sibling ☐
Other (please specify) ☐
____________________

Living with patient: Yes ☐ No ☐

Main caregiver: Yes ☐ No ☐

Duration of caregiving: <1 year ☐
1 – 3 years ☐
>3 years ☐

Hours of care per week: < 1 hour ☐
1 – 4 hours ☐
5 – 10 hours ☐
>11 hours ☐

Number of Haemodialysis sessions: ≤ 20 ☐
21 - 40 ☐
> 40 ☐

Place of residence: Urban: formal ☐
Urban: informal ☐
Rural: formal ☐
Rural: informal ☐
Household income per month (approximate):________________________________
Number of people in household: __________________________________________

**Child Demographics: (From clinical record)**

Gender: Female ☐

Male ☐

Age (Years): 0 – 1 ☐

2 – 5 ☐

6 – 11 ☐

12 - 18 ☐

CKD Stage: ____________________

CKD Treatment: __________________

CKD diagnosis: Nephrotic syndrome (Please specify) ☐

______________________________

Nephritic syndrome (Please specify) ☐

______________________________

Congenital kidney malformation ☐

Heritable renal disease ☐

Other ☐

Unknown ☐

Time since diagnosis (years): 0 – 1 ☐

2 – 5 ☐

6 – 10 ☐

>10 ☐

**12 – Item General Health Questionnaire: (Goldberg and Williams, 1988)**

Please tick the appropriate response, as honestly as possible, in order to give an accurate assessment of your perceptions and experiences of the burden of caregiving for the child with CKD.

| **GHQ - Item** | **Less than usual (rating 0)** | **No more than usual (rating 1)** | **Rather more than usual (rating 2)** | **Much more than usual (rating 3)** |
|---|---|---|---|---|
| 1. Able to concentrate on what you are doing? | | | | |
| 2. Lost much sleep over worry? | | | | |
| 3. Felt that you are playing useful part in things? | | | | |
| 4. Felt capable of making decision about things? | | | | |
| 5. Felt constantly under strain? | | | | |
| 6. Felt that you could not overcome your difficulties? | | | | |
| 7. Been able to enjoy your | | | | |

| | | | | |
|---|---|---|---|---|
| normal day-to-day activities? | | | | |
| 8. Been able to face up to your problem? | | | | |
| 9. Been feeling unhappy or depressed? | | | | |
| 10. Been losing confidence in yourself? | | | | |
| 11. Been thinking of yourself as a worthless person? | | | | |
| 12. Been feeling reasonably happy, all things considered? | | | | |

**The Paediatric Renal Caregiver Burden Scale: (Parham et al., 2016)**

Please tick the appropriate response, as honestly as possible, in order to give an accurate assessment of your experiences as a caregiver of a child with CKD.

| Item | Never | Rarely | Some times | Often | Always |
|---|---|---|---|---|---|
| 1. Worrying about the effect of caring for my child on my health | | | | | |
| 2. Feeling that I am not able to 'switch off' to my child's condition | | | | | |
| 3. Worrying about the future | | | | | |
| 4. Feeling trapped because of caring for my child | | | | | |
| 5. Worrying if my child has had the correct amount of fluid | | | | | |
| 6. Blaming myself for my child's kidney problems | | | | | |
| 7. Feeling preoccupied with checking my child for signs of illness | | | | | |
| 8. Worrying about money due to the costs of my child's care | | | | | |
| 9. Feeling helpless when my child is ill or in pain | | | | | |
| 10. Frustration when dealing with staff that do not know my child | | | | | |

| | | | | | |
|---|---|---|---|---|---|
| 11. Feeling troubled by difficult memories of when my child was first diagnosed or has been very ill in the past | | | | | |
| 12. Worrying about my child during the night | | | | | |
| 13. Feeling that my child’s condition has taken over life | | | | | |
| 14. Worrying about the impact of my child’s condition on my other children | | | | | |
| 15. Worrying about my child getting very ill or dying | | | | | |
| 16. Feeling that other people do not understand my situation | | | | | |
| 17. Blaming myself if my child gets ill or has bad test results | | | | | |
| 18. Feeling guilty about spending less time with my other child/children/partner | | | | | |
| 19. Difficult feelings due to the uncertainty of my child’s condition | | | | | |
| 20. Feeling unable to think about my our needs | | | | | |
| 21. Sadness about not socialising as much as I want to because of caring for my child | | | | | |

| | | | | | |
|---|---|---|---|---|---|
| 22. Feeling overwhelmed by trying to fit family life around my child's condition | | | | | |
| 23. Difficult feelings due to having no privacy when at the hospital | | | | | |
| 24. Worrying about getting medical procedures wrong (e.g. dialysis, injections, tube feeding) or taking measurements incorrectly | | | | | |
| 25. Feeling under pressure to be strong for my child and family | | | | | |
| 26. Sadness that I cannot do things that I used to do because of caring for my child (e.g. work, leisure activities, hobbies) | | | | | |
| 27. Feeling alone in caring for my child | | | | | |
| 28. Worrying that my child may have to be admitted to hospital | | | | | |
| 29. Feeling overwhelmed by decisions that I have to make about my child's condition | | | | | |
| 30. Sadness about the things that my child misses out on | | | | | |
| 31. Feeling unable to 'switch off' when waiting for test results or a telephone call from the hospital | | | | | |

| | | | | | |
|---|---|---|---|---|---|
| 32. Arguing with my partner/family about my child’s care | | | | | |
| 33. Worrying about how my child is coping | | | | | |
| 34. Feeling uncertain about how to manage my child’s emotions and difficult behaviour | | | | | |
| 35. Sadness that I am not the person that I used to be | | | | | |
| 36. Worrying about the disruptions to my child’s education | | | | | |
| 37. Feeling overwhelmed by changes in my child’s usual treatment | | | | | |
| 38. Sadness that I do not have a ‘normal’ relationship with my child | | | | | |
| 39. Worrying about getting my child’s medicines wrong | | | | | |
| 40. Feeling bored when having to spend time at the hospital | | | | | |
| 41. Holding back when I disagree with medical staff | | | | | |
| 42. Feeling overwhelmed by feeding difficulties (e.g. lack of appetite, managing diet restrictions, vomiting) of my child | | | | | |
| 43. Worrying about having to deal with unexpected changes in my | | | | | |

|  |  |  |  |  |  |
|---|---|---|---|---|---|
| child's condition (e.g. unexpected hospital admissions) |  |  |  |  |  |
| 44. Feeling frustrated when having to spend time at the hospital |  |  |  |  |  |
| 45. Worrying about my child's growth and development |  |  |  |  |  |
| 46. Feeling that I should be doing more for my child |  |  |  |  |  |
| 47. Worrying that I have not understood medical information |  |  |  |  |  |
| 48. Feeling exhausted from caring for my child |  |  |  |  |  |
| 49. Difficult feelings due to my child taking responsibility in his or her care (e.g. worrying if medicines have been taken) |  |  |  |  |  |
| 50. Feeling preoccupied with keeping my child safe from illness |  |  |  |  |  |
| 51. Sadness about the impact of my child's kidney problems on my relationship with my partner |  |  |  |  |  |

**The following practices will assist me to cope with my caregiver burden:**

Please tick the appropriate response, as honestly as possible, in order to give an accurate assessment of practices that will ease your burden of caregiving.

| **Practice** | **Strongly agree** | **Agree** | **Neutral** | **Disagree** | **Strongly disagree** |
|---|---|---|---|---|---|
| 1. Dedicated times for self-care (e.g. for exercise) | | | | | |
| 2. Continuous education and information from the treatment centre (e.g. managing the disease as it progresses) | | | | | |
| 3. Family or friend support (e.g. physical or emotional) | | | | | |
| 4. Financial support from friends, family or government grant | | | | | |
| 5. Support group for caregivers of children with CKD | | | | | |
| 6. Faith-based or spiritual practices | | | | | |
| 7. Other practices that I use to cope with my caregiving burden. Please indicate | | | | | |

|  |  |  |  |  |  |
|---|---|---|---|---|---|
|  |  |  |  |  |  |

Signature: ____________________ Date: ___________________

*Thank you for your participation. All information is strictly* ***confidential*** *and will be used for research and educational purposes only.*

# Appendix 9 Caregiver Questionnaire IsiZulu

DURBAN UNIVERSITY OF TECHNOLOGY

**UMBUZO WESIGULI** **Ikhodi yokufunda:**

**Leli phepha lemibuzo lenzelwe ukungitshela kabanzi ngokuhlangene nokuqonda kwakho futhi nemibono yakho njengomnakekeli wengane enesifo sezinso (CKD).**

**Imininingwane yabanakekeli:**

Igama nesibongo: (Abaphenduli bazohlala bengaziwa futhi bazonikezwa ikhodi)

______________________________________________

Ubulili: Owesifazane ☐ Owesilisa ☐

Iminyaka: ____________

Ubuhlanga: White ☐ Black ☐ Indian ☐ Coloured ☐ Other ☐

Marital Status:
Ongashadile ☐
Oshadile ☐
Ohlukanisile ☐
Umfelokazi ☐
Ohlala NoMlingani ☐
Ohlukene ☐

Isimo Sokusebenza:
Oqashwe unomphela: ☐
Osebenza itoho: ☐
Ongasebenzi: ☐
Umenzi wekhaya: ☐
Uthathe umhlalaphansi: ☐

Ezemfundo:
Isikole sebanga eliphansi: ☐
isikole sebanga eliphezulu: ☐
☐

Imfundo ephakeme:

Ubudlelwano nesiguli:
- Ingane yakho yemvelo ☐
- Ingane yokutholwa ☐
- Ingane okungeyona eyakho ☐
- Ingane yokutholwa emshadweni ☐
- Umzukulu ☐
- Ingane yakini ☐
- Okunye (ngicela uchaze) ☐ ____________________

Uhlala nesiguli: Yebo ☐ Cha ☐

Umnakekeli omkhulu: Yebo ☐ Cha ☐

Isikhathi sokunakekela:
- ngaphansi konyaka owodwa ☐
- Iminyaka emibili noma emithathu ☐
- Ngaphezulu kweminyaka emithathu ☐

Amahora wokunakekela ngesonto:
- Ngaphansi kwehora elilodwa ☐
- Ihora elilodwa kuya kwelesine ☐
- Amahora amahlanu ukuya kwishumi ☐
- Ngaphezu kwamahora ayishuni nanye ☐

Inani lezikhathi zeHemodialysis:
- cishe - 20 ☐
- 21 - 40 ☐
- 40 - ukudlulela ☐

Indawo yokuhlala
- zasemadolobheni: Izindlu ezihlelekile ☐
- zasemadolobheni: Imijondolo ☐
- Emaphandleni: Izindlu ezihlelekile ☐
- Emaphandleni: Imijodolo ☐

Imali engenayo ngenyanga ekhaya (cishe):______________________________

Inani labantu abahlala endlini: ________________________________________

**Imininingwane yengane: (Kusuka kurekhodi lomtholampilo)**

Ubulili: Owesifazane ☐

Owesilisa ☐

Ubudala (ngeminyaka): 0 – 1 ☐

2 – 5 ☐

6 – 11 ☐

12 – 18 ☐

Isigaba akusona sesifo sezinso esingalapheki: ____________________

Ukwelashwa kwesifo esingapheliyo sezinso: __________________

ukuxilongwa kwesifo esingapheliyo sezinso : I-Nephrotic syndrome (Ngicela uchaze) ☐

______________________________

I-Nephritic syndrome (Ngicela uchaze) ☐

______________________________

Ukungasebenzi kahle kwezinso ☐

Isifo sezinso osizuzile ☐

Okunye ☐

Okungaziwa ☐

Isikhathi selokhu kutholakala ukuxilongwa kwe-dialysis (ngeminyaka): 0 – 1 ☐

2 – 5 ☐

6 – 10 ☐

Ngaphezulu kwa -10 ☐

**12 – Item General Health Questionnaire: (Goldberg and Williams, 1988)**

Sicela ubeke uphawu kwimpendulo efanele, ngokuthembeka, ukuze unikeze ukuhlolwa okunembile kwemibono yakho kanye nesplilyoni somthwalo wokunakekela ingane ene-CKD.

| **GHQ - Item** | **Ngaphansi kunokujwayelekile (isilinganiso esingu0)** | **Akukho okungaphezu kokujwayelekile (isilinganiso 1)** | **Esikhundleni esingaphezulu kokujwayelekile (isilinganiso 2)** | **Okungaphezulu kokujwayelekile (isilinganiso 3)** |
|---|---|---|---|---|
| 13. Uyakwazi ukugxila kulokho okwenzayo? | | | | |
| 14. Ulahlekelwe kakhulu ukulala ngenxa yokukhathazeka? | | | | |
| 15. Uzwa ukuthi udlala indima ewusizo ezintweni? | | | | |
| 16. Uzizwa ukwazi ukwenza isinqumo ngezinto? | | | | |
| 17. Uzizwa njalo ungaphansi kwengcindezi? | | | | |
| 18. Uzwe ukuthi awukwazi ukunqoba | | | | |

| | | | | |
|---|---|---|---|---|
| ubunzima bakho? | | | | |
| 19. Uyakwazi ukujabulela imisebenzi yakho ejwayelekile yansuku zonke? | | | | |
| 20. Uyakwazi ukubhekana nenkinga yakho? | | | | |
| 21. Uzizwa ungajabule noma ucindezelekile? | | | | |
| 22. Ulahlekelwa ukuzethemba kuwe? | | | | |
| 23. Ngabe ubuzicabanga njengomuntu ongelutho? | | | | |
| 24. Uzizwe ujabule ngokufanele, zonke izinto zicatshangelwa? | | | | |

**The Paediatric Renal Caregiver Burden Scale: (Parham et al., 2016)**

Sicela ubeke uphawu kwimpendulo efanele, ngokuthembeka, ukuze unikeze ukuhlola okunembile okuhlangene nakho konke okuhlangene nawe njengomnakekeli wengane ene-CKD.

| Izinto | Angika - ze | Ngoku - vamile | Ngezinye izikhathi | Kanin -gi | Njalo |
|---|---|---|---|---|---|
| 52. Ukukhathazeka ngomphumela wokunakekela ingane yami empilweni yami | | | | | |
| 53. Ngizwa ukuthi angikwazi 'ukucisha' isimo sengane yami | | | | | |
| 54. Ukukhathazeka ngekusasa | | | | | |
| 55. Ukuzizwa ngivalelekile ngenxa yokunakekela ingane yami | | | | | |
| 56. Kuyakhathaza uma ingane yami ithole inani elifanele loketshezi | | | | | |
| 57. Ngizisola ngezinkinga zezinso zengane yami | | | | | |
| 58. Ukuzizwa ngimatasa ngokuhlola ingane yami ukuthi ayinazo yini izimpawu zokugula | | | | | |
| 59. Ukukhathazeka ngemali ngenxa yezindleko zokunakekela kwengane yami | | | | | |
| 60. Ngizizwe ngingenalusizo lapho ingane yami igula noma isezinhlungwini | | | | | |
| 61. Ukukhungatheka lapho usebenza nabasebenzi abangayazi ingane yami | | | | | |

| | | | | | |
|---|---|---|---|---|---|
| 62. Ngizizwa ngikhathazekile ngezinkumbulo ezinzima zokuthi ingane yami yatholwa nini ukuthi iyagula okokuqala, noma yagula kakhulu esikhathini esedlule | | | | | |
| 63. Ukukhathazeka ngengane yami ebusuku | | | | | |
| 64. Ukuzwa ukuthi isimo sengane yami sithathe phez'kwempilo yami | | | | | |
| 65. Ukukhathazeka ngomthelela wesimo sengane yami kwezinye izingane zami | | | | | |
| 66. Ukukhathazeka ngengane yami ngokugula kakhulu noma ngokufa | | | | | |
| 67. Ukuzwa ukuthi abanye abantu abasiqondi isimo sami | | | | | |
| 68. Ngizibeka icala uma ingane yami igula noma inemiphumela emibi yokuhlolwa | | | | | |
| 69. Ngizizwa nginecala ngokuchitha isikhathi esincane nenye ingane / izingane / umlingani wami | | | | | |
| 70. Imizwa enzima ngenxa yokungaqiniseki kwesimo sengane yami | | | | | |
| 71. Ngizizwa ngingakwazi ukucabanga ngezidingo zami | | | | | |
| 72. Ukudabuka ngokungazihlanganisi ngendlela engifuna ngayo ngenxa yokunakekela ingane yami | | | | | |
| 73. Ukuzizwa ngicindezelekile ngokuzama ukulinganisa impilo | | | | | |

| | | | | | |
|---|---|---|---|---|---|
| yomndeni wami nesimo sengane yami | | | | | |
| 74. Imizwa enzima ngenxa yokungabi nabumfihlo lapho usesibhedlela | | | | | |
| 75. Ukukhathazeka ngokuthola ukuthi izinqumo zokwelashwa azilungile (isb. I-dialysis, imijovo, ukudla kwe-tube) noma ukuthatha izilinganiso ngokungalungile | | | | | |
| 76. Ukuzizwa ngingaphansi kwengcindezi yokuba namandla aqinile enganeni yami nasemndenini wami | | | | | |
| 77. Ukudabuka kokuthi angisakwazi ukwenza izinto ebengizenza ngenxa yokunakekela ingane yami (isb. Umsebenzi noma imisebenzi yokuzilibazisa) | | | | | |
| 78. Ukuzizwa ngingedwa ngokunakekela ingane yami | | | | | |
| 79. Ukukhathazeka ngokuthi ingane yami kungenzeka ingeniswe esibhedlela | | | | | |
| 80. Ukuzizwa ngicindezelekile ngezinqumo okufanele ngizenze ngesimo sengane yami | | | | | |
| 81. Ukudabuka ngezinto ingane yami ephuthelwa yizo | | | | | |
| 82. Uzizwa ungakwazi 'ukucisha' lapho ulinde imiphumela yokuhlolwa noma ucingo oluvela esibhedlela | | | | | |
| 83. Ukuphikisana nomlingani wami noma umndeni wami ngokunakekelwa kwengane yami | | | | | |

| | | | | | |
|---|---|---|---|---|---|
| 84. Ukukhathazeka ngokuthi ingane yami ibhekana kanjani nesimo sayo | | | | | |
| 85. Ngizizwa ngingaqiniseki ngokuthi ngiyilawula kanjani imizwa yengane yami nokuziphatha kulob'unzima | | | | | |
| 86. Okudabukisayo ukuthi angiyena lo muntu ebengikade nginguye | | | | | |
| 87. Ukukhathazeka ngokuphazamiseka kwemfundo yengane yami | | | | | |
| 88. Ukuzizwa ngicindezelwe izinguquko ekwelashweni okujwayelekile kwengane yami | | | | | |
| 89. Okubuhlungu ukuthi anginabo ubudlelwano 'obujwayelekile' nengane yami | | | | | |
| 90. Ukukhathazeka ngokuthola imithi yengane yami ngokungalungile | | | | | |
| 91. Ukuzizwa unesithukuthezi lapho kufanele uchithe isikhathi sakho esibhedlela | | | | | |
| 92. Ukuzibamba lapho ngingavumelani nabasebenzi bezokwelapha | | | | | |
| 93. Ngizizwa ngicindezelwe ubunzima bokudla (isb. Ukungabi nasifiso sokudla, ukuphatha imikhawulo yokudla, ukuhlanza) kwengane yami | | | | | |
| 94. Ukukhathazeka ngokubhekana nezinguquko ezingalindelekile esimweni sengane yami (isb. | | | | | |

| | | | | | |
|---|---|---|---|---|---|
| Ukwamukelwa esibhedlela okungalindelekile) | | | | | |
| 95. Ukuzizwa ukhungathekile lapho kufanele uchithe isikhathi esibhedlela | | | | | |
| 96. Ukukhathazeka ngokukhula nentuthuko yengane yami | | | | | |
| 97. Ngizwa ukuthi kufanele ngabe ngenzela ingane yami okuningi | | | | | |
| 98. Kuyakhathaza ukuthi angiluzwisisi ulwazi lwezokwelapha | | | | | |
| 99. Ukuzizwa ngikhathele ukunakekela ingane yami | | | | | |
| 100. Imizwa enzima ngenxa yokuthi ingane yami ithatha umthwalo wokuzinakekela (isb. Ukukhathazeka ngokuthi imithi isithathiwe) | | | | | |
| 101. Ukuzizwa ngimatasa ngokugcina ingane yami iphephile ekuguleni | | | | | |
| 102. Ukudabuka ngomthelela wezinkinga zezinso zengane yami ebudlelwaneni bami nomlingani wami | | | | | |

**Le mikhuba elandelayo izongisiza ukubhekana nemithwalo wami wokunakekela**:

Sicela ubeke uphawu kwempendulo efanele, ngokuthembeka ukuze unikeze ukuhlolwa okunembile kwemikhuba ezokwehlisa umthwalo wakho wokunakekela.

| **Zijwayeze** | **Ngivuma kakhulu** | **Ngiyavuma** | **Ukungathathi hlangothi** | **Angivumi** | **Ngiyavuma kakhulu** |
|---|---|---|---|---|---|
| 8. Izikhathi ezinikezelwe zokuzinakekela (isb. Ukuzivocavoca umzimba) | | | | | |
| 9. Imfundo eqhubekayo nolwazi oluvela esikhungweni sezokwelapha (isb.ukulawula lesi sifo njengoba siqhubeka) | | | | | |
| 10. Ukuxhaswa komndeni noma komngane (isb. Ngokomzimba nozwelo) | | | | | |
| 11. Ukuxhaswa kwezezimali okuvela kubangani, umndeni noma | | | | | |

| | | | | | |
|---|---|---|---|---|---|
| isibonelelo sikahulumeni | | | | | |
| 12. Iqembu lokusekela labanakekeli bezingane abane-CKD | | | | | |
| 13. Imikhuba esekwe okholweni noma ngokomoya | | | | | |
| 14. Eminye imikhuba engiyisebenzisayo ukubhekana nomthwalo wami wokunakekela. (Ngiyacela) | | | | | |

Eminye imikhuba engiyisebenzisayo ukubhekana nomthwalo wami wokunakekela. Sicela ucacise.

________________________________________________________

Isiginesha: ______________ Usuku: ____________________

*Siyabonga ngokubamba kwakho iqhaza. Yonke imininingwane iyimfihlo ngokuphelele futhi izosetshenziselwa ucwaningo kanye nezinhloso zokufundisa kuphela*.

## Appendix 10 Staff Questionnaire

**Staff Questionnaire** **Study Code: ________**

Surname: ____________________ First Name: ___________________

Occupation: _______________________

Welcome and introduction. Introduction of members in the focus group.

Brief introduction of aims and objectives of the focus group.

Possible questions to elicit information

1. Is there a formal instrument to assess the following attributes of the caregiver of the child with CKD:

| | YES | NO |
|---|---|---|
| a) The knowledge | ☐ | ☐ |
| b) The skills | ☐ | ☐ |
| c) The attitudes | ☐ | ☐ |

2. How caregivers are advised about the caregiving tasks of the child with CKD?

a) Verbal, informal sessions ☐
b) Written information (for example, pamphlets) ☐
c) None ☐
d) Other (please specify) ☐

____________________________________________ ☐

3. How is communication fostered to address any concerns of the caregiver (outside the scheduled dialysis sessions?)

a) Make an appointment to address issue/s ☐

b) Telephonically ☐

c) Electronically (for example, emails) ☐

d) None ☐

e) Other ☐

4. Are there interventions/counselling within the Renal Unit that assists the caregiver manage their caregiver burdens to improve overall patient outcomes? If yes, please describe them.

5. Suggest strategies that can provide support interventions to assist the caregiver manage their caregiver burdens to improve overall patient outcomes.

Thank you for your co-operation.

All your responses are confidential and will be used for educational purposes only.

# Appendix 11 Publication--Identification of medicinal plants used for chronic kidney disease

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Page 1 of 8 Review Article

## Identification of medicinal plants used for chronic kidney disease: An update of reported literature in South Africa

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**Background:** Chronic kidney disease (CKD) is a debilitating condition that is becoming more common around the world, as well as a financial and social burden on healthcare systems. If not treated with kidney replacement therapies, kidney failure, the final stage of CKD, can be fatal. Chronic kidney disease patients are now seeking the use of alternative remedies, including medicinal plants, as the primary source of healthcare.

**Aim:** This review aimed to evaluate the use of medicinal plants in the treatment of CKD and other associated kidney diseases in South Africa.

**Method:** This article summarises previous research (2010–2021) on the impact of traditional plant-based medicine in CKD treatment and identifies the context between traditional and conventional medicines. Various scientific databases were used to source key literature.

**Results:** The findings of this study revealed 10 medicinal plant species from nine different botanical families that are commonly used for the treatment of CKD and other kidney-related diseases in South Africa. In addition, the study demonstrated that despite medicinal plants having toxic impacts, they were still the preferred choice of medication for CKD, especially in developing countries.

**Conclusion:** It is crucial to validate the balance between the risks and benefits of medicinal plants in CKD treatment to further enhance the credibility of medical plants in drug development.

**Contribution:** This study contributes to the existing knowledge of medicinal plants used in CKD treatment primarily in South Africa.

**Keywords:** medicinal plants; chronic kidney disease; traditional medicine; conventional medicine; renal therapies.

## Introduction

Over the last two decades, there has been significant global population growth, ageing and an accelerated rate of epidemiologic transition, with lower communicable disease mortality and an increased burden of noncommunicable diseases (Piret & Boivin 2021). Chronic kidney disease (CKD), a well-known health problem worldwide (Herrera-Añazco et al. 2019), is a debilitating condition that is becoming more common around the world, as well as a financial and social burden on healthcare systems in developed and developing countries (Khan et al. 2022). Diabetes and hypertension are widely regarded as the two leading causes of CKD disease (Zhao et al. 2021). Although statistics vary by country, the prevalence of this disease has recently increased from year to year (Khan et al. 2022). Chronic kidney disease rates rise rapidly with age, with prevalence in those aged 75 years and up being twice as high as those aged 65–74 years, and nearly seven times higher than those aged 18–54 years (42%, 21% and 6%, respectively). The prevalence of CKD is generally higher in lower socio-economic groups (14% vs. 8% in higher socio-economic groups) (Khan et al. 2022). Indigenous populations are frequently at a higher risk of CKD than nonindigenous populations because of their limited access to hospitals and healthcare centres (Herrera-Añazco et al. 2019; Khan et al. 2022). Current therapies using commercially available drugs only delay the progression of CKD, ultimately creating a financial burden on healthcare systems and an expectation of a rise in hospitalisations and treatments. Therefore, poorer countries and disadvantaged people have adopted the use of medicinal plants as a major source of CKD treatment.

Medicinal plants have been recognised as potential drug candidates because they possess drug-like properties (Shakya 2016). The term 'medicinal plants' refers to a variety of plants used in herbalism, some of which have medicinal properties. These medicinal plants are regarded as a rich source of phytocompounds for drug development and synthesis. Furthermore, these plants play an important role in the development of human cultures all over the world (Mothibe & Sibanda 2019). Many patients, particularly in developing countries, continue to seek both traditional and allopathic treatments. People are increasingly turning to traditional medicine for a variety of reasons, including high costs of contemporary medicines, a lack of proper treatment options and allopathic treatment side effects that are frequently unpleasant and/or serious (Xego, Kambizi & Nchu 2021). A wide variety of medicinal plants are used in South African traditional medicine to treat CKD. This article focuses on the potential of South African traditional medicine and medicinal flora to supplement conventional medicine in the treatment of CKD for future research and development.

## Methods

This article summarised previous research (2010–2022) on the impact of traditional herbal medicine in CKD management and generated a list of some species that have traditionally been used in South Africa to manage and treat CKD.

## Review findings

### Conventional medicines in South Africa

South Africa's primary healthcare system is based on conventional medicine (Western, orthodox, allopathic or modern medicine) (Mothibe & Sibanda 2019). Conventional medicine is entirely based on biochemical reactions that occur within the body (Xego et al. 2021). Although conventional medicine is mostly used as a first line of defence for human ailments, it is often not a preferred choice by indigenous people (Mothibe & Sibanda 2019). Xego et al. (2021) highlighted the shortfalls in conventional medicine in South Africa and further emphasised the lack of proper healthcare facilities in rural areas being a driving force in deaths from treatable diseases. While there is no cure for CKD, there are prescribed treatments to help relieve symptoms and prevent it from getting worse. Lifestyle changes, preferably a healthy lifestyle and drugs used to control associated problems such as high blood pressure and high cholesterol, are often the initial prescribed treatment for kidney disease (Khan et al. 2022). Treatment with agents such as an angiotensin-converting enzyme inhibitor (ACEI) and angiotensin receptor blocker (ARB) remains the mainstay for retarding the progression towards end-stage renal disease (CKD5) (Zhao et al. 2021). Many studies have shown that despite treatment with ACEIs and ARBs, there is incomplete blockade of the renin-angiotensin cascade, as evidenced by persistent or increasing plasma aldosterone levels. This phenomenon is known as 'aldosterone escape', and it is thought to be one of the primary causes of CKD progression (Lu, Ku & Campese 2010; Romagnani et al. 2017; Zhao et al. 2021). For a small proportion of people with CKD, the kidneys will eventually stop functioning. Therefore, as the disease gradually progresses, dialysis, which is known to replicate some of the kidney functions, is required to remove the waste products and excessive fluid from the blood (Vadakedath & Kandi 2017). According to Vadakedath and Kandi 2017, there are two main types of dialysis:

- Haemodialysis: Blood is diverted into an external machine, where it is filtered before being returned to the body. This is usually carried out three times per day at a hospital or at home.
- Peritoneal dialysis: This entails pumping dialysis fluid into a space inside the stomach to draw waste products from the blood as it passes through vessels lining the inside of the stomach. This process is often done at home several times a day or overnight.

Dialysis is often a lifelong treatment, especially if the patient has not received a kidney transplant. A kidney transplant is the most effective treatment for advanced kidney disease, but it requires major surgery and the use of medications (immunosuppressants) for the rest of one's life to prevent the body from attacking the donor organ (Vadakedath & Kandi 2017). However, there is still a donor shortage; an individual could wait months or years for a transplant. In developing countries, proper healthcare facilities and cost-effective treatment measures are often a challenge. Unfortunately, the African continent remains unable to deal with the ongoing CKD scourge because of a lack of resources, among other factors. In South Africa, the difficulties that poor and marginalised rural communities face in accessing healthcare cannot be overstated (Mothibe & Sibanda 2019). In addition, conventional treatments often have harsh side effects. Therefore, most underprivileged communities are seeking the use of medicinal plants as a more effective, easily accessible and safer treatment option (Khan et al. 2022).

### Traditional medicines in South Africa

It has become clear in recent decades that there is a plethora of plants with medicinal potentials, and it is increasingly being accepted that medicinal plants may offer potential template molecules in the drug discovery process (Suntar et al. 2020). Traditional medicine is also known as phytomedicine, folk medicine, ethnomedicine and alternative medicine, and it is increasingly becoming one of the most important aspects of speedily flourishing global commercial health enterprise (Djordjevic 2017). Recognition of plant-based medicines is gaining momentum in most countries. From 1960 to 2019, more than 110 000 studies related to medicinal plants have been published, emphasising a list of over 70 000 medicinal plants (Ghirga et al. 2021). The safety and efficacy of traditional medicines are increasing and becoming a more preferred choice over conventional medicine, as plants are easily accessible and a cheaper alternative (Mothibe & Sibanda 2019). Based on estimates by the World Health Organization (2013), 80% of the world's population rely on plant-based medicines. The use of plants as medicinal remedies remains an integral and important part of the people's traditions and culture in South Africa, and this is expected to continue in the near future (Ayele 2018; Mothibe & Sibanda 2019; Xego et al. 2022). To corroborate this point, traditional medicine has been found to be highly concentrated in rural areas because of the rural population's preference for traditional ways of life such as health maintenance, as well as the prevention, diagnosis, treatment and improvement of physical and mental illness (Xego et al. 2022). However, the situation has changed in the 21st century, with traditional healthcare overlapping with conventional medicine. The report of Mothibe and Sibanda (2019) indicated that the affordability and accessibility of medicinal plants are the major driving forces for their exploration. Interestingly, although current advancements in modern medicine have provided remarkable outcomes in the treatment of various human ailments, many people in rural areas still depend on traditional medicine for their primary healthcare needs (Ayele 2018). New drug discoveries and syntheses of new and novel formulations are based on herbal medicines, as plants possess an array of bioactive compounds that have many pharmacological properties (Süntar 2020). Despite the success of drug development using medicinal plants over the past three decades, future endeavours face many challenges. The quality of the plant-based product is questionable (Shakya 2016). Plants can easily be contaminated during harvesting and processing. Heavy metal contamination is one of the major problems encountered in plant-based products (Shakya 2016). Therefore, it is of paramount importance to improve the quantity and quality of plant-based products.

## Use of medicinal plants in chronic kidney disease therapy

Until the 18th century, the therapeutic properties of many plants, their effect on human ailments and their method of treatment were known, but the bioactive compounds were unknown (Falaro & Tekle 2020). Plant bioactive compounds (phytocompounds) are known as the 'key' factor in the medicinal properties of plants (Falaro & Tekle 2020). Many human diseases, including cardiovascular disease, hepatorenal disease, diabetes, cancer and neurodegenerative disorders, have been reduced by phytocompounds (Shakya 2016). By use of traditional medicinal plants, several African plants have found their way to modern medicine. Medicinal plants date back centuries and have been an important source and component of modern drugs developed using cutting-edge scientific techniques (Majolo et al. 2019). It is estimated that 700 000 tonnes of plant materials are used in South Africa each year to produce herbal therapeutics worth 1.2–2.5 billion rands (Cock, Mavuso & Van Vuuren 2021).

Ethnomedicinal information of South African plants used in the treatment of CKD and associated ailments is shown in Table 1. A total of 10 species belonging to nine botanical families are used to treat CKD and related kidney ailments in South Africa, as documented between 2015 and 2020. A comprehensive review by Cock et al. (2021) revealed over 100 plant species used for the treatment of kidney, bladder and urinary tract ailments. Their findings show that the usage of

**TABLE 1:** Medicinal plants recommended for chronic kidney disease treatment and associated diseases in South Africa.

| Scientific name | Family | Common name(s) | Plant part(s) | Usage | Therapeutic effect | References |
|---|---|---|---|---|---|---|
| Aloe vera and A. ferox | Xanthorrhoeaceae | Cape aloes | Gel, leaves, rind, stem | Gel extracts or decoctions | Kidney inefficiency | Christaki and Florou-Paneri, 2010; Nalimu et al. 2021 |
| Lessertia frutescens | Fabaceae | Sutherlandia, cancer bush, turkey flower, balloon pea (English); *umnwele, unwele* (isiXhosa and isiZulu); *kankerbossie, blaasbossie, blaas-ertjie, eendjies, gansiekeurtjie, klappers, hoenderbelletjie* (Afrikaans); *phetola, mokakana* (Setswana); *lerumo-lamadi* (Sepedi); *muso-pelo, motlepelo* (Sesotho) | Leaves and young stems | Decoctions | Kidney ailments | Aboyad et al. 2013 |
| Harpagophytum procumbens | Pedaliaceae | Devil's claw (English); *sengaparile* (Setswana) | Root or tuber | Decoctions | Kidney and bladder disorders | Brendler 2021 |
| Hypoxis hemerocallidea | Hypoxidaceae | African potato (English); *sterretjie, afrika-patat* (Afrikaans); *inkomfe, ilabatheka* (isiZulu); *inongwe* (isiXhosa); *moli kharatsa, lotsane* (Sesotho) | Tuber, leaves, bulbs | Decoctions | Urinary tract and kidney infections | Matyanga et al. 2020 |
| Eucomis autumnalis | Hyacinthaceae | Pineapple flower, pineapple lily (English); *wildepynappel, krulkoppie* (Afrikaans); *umathunga* (isiZulu) | Bulb | Decoctions | Urinary tract and kidney infections | Alaribe et al. 2018 |
| Plumbago auriculata | Plumbaginaceae | Cape leadwort, Blue plumbago, *blousyselbos* (Afrikaans); *umabophe* (isiXhosa and isiZulu); *umasheleshele* (isiZulu) | Leaves, stems | Decoctions | Kidney disease and urinary tract infections | Singh et al. 2018 |
| Agathosma betulina | Rutaceae | *Buchu* (English); *boegoe* (Afrikaans); *bocho* (Sotho) | Leaves | Decoctions | Kidney ailments | Van Wyk and Gorelik 2017 |
| A. capensis | Rutaceae | Spicy *buchu* (English); *anysboegoe, steenbokboegoe* (Afrikaans) | Leaves | Decoctions | Urinary and kidney ailments | Hulley and Van Wyk 2017 |
| Solanum aculeastrum | Solanaceae | Soda apple, soda apple nightshade, goat apple, poison apple, bitter apple, *Gifappel* (Afrikaans); *umthuma, untumane* (isiZulu). | Fruit | Decoctions | Urinary tract infections and kidney ailments | Mhlongo and Van Wyk 2019 |

Note: Please see the full reference list of Govender, S., Singh, K., Coopoosamy, R.M. & Adam, J., 2023, 'Identification of medicinal plants used for chronic kidney disease: An update of reported literature in South Africa', *Journal of Medicinal Plants for Economic Development* 7(1), a182. https://doi.org/10.4102/jomped.v7i1.182 the article for more information.

medicinal plants for kidney and associated ailments dates to 1923. These records put into perspective the extraordinary value of medicinal plants against human ailments. Roots, stems, leaves, bulbs and gel exudates of plant species were administered as decoctions by local traditional communities. The results of their study revealed that decoctions made with medicinal plants were the common form of consumption. Decoctions are made by boiling desired plant parts in water, and the plant material used is frequently not weighed or measured. In some cases, administering the incorrect dosage can result in toxicity.

The ability of medicinal plants to boost the body's natural antioxidant defence mechanisms is often responsible for their beneficial effect on kidney disease (Khan et al. 2022). Previous studies conducted in patients with CKD in Tanzania, Peru and China found frequent use of medicinal plants (Herrera-Añazco et al. 2019; Stanifer et al. 2015; Wu et al. 2021). However, the characteristics of their use could be different in the South African population because of cultural differences between the countries. A brief description of plants utilised for CKD in South Africa follows.

### Aloe vera Linn. (Figure 1a) and Aloe ferox Mill. (Figure 1b)

These species belong to the family Xanthorrhoeaceae. *Aloe vera* is widely distributed in tropical and subtropical regions, and *Aloe ferox* is indigenous to South Africa (Christaki & Florou-Paneri 2010; Nalimu et al. 2021). Both are succulent species in the *Aloe* genus and are often harvested for commercial products. While *A. vera* is the most utilised species, both species have pharmacological properties against various human ailments, such as antidiabetic, anti-inflammatory, antioxidant, respiratory disorders, antimicrobial and antiviral properties (Christaki & Florou-Paneri 2010; Nalimu et al. 2021). Furthermore, both plant species are also used in many consumer products, including beverages, skin lotion, cosmetics, ointments or gels for minor burns and sunburns (Christaki & Florou-Paneri 2010; Nalimu et al. 2021).

### Lessertia frutescens (syn. Sutherlandia frutescens) (L.) Goldblatt & J.C. Manning (Figure 1c)

Belonging to the Fabaceae family, *Lessertia frutescens* is a long-used medicinal and ornamental plant (The Plant List 2022). This species is found in the dry parts of southern Africa, including the Western Cape and up the west coast as far north as Namibia and into Botswana, as well as the western Karoo and the Eastern Cape (Lei et al. 2015). It is also found in Mpumalanga and KwaZulu-Natal. It has a wide range of variations within its distribution. The common name 'cancer bush' derives from its reputation as a cancer cure. *L. frutescens* is also used as a therapeutic to treat heartburn, gastrointestinal disorders, backache, diabetes, inflammation, kidney disease, emotional stress and liver problems (Lei et al. 2015).

### Harpagophytum procumbens (Burch.) DC ex Meisn. (Figure 1d)

This species is commonly known as devil's claw in the family Pedaliaceae; it is one of the chief medicinal plants in southern Africa (Brendler 2021). It is widely distributed in North West, the Free State region and the Northern Cape. Devil's claw is a miracle cure-all, but only whole extracts, not isolated parts, have therapeutic properties such as being useful for kidney and bladder disorders, as well as anti-arrhythmic, antibacterial, anti-inflammatory, antirheumatic, diuretic, hypotensive, laxative, purgative, sedative and bitter tonic properties (Brendler 2021).

### Hypoxis hemerocallidea Fisch., C.A. Mey. & Avé-Lall. (Figure 1e)

Hailed as a 'miracle muti' and 'wonder potato', this species is in the family Hypoxidaceae. *Hypoxis hemerocallidea* is distributed in KwaZulu-Natal, the Free State, the Eastern Cape, North West, Limpopo, Gauteng and Mpumalanga, where it is used for its many medicinal benefits (Matyanga et al. 2020). These include its use as a laxative and to expel intestinal worms; it is used to treat prostate hypertrophy, urinary tract infections and testicular tumours (Matyanga et al. 2020). The plant is also used to treat anxiety, palpitations, depression and rheumatoid arthritis. Although the plant derivatives are sold in many multimarkets, the raw products can be toxic and need to be administered with caution (Matyanga et al. 2020).

### Eucomis autumnalis (Mill.) Chitt. (Figure 1f)

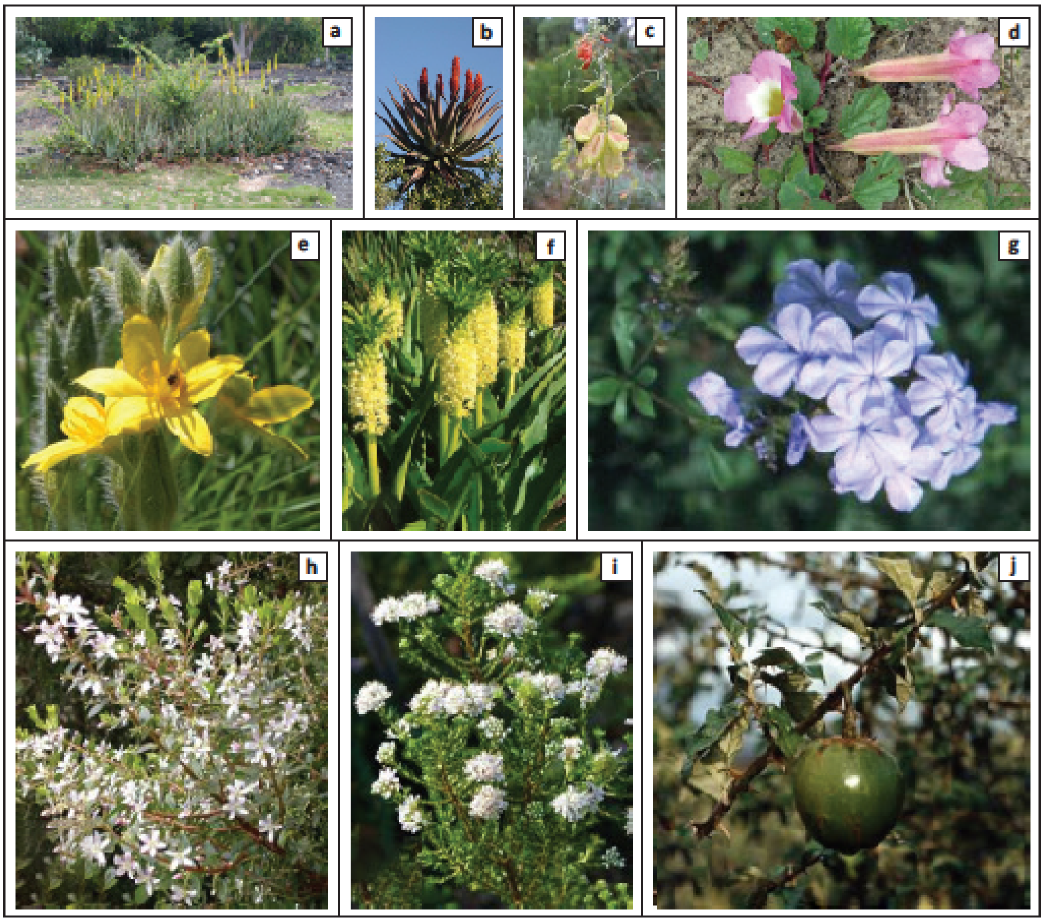
Commonly known as the 'pineapple flower', this species, belonging to the family Hyacinthaceae are distributed in open grasslands and forest margins in Limpopo, the Eastern Cape, KwaZulu-Natal, Zimbabwe and Malawi (Alaribe et al. 2018). *Eucomis autumnalis* is used medicinally in South Africa even though the bulb is toxic. Decoctions are also used to treat urinary diseases, stomach aches, fevers, colic, diabetes, inflammation, viral and bacterial infections, flatulence, hangovers and syphilis, as well as to aid in childbirth (Alaribe et al. 2018).

### Plumbago auriculata Lam. (Figure 1g)

Common in South Africa, *Plumbago auriculata*, in the family Plumbaginaceae, is distributed in KwaZulu-Natal, the Southern and Eastern Cape, the Free State, Gauteng and North West provinces (Singh et al. 2018). This species is used traditionally to treat various human illnesses including diabetes, cardiovascular disease, kidney infections, gastrointestinal disorders, respiratory disorders, warts, skin disease, wounds, cancer therapy, microbial infections and inflammation (Singh et al. 2018). Plumbagin, also known as the *Plumbago* genus' marker compound, is toxic (Singh, Naidoo & Baijnath 2018). Therefore, the use of the plant for medicinal purposes needs to be administered cautiously.

### Agathosma betulina (L.) Pillans (Figure 1h)

*Agathosma betulina* is a flowering plant in the Rutaceae family native to western South Africa's lower-elevation mountains, where it grows near streams in fynbos habitats (Van Wyk & Gorelik 2017). *Buchu* is a part of the Khoi and San people's cultural heritage, and they used the dried and powdered leaves mixed with sheep fat to anoint their bodies. To alleviate



*Source*: The Plant List, 2022, viewed 10 September 2022 from http://www.theplantlist.org/ and iNaturalist, 2022, viewed 10 September 2022 from https://www.inaturalist.org/home.

**FIGURE 1:** Medicinal plants used in chronic kidney disease treatment in South Africa: (a) *Aloe vera*; (b) *A. ferox*; (c) *Lessertia frutescens*; (d) *Harpagophytum procumbens*; (e) *Hypoxis hemerocallidea*; (f) *Eucomis autumnalis*; (g) *Plumbago auriculata*; (h) *Agathosma betulina*; (i) *A. capensis*; (j) *Solanum aculeastrum*.

stomach discomfort, the leaves were also chewed. *A. betulina* leaves steeped in vinegar or brandy were an important part of the early Cape colonists' medicine cabinet (Van Wyk & Gorelik 2017). They used it to treat stomach problems, worms, indigestion, kidney and bladder problems, among other things (Van Wyk & Gorelik 2017).

### Agathosma capensis (L.) Dummer (Figure 1i)

Like *A. betulina*, this species is also part of the Rutaceae family and distributed in Western Cape, Eastern Cape and Northern Cape (Hulley & Van Wyk 2017). The common characteristic of the Rutaceae (*buchu*) family is the presence of translucent cavities (glands) containing aromatic oils found on the leaves and fruit. The medical properties of *A. capensis* are the same as *A. betulina*. However, *A. betulina* was the preferred choice for medicinal use in the Rutaceae family (Hulley & Van Wyk 2017).

### Solanum aculeastrum Dunal. (Figure 1j)

Soda apple, goat apple, poison apple or, more ambiguously, 'bitter-apple' are all names for *Solanum aculeastrum*. It is a poisonous nightshade species native to Africa that is unrelated to true apples (Mhlongo & Van Wyk 2019). Belonging to the family Solanaceae, *S. aculeastrum*'s extremely bitter fruit is used medicinally (fresh, boiled or burned) in a variety of ways for humans and domestic animals. The poisonous alkaloid, solanine, is found in both mature and immature fruits and hence needs to be administered with caution (Mhlongo & Van Wyk 2019).

### Herbal medicine toxicity and kidney injury

Herbal remedies' nephrotoxic potential is becoming more widely recognised. Causality is suspected when there is a temporal relationship between the ingestion of an agent and the injury. Herbal toxicity can develop in any of the following situations (Jha 2010):

- Consumption of a plant with unknown toxicity.
- Incorrect identification leading to the substitution of a nontoxic plant with a toxic one.
- Contamination with nephrotoxic nonherbal drugs (e.g. nonsteroidal anti-inflammatory agents), pesticides or chemicals (e.g. heavy metal contamination from soil or water) can occur intentionally or inadvertently.
- Enhancing the toxic effect of a conventional drug because of interaction with a compound(s) present in the medicinal plant.
- Consumption of meat from an animal that has grazed on a toxic or poisonous plant.

As the kidneys are the main route of excretion from the body, renal involvement with the use of medicinal plants can take several forms, such as tubular function defects, CKD, acute kidney injury, renal papillary necrosis, urolithiasis and urothelial cancer and systemic hypertension (Jha 2010). Furthermore, patients with existing CKD can develop complications because of prolonged use of herbal medicines. Jha (2010) has provided a compelling report on the impact of certain plant species on CKD, but the precise mechanism of renal injury was unknown. His study further highlighted that nephrotoxicity is a direct effect of aristolochic acid, which is found in most leaves, stems, fruits and roots of certain plant species such as plants in the genera *Aristolochia* and *Asarum*. However, the exact mechanism of nephrotoxicity remains unknown. Although the nephrotoxicity of some Chinese medicinal plants containing aristolochic acid is well known, other nephrotoxic elements in medicinal plants have been identified, including oxalic acid, djenkolic acid and arabinogalactans (Herrera-Añazcoa et al. 2019). Nevertheless, medicinal plants are not screened for the presence of these toxic substances prior to administration, especially when administered by a traditional practitioner (Xego et al. 2021).

The limited information provided in the previous investigation reveals that not all medicinal plants are toxic as CKD treatment. This was further emphasised by Stanifer et al. (2015), who reported the use of medicinal plants for CKD in Tanzania. In their study, most of the participants were from urban areas and were above 45 years old, with underlying conditions such as diabetes, heart disease, hypertension and HIV. Their findings showed that 70% of the participants made use of traditional medicine for CKD, while the remaining 30% used a combination of traditional and conventional medicine. Patients did exhibit adverse side effects such as increased bleeding risk, diarrhoea, nephrotoxicity and hepatotoxicity from the use of medicinal plants; however, their findings agreed that not all medicinal plants are toxic, as CKD treatment and nephrotoxicity are dose dependent. As with most medication (traditional or conventional), the higher the recommended dosage, the greater the risk of side effects. Therefore, traditional medication needs to be administered cautiously.

This coincides with a more recent study by Herrera-Añazco et al. (2019) on the use of medicinal plants to treat CKD in Peru. They reported that more than 50% of their CKD patients preferred the use of medicinal plants as a source of treatment, as they found it to be less harmful than typical CKD drugs. Patients also divulged that they stopped using their prescribed conventional medication to switch over to traditional medicine.

In another study, Wu et al. (2021) reported on the use of Chinese traditional medicine (CTM) as CKD treatment. The findings of their study revealed that the administering of CTM in a clinical practice had beneficial effects on CKD, which included slowing down disease progression, improving patients' clinical symptoms, reducing certain complications, lower risk of mortality, improving overall health and delaying the onset of dialysis and kidney transplantation. However, there is still a lack of high-quality evidence-based research that supports the use of medicinal plants for CKD treatment. Most of the medicinal plants recommended by traditional practitioners have not been investigated in animal and human models of renal stones, which provides a new area of research. They can be refined and processed to produce natural drugs in terms of safety and effectiveness.

### Interactions between herbal medicines and Western medicines

Although a sizeable number of CKD patients use both traditional and conventional medicine, reports indicate that a greater number of these patients use traditional herbal medicines after diagnosis (Zhao et al. 2021; Khan et al. 2022). According to studies (2015–2021), CKD patients use traditional medicine alone or in conjunction with conventional medicine (Zhao et al. 2021). Current therapies using commercially available drugs, such as ACEIs, angiotensin II receptor blockers and calcium channel blockers, generally only delay the progression of CKD (Wu et al. 2021). Therefore, conventional doctors rely on plant-based medicines as a supplementary option to conventional medicine for an array of human ailments (Xego et al. 2021). Many studies have aimed to evaluate the synergistic effect of traditional medicine and conventional medicine. Zhao et al. (2021), demonstrated that Chinese herbal medicines as an adjuvant to conventional medicines may benefit patients with CKD. In addition, the plant species listed in their study also displayed a renoprotective role in various ways rather than a single target such as anti-inflammatory, antioxidative, anti-apoptotic, antifibrotic and antidiabetic. Furthermore, when compared with conventional medicine, treatment with Chinese medicine combined with conventional medicine resulted in a significantly lower risk of dialysis.

Despite most traditional medicines needing to be thoroughly investigated and scientifically validated, integrating traditional and conventional medicine has the potential to play a major role in the healthcare delivery system of South Africa and other developing countries.

## Conclusion

Chronic kidney disease has a significant health impact on the South African population and is predicted to increase over the years. Modern healthcare systems have become a challenge in South Africa as the majority of the underprivileged find it difficult to access conventional medicine, and it is often too expensive. Many patients seek out traditional plant-based medicine as their primary healthcare.

The development and use of medicinal plants as phytomedicine against various human ailments have a very long historical background. Plants are easily accessible and are often a cheaper option than conventional drugs. The biologically active compounds found within these plants are the major source of the plant's medicinal properties. This review highlighted the use of medicinal plants used to treat CKD in South Africa. Traditional medicine has become a preferred choice of treatment for most patients in rural and urban areas.

Although some previous research has suggested that certain medicinal plants have beneficial effects in patients with CKD (such as slowing disease progression with traditional medicine), these studies also acknowledge the potentially toxic effects of medicinal plants. As a result, while the use of medicinal plants may be promising, a fair balance of risks and benefits is yet to be established. This is important because, in the South African population, one out of every three CKD patients discontinues conventional medicine in order to use medicinal plants. Therefore, better screening methods for plants and other natural sources are required to advance research for the development and characterisation of new natural drugs.

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### Data availability

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