Impact of socio-economic factors and Health Related Quality of Life on patients on renal dialysis in Cape Town

by

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TABLE OF CONTENTS

Declaration

I, *Waldo Welgemoed*, hereby declare that the work, on which this dissertation/thesis is based, is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.
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Abstract

Background: South Africa [SA] has a growing burden of chronic kidney disease [CKD], with limited health resources. Cape Town offers a PD-First policy due to both limitations on haemodialysis slots and cost saving measures. This study aimed to compare health related quality of life [HRQOL] between haemodialysis [HD] and peritoneal dialysis [PD], given the lack of autonomy in modality choice and socio-economic challenges our patients face.

Methods: This cross-sectional study was performed at Groote Schuur Hospital between July 2015 and December 2016. Demographic, socio-economic variables and perception of safety were collected. HRQOL was assessed using the Kidney Disease Quality of Life-Short Form [KDQOL-SF^{TM}] version 1.3. All data was compared between the two dialysis modalities.

Results: 77 HD patients and 33 PD patients were included in the study (Total n=110). There were no significant differences in demographics. The median age was 42.5 years [IQR: 32.4-48.6] and 57.3% were female. HD patients had less pain [p=0.036], better emotional well-being [p=0.020] and better energy/fatigue score [p=0.015]. Both cohorts experienced impairment in physical health, with PD having significant limitation [p=0.05]. The only significant symptoms in the renal domain was that PD experienced more shortness of breath [p=0.0001]. Overall, patients in both groups had very poor socio-economic circumstances. Safety was a major concern with the majority reporting feeling unsafe in their homes.

Conclusions:

The patients in our dialysis service have very challenging social circumstances with high rates of poverty and profound safety concerns. Patients on PD scored worse in 4 HRQOL domains, possibly due to a lack of autonomy in dialysis modality choice and less frequent contact with dialysis staff to provide encouragement and support. Additional psychological and social support needs to be instituted to help improve our patient's wellbeing on PD.

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List of Tables and Figures:

Abbreviations

APD	Automated **peritoneal** dialysis
Avg	Average
CI (95%)	95% confidence interval
CKD	Chronic kidney disease
CT	Cape Town
ESRD	End-stage renal disease
GDP	Gross domestic product
GSH	Groote Schuur Hospital
HD	Haemodialysis
HIV	Human immunodeficiency virus
HRQOL	Health-related quality of Life
IQR	Interquartile range
KDQOL-SF™	Kidney Disease Quality of Life-Short Form
Km	Kilometer
Med	Median
PD	Peritoneal dialysis
pmp	Per million population
Pop	Population
QOL	Quality of life
R	South African Rands
RRT	Renal replacement therapy
SA	South Africa
SD	Standard deviation
SF-36	36-item Short Form Survey
StatsSA	Statistics South Africa
TB	Tuberculosis
WC	Western Cape

CHAPTER 1: LITERATURE REVIEW

South Africa and its burden of poverty

Although South Africa [SA] is an upper-middle-income country, with a gross domestic product [GDP] of 348.872 Billion US$ in 2017,[1] its distribution of wealth is grossly unequal, with a Gini coefficient of 63 in 2014.[2] This leads to wide-spread poverty: 25.2% of the population (13.8 million) is extremely poor and lives below the food poverty line.[3] There is also inequality in the distribution of health care. These inequalities are remnants of South Africa's colonial and apartheid past.[4] The health inequality favours the rich with better education, employment opportunities and housing contributing to the disparity in health.[5]

The Western Cape [WC], like the rest of South Africa, has poor socio-economic circumstances – 16,6% of households live in informal housing, and almost 7% do not have access to clean drinking water or a flushing toilet, (3,6% having access to only a bucket toilet). In addition, 13,2% of households reported hunger during the previous year.[6]

Table 1: Compares socio-economic variables between overall population of the City of Cape Town [CT], the Western Cape and South Africa.[6]

	City of Cape Town (n=4 005 016)	Western Cape (n=6 279 730)	South Africa (n=55 653 654)
Female	51.6%	50.7%	---
Race			
African	42.6%	35.7%	80.4%
Mixed	39.9%	47.5%	7.2%
White/Asian	17.6%	16.8%	12.4%
Married (population aged >18)	41.1%	40.2%	30.7%
Education (population aged 20+)			
Primary	4.2%	5.1%	---
Secondary	35.0%	33.8%	---
Tertiary	14.8%	12.7%	---
Employed	---	---	42.4 % *

Average household income per month †	---	R 18 580	R 11 514
Reporting hunger	12.7%	13.2%	19.9%
Dwelling			
Formal	81.6%	82.4%	79.2%
Informal	17.6%	16.6%	13.0%
Traditional/Other	0.7%	1.0%	7.8%
Home occupants	3.2	3.2	---
Water	93.7%	93.2%	84.5%
Electricity	97.8%	97%	---
Flushing toilet	92.8%	93.4%	63.4%

* [7]

† at time of study (2015) [8]
Abbreviations: R, South African Rand

Ethnicity

The ethnicities of patients in the renal unit at Groote Schuur Hospital [GSH] are mostly African and mixed ancestry(coloured).[9, 10] Although this is not representative of the broader South African population, it reflects that of the Western Cape [WC] and City of Cape Town [CT] where the study was done. Compared to the rest of the CT/WC population, there are fewer white and Asian patients at GSH's Renal unit. These two groups generally seek renal replacement therapy [RRT] in the private health sector.[11, 12]

Safety

In addition to poor socio-economic conditions, South Africans feel unsafe.[13] This is not surprising, considering the violent crime and murder rates – 1 055 per 100 000 and 33 per 100 000 respectively.[14] Compared to the global average of 6,04 per 100 000 the murder rate is extremely high.[15] Cape Town has an even higher rate of violence than the rest of South Africa. It is the metro with the highest reported violent crime and murder rate in the country (1 647 per 100 000 and 63 per 100 000 respectively). These numbers represent an underestimation due to underreporting by the affected victims due to a lack of trust in the police, prosecutors, courts and

correctional services.[13] In Cape Town this high murder rate is mostly driven by gang violence.[16]

Limitations to renal replacement therapy [RRT] in SA

South Africa has both a public and private health care sector. The public health sector serves 84% of the population, yet this sector accounts for only half of the total health expenditure in South Africa.[17, 18] Furthermore, it has been shown that the lower socio-economic group bears the greatest burden of disease, yet utilizes health services the least.[19-21] The Western Cape has an estimated population of 6,36 million, with 74.8% (4.76 million) requiring access to public health care.

South Africa carries a heavy burden of Human Immunodeficiency Virus [HIV] infection, with approximately 13.1% of the population (approximately 7.5 million people) living with HIV.[22] This is complicated by extremely high rates of tuberculosis (567 per 100 000 population).[23] Morbidity and mortality are further compounded by an increasing burden of non-communicable diseases.[24] All these illnesses compete for the already limited health resources in the public sector.

Due to the large costs of RRT, dialysis is rationed in the public sector in SA, including Groote Schuur Hospital [GSH] in the Western Cape.[25] This practice of rationing is ethically endorsed and strictly adhered to. Transplantability is the fundamental criterion for acceptance.[26] In addition to limited financial resources, there is a shortage of skilled personnel, including nursing staff, dialysis technicians, physicians and nephrologists. For example, there are only 2.1 nephrologists per million population (pmp) in South Africa. This contrasts with the global average of (8,83 pmp) as well as (7,23 pmp) in upper-middle-income-countries.[27, 28] Nephrologists are also mal-distributed within SA – the majority of public-sector nephrologists work in academic centres and private-sector nephrologists concentrating near bigger cities.[25]

Due to rationing most of our population do not meet entry criteria to qualify for RRT in the public sector: 49.6% of patients assessed for dialysis at GSH renal unit are

rejected.[29] This leads to a low prevalence of RRT in the public sector 67,5 pmp, as compared to 797,5 pmp in the private sector.[30]

PD-First in SA

The GSH renal unit is one of 5 that offers RRT in the public sector of the Western Cape.[30] Currently our unit offers HD to 98 patients and PD to 50 patients. This distribution of dialysis modalities is similar across South Africa, where the ratio of PD to HD in the public sector was 881 to 1401 compared to 426 to 6124 in private.[30]

There is a PD-First programme offered at GSH. This is due to limitations on both haemodialysis slots and resource constraints. The annual per-patient cost for PD is about half that of HD.[31] This PD-First policy ensures all patients are commenced on PD unless a contra-indication exists (inadequate social amenities, lack of running water, lack of storage space for PD fluid et cetera). Therefore, our patients do not have a choice in the modality that they are started on. Patients can be switched to HD if PD fails and a patient remains transplantable. Other countries with a PD-First policy include Hong Kong and Thailand.[32, 33]

Health Related Quality of Life [HRQOL] in End-stage Renal Disease [ESRD]

Despite being on RRT, patients with ESRD have a lower Health Related Quality of Life [HRQOL] compared to an age-matched population. However, there is no consensus as to which modality (HD versus PD) is superior in terms of HRQOL.[34] HRQOL has been directly linked to mortality and hospitalisation rates.[35, 36]

HRQOL questionnaire

The Kidney Disease Quality of Life-Short Form [KDQOL-SF^{TM}] has been validated to evaluate Health-related Quality of Life [HRQOL] in Kidney disease.[37-39] This survey includes 36 general health and 54 renal-specific questions, which are used to calculate scores for 8 general health domains and 11 renal-specific domains as listed in Table 2 below.

Table 2: Domains of the KDQOL-SF 1.3 survey

36-item health survey (SF-36)	ESRD- targeted areas
Physical functioning	Symptoms
Role limitations due to physical problems	Effects of kidney disease
Pain	Burden of kidney disease
General health	Work status
Emotional well-being	Cognitive function
Role limitations due to emotional problems	Quality of social interaction
Social functioning	Sexual function
Vitality (energy/fatigue)	Sleep
	Social support
	Dialysis staff encouragement
	Patient satisfaction

According to the KDQOL-SF^{TM} scoring manual, responses to the questions are coded into a calculated numeric value. These coded values are then recoded to a value between 0 and 100 and converted to a percentage, where 100 represents the most favourable quality of health. For example, patients with less pain had a higher HRQOL and thus a higher score in the pain domain. The second step is averaging the scores of selected items to form aggregated scores for 8 general health domains and 11 renal-specific domains.[40]

HRQOL between different modalities

There are a limited amount of studies comparing HRQOL between HD and PD patients. Although there has been heterogeneity in the HRQOL scores as reported in studies in different regions of the world, as seen in Table 3, more recent studies suggest that PD has better HRQOL scores.[41-44] However, a recent meta-analysis failed to show any significant difference between HD and PD overall.[45] Another meta-analysis showed that the only significant difference between HD and PD was in the subdomain of “effect of kidney disease” in which the PD group had a higher score, suggesting they were less bothered by the effects of kidney disease.[46]

Table 3: summarizes which group (HD or PD) had the higher HRQOL score for the different KDQOL-SF™ 1.3 domains

	Okpechi *et al*, 2013 [47] South Africa	Tannor *et al*, 2017 [48] South Africa	de Abreu *et al*, 2011 [49] Brazil	Goncalves *et al*, 2015 [50] Brazil	Turkmen *et al*, 2012 [51] Turkey	Mau *et al*, 2008 [41] Taiwan	Zhang *et al*, 2007 [42] China	Al Wakeel *et al*, 2012 [43] Saudi Arabia	García-Llana *et al*, 2013 [44] Spain	Atapour *et al*, 2016 [52] Iran	Reynaga-Ornelas *et al* [53] Mexico
36-item health survey (SF-36)											
Physical function				HD					PD	PD	
Role physical					HD			PD		PD	
Pain						PD	PD	PD	PD	HD	
General health					HD		PD	PD		PD	
Emotional well-being				HD	HD		PD	PD			
Role emotional					HD	PD	PD	PD			
Social function		HD			HD		PD	PD			HD
Energy/fatigue		HD			HD		PD	PD		PD	HD
ESRD- targeted areas											
Symptoms		HD									
Effects of kidney disease			PD								
Burden of kidney disease			PD								
Work status		PD		PD							
Cognitive function											
Quality of social interaction											
Sexual function											
Sleep		HD									
Social support											
Dialysis staff encouragement		PD	PD	PD							
Patient satisfaction			PD	PD							

Abbreviations: ESRD, End Stage Renal Disease; HD, haemodialysis; PD Peritoneal dialysis

Some studies showed patients on PD had better HRQOL than those on HD. In China, Zhang *et al.* found that PD patients had better scores for physical pain, general health, emotional well-being, role limitations due to emotional problems, social functioning and vitality (energy/fatigue).[42] In Saudi Arabia, Al Wakeel *et al.* had similar results with PD patients reporting significantly better HRQOL scores in all SF-36 domains, except for the physical function where this better score was not significant.[43] Mau *et al.* found PD patients in Taiwan had better scores for the physical pain and emotional role limitations domains, with no other significant differences.[41] Garcia-Llana *et al.* found that PD patients in Spain had better scores for the domains of both physical pain and function.[44]

In certain regions, there were mixed results. In Iran, Atapour *et al*. found that patients on PD had better HRQOL scores in the domains of physical functioning, role limitations due to physical problems, general health and vitality, but HD patients experienced less pain.[52] In Brazil, de Abreu *et al*. found PD patients had better scores for the HRQOL domains of kidney disease burden, effects of kidney disease, dialysis staff encouragement and patient satisfaction, with the HD group having greater improvement in sleep, social support and general health on follow up over time.[49] Goncalves *et al*. similarly found that PD patients had better dialysis staff encouragement, patient satisfaction and a better work status, however they found HD patients had better physical and emotional functioning.[50]

There are also studies showing that patients on HD had a better HRQOL in certain regions. Turkmen *et al.* found that HD patients in Turkey had better HRQOL compared to PD patients, with higher domain scores for role limitations due to physical and emotional problems, general health, emotional well-being, social functioning and vitality.[51] According to a study by Reynaga-Ornelas *et al*. patients on HD in Mexico had better domain scores for social functioning and vitality.[53]

In South Africa, there are only 2 published studies on HRQOL in RRT patients. A study of smaller sample size, conducted by Okpechi *et al.* in our unit, found no significant differences in terms of HRQOL between the HD and PD.[47] A more recent study, conducted at Tygerberg Hospital, Cape Town, showed that the only significant differences in overall HRQOL between HD and PD patients, were that patients on HD

scored significantly higher in the specific domains of social functioning, vitality, symptoms, and sleep, but significantly lower in the work status and dialysis staff encouragement domains.[48]

Socio-economic factors and HRQOL

Although it was shown by Martin *et al.* that education level affects the incidence of first onset of peritonitis in PD patients in Brazil,[54] Dos Santos *et al.* showed that education level and family income did not affect the perception of HRQOL in PD patients in Brazil.[55]

Study rationale

It has been shown that there are benefits to starting patients on PD first, including better survival, preservation of vascular access site and residual renal function and better patient satisfaction.[56] However, research comparing HRQOL between ESRD patients on HD and PD is unfortunately lacking in regions with PD-First policy (like Hong Kong and Thailand). Groote Schuur hospital [GSH] has a PD-First policy, with patients not offered any input into choice of dialysis modality. Given this lack of autonomy, our objective was to ascertain whether HRQOL differed between those commenced on PD and those on HD in our unit. A secondary objective was to evaluate the socio-economic challenges our patients face that could affect HRQOL.

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CHAPTER 2: PUBLICATION-READY MANUSCRIPT

Impact of socio-economic factors and Health Related Quality of Life on patients on renal dialysis in Cape Town

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Background

Despite South Africa [SA] being a middle-income country, distribution of wealth remains grossly unequal, with the highest Gini coefficient in the world.[1] There is a high unemployment rate (29.1%)[2] with low access to formal housing and sanitation.[3] This is further complicated by gang violence and high crime rates.[4] Compounding these significant social stressors is a high burden of both communicable (human immunodeficiency virus [HIV] and tuberculosis [TB]) and non-communicable diseases.[5] End-stage Renal Disease [ESRD] is influenced by, and contributes to this burden.

There are also competing priorities for health resources. HIV and TB currently overwhelm a predominantly public health care sector, which serves >80% of the population.[6] Despite the growing burden of Chronic Kidney Disease [CKD] in SA,[7] the number of patients able to access renal replacement therapy [RRT] in the public sector is 68 per million population [pmp]. This compares to 798 pmp in the private sector of SA, which is on par with many developed countries.[8] Due to severe resource constraints, national guidelines mandate that only patients who are transplantable can be accepted onto most public sector dialysis programmes.[9, 10]

The Western Cape has an estimated population of 6,36 million, with 74.8% (4.76 million) accessing public health care. Groote Schuur Hospital [GSH] is one of 5 units that offers RRT in the public sector of the Western Cape. At the time of the study the unit had the capacity to dialyse 148 patients, 98 on haemodialysis [HD] and 50 peritoneal dialysis [PD]. It also practices dialysis rationing which is ethically endorsed and strictly adhered to.[11] There is a PD-First policy. This is due both to limitations on haemodialysis slots and cost saving measures.[12] The PD-First programme ensures all patients are commenced on PD unless a contra-indication exists. Contraindications include; inadequate social amenities, lack of running water, lack of storage space for PD fluid or a medical contraindication. If PD fails, patients are only able to be switched from PD to HD if they remain transplantable.

Health related quality of life [HRQOL] has been directly linked to mortality and hospitalisation rates.[13, 14] Even with RRT, ESRD has been shown to have a lower

HRQOL compared to an age-matched population. However, there is no consensus as to which modality (HD versus PD) is superior in terms of HRQOL.[15] Limited studies show contradictory results in different regions and meta-analyses have not shown any significant difference between HD and PD overall.[16]

In our PD-First programme the patient has no choice for dialysis modality. Given this lack of patient autonomy understanding our patient's HRQOL and challenges is essential. Research concerning HRQOL in this setting is currently lacking. This study was therefore aimed to assess whether HRQOL differed between those on PD versus HD in a resource constrained setting serving a population with significantly poor social circumstances. The primary objective was to compare the HRQOL between HD and PD patients and describe socio-economic and safety challenges our patients face.

Methods

This cross-sectional study examined the HRQOL of patients on HD and PD, at GSH, Cape Town. The surveys were performed between July 2015 and December 2016. Ethics approval was granted by the University of Cape Town Human Research Ethics committee (HREC:REF 480/2015). Inclusion criteria consisted of all patients older than 18 years and established on a dialysis modality for at least 3 months. Exclusion criteria included age <18 years, patients not established on dialysis and those not granting consent.

Demographic data was collected including age, sex, ethnicity and marital status. Socio-economic information was collected from an adapted census questionnaire from Statistics South Africa (Stats SA). This included information regarding education, employment status, income, food security, living circumstances (e.g. dwelling type, home occupants, access to water, electricity and sanitation), mode of transportation, and distance to hospital. Patients thereafter completed a validated renal health related quality of life survey (the Kidney Disease Quality of Life Short form - [KDQOL-SF^{TM}] survey, version 1.3).[17] This validated survey includes 36 general health and 54 renal specific questions, which are used to calculate scores for 8 general health domains and 11 renal-specific domains. The general health domains

include: physical and social functioning, role limitation due to physical and emotional problems, pain and health perceptions, emotional well-being and energy/fatigue levels. The renal specific domains include: symptoms, effects and burden of kidney disease, work status, cognitive function, quality of social interaction, sexual function, sleep, social support, dialysis staff encouragement and patient satisfaction.[17] The questionnaire was verbally administered in the primary language of the patient.

The KDQOL-SF™ scoring of the HRQOL was done according to the validated methods described in the original KDQOL-SF™ guidelines.[17] Responses to the items of the KDQOL-SF™ were coded into a numeric value as per the scoring key in the scoring manual. The coded values were then recoded to a value between 0 and 100 and converted to a percentage, where 100% represented the most favourable quality of health. For example, patients with less pain had a higher HRQOL and thus a higher score in the pain domain. The second step averaged the scores of selected items, to form aggregated scores for 8 general health domains and 11 renal-specific domains. Missing data was not taken into account when averaging the domain scores.[17] Patients completed the survey only once and were not re-interviewed if they switched dialysis modality.

Statistical analysis

Data was analyzed using STATA 13.0 statistical software. Demographic variables, socio-economic characteristics, SF-36 health survey items, and ESRD-targets were summarised using descriptive statistics. All SF-36 health survey items and ESRD-target scores were presented as mean (standard deviation [SD]). Skewed continuous variables were presented as median with interquartile range [IQR]. Categorical variables were summarized by frequency with proportion. Variables were compared between dialysis groups with the level of significance was set at α=0.05. Two sample t-test was used to compare normally distributed continuous variables, while Wilcoxon rank-sum test was used for non-normally distributed data. Categorical variables were compared between dialysis groups using either chi-squared test or Fisher's exact test (if expected number of frequencies was <5). All analyses were performed using Stata/IC version 15 (StataCorp, College Station, TX, USA).

Results

Patient characteristics

The study population consisted of 77 HD patients and 33 patients in the PD group. Figure 1 demonstrates the flow diagram of the study. A total of 154 patients were screened for study inclusion. There were 32 patients that were not interviewed [9 HD patients and 23 PD patients as they missed their dedicated appointment]. A further 12 patients were excluded from the study, 5 did not meet entry criteria, 5 did not consent and 2 had incomplete forms.

FIGURE 1: Flow diagram of the study participants

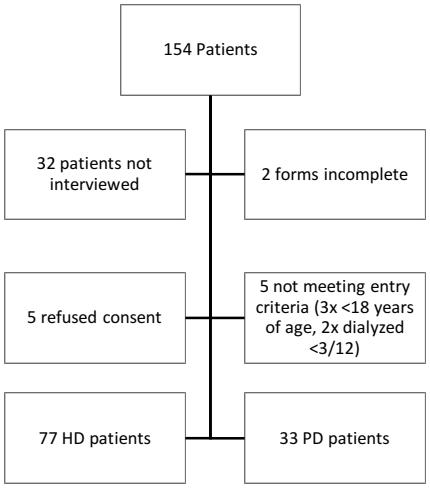


Table 1 demonstrates the demographic data of the two groups. There were no significant differences in demographics between the HD and PD cohorts. Most patients were female, n=63 (57.3%). Patients in the HD group were predominantly African (53.3%) while the majority of those on PD were of mixed-ancestry (60.6%). The median age for the two groups was 42.5 years [IQR: 32.4-48.6 years]. Most patients were not married (38.2%).

TABLE 1 – Patient Demographic Characteristics

Total n= 110	Total n (%)	HD (n=77)	PD (n=33)	p-value
Gender				
Female	n (%)	44/77 (57.1%)	19/33 (57.6%)	0.966
Race *	n (%)			0.242
African	n (%)	40/75 (53.3%)	12/33 (36.4%)	
Mixed Ancestry	n (%)	32/75 (42.7%)	20/33 (60.6%)	

White/Asian	n (%)	3/75 (4.0%)	1/33 (3.0%)	
Age (in years)	Med (IQR)	44.0 (32.9 – 48.7)	40.8 (31.5 – 48.1)	0.333
Marital status		HD	PD	0.797
Single/Widowed/Divorced	n (%)	47/77 (61.0%)	21/33 (63.6%)	
Married	n (%)	30/77 (39.0%)	12/33 (36.4%)	

*n = number [varies due to missing values]

Abbreviations: HD, haemodialysis; PD peritoneal dialysis

Socio-economic status

Table 2 demonstrates the socio-economic and educational status of the patients. Less than half the patients had completed secondary school in both groups (46.8% in HD and 40.6% in the PD group). There were no significant differences between groups except for tertiary education (HD group, 38.7% versus PD group,18.8%). Employment was around one third in each group with only 32.9% and 29.0% of patients working at the time of the survey in HD and PD groups respectively. Over 40% of patients in both groups relied on disability grants or pensions as a source of income. The average income for our patients overall was low, with a median income of R3 750 per month, equivalent to 261.46 US$. Around one fifth of patients reported as having experienced hunger at some point over the past year.

TABLE 2 – Education and Socioeconomic status.

		HD (n=77)	PD (n=33)	p-value
Education				
Primary	n (%)	6/77 (7.8%)	2/32 (6.3%)	1.000
Secondary	n (%)	36/77 (46.8%)	13/32 (40.6%)	0.673
Tertiary education*	n (%)	29/75 (38.7%)	6/32 (18.8%)	0.044
Currently studying	n (%)	2/75 (2.7%)	3/32 (9.4%)	0.157
Employment/ income				
Employed currently	n (%)	24/73 (32.9%)	9/31 (29.0%)	0.700
Disability grant/Pension	n (%)	33/77 (42.9%)	14/33 (42.4%)	0.966
Household Income in South African Rand [ZAR]	Med (IQR)	R 3750 (1600 – 6000)	R 3750 (1400 – 5400)	0.546
Hunger reported in the last year	n (%)	16/77 (20.8%)	6/33 (18.2%)	0.755

*Denominator varies due to missing values

Abbreviations: HD, haemodialysis; PD peritoneal dialysis; MED, median; IQR, inter-quartile range; R, South African Rand

Living circumstances

Table 3 describes the living circumstances of the cohort. Thirty percent of patients lived in an informal dwelling or a room detached from the main abode. In the HD group 75.3% had access to tap water in their house, compared to 87.9% in the PD group. Flushing toilets were not present in 17(19%) of patient homes. Most patients used public transportation to access dialysis, 81.8% in the HD group and 72.7% in the PD group. On average, patients lived 18-20km from the dialysis unit.

Patients felt generally unsafe in their home environment, rating their safety an average at 47.9 on a scale from 0-100 in the HD group, and 52.4 in the PD group, where 0 describes a feeling of being totally unsafe and 100 equates to complete safety.

TABLE 3 – Living circumstances, Transportation and Safety

		HD (n=77)	PD (n=33)	p-value
Dwelling type				
House/flat/townhouse	n (%)	54 /77 (70.1%)	23/33 (69.7%)	0.964
Shack/Back room	n (%)	23/77 (29.9%)	10/33 (30.3%)	
Home occupants	Mean (SD)	3.96 (2.4)	4.06 (2.0)	0.554
Occupant/Bedroom	Mean (SD)	2.06 (1.2)	1.77 (1.0)	0.231
Amenities				
Water in house	n (%)	58/77 (75.3%)	29/33 (87.9%)	0.107
Electricity in house	n (%)	75/77 (97.4%)	30/33 (90.9%)	0.158
Toilet in house *	n (%)	50/62 (80.7%)	24/29 (82.8%)	0.528
Safety score †	Avg (SD; CI)	47.9 (33.0; 40.4-55.4)	52.4 (31.5; 41.2-63.6)	0.508
Mode of transportation				0.205
Public	n (%)	63/77 (81.8%)	24/33 (72.7%)	
Private	n (%)	14/77 (18.2%)	9/33 (27.3%)	
Distance from unit	Km Med (IQR)	18 (13 – 23)	20 (13 – 25)	0.121

* Denominator varies due to missing values

† The safety score was generated from 1 – 10 and multiplied by 10. Where 0 = completely unsafe and 100 = completely safe.

Abbreviations: HD, haemodialysis; PD peritoneal dialysis; SD, standard deviation; Avg, average; CI, confidence interval; Km, kilometer; Med, median; IQR, inter-quartile range

Table 4 describes the results of the general health domains of the KDQOL-SF^{TM}. Both groups experienced similar limitations due to their physical health, however PD was found to be more limited (p=0.05). There was a significant difference in pain between the groups. The HD group had a higher composite score for pain, compared to in the PD group (77.5 versus 65.3, p=0.036). Despite PD having a worse pain score, there was no difference in pain limiting activity. The emotional well-being was significantly higher in the HD group compared to the PD group, (72.9 versus 62.5, p=0.020), with the HD group reporting to be less nervous, calmer and happier. Additionally, the HD group had significantly better energy/fatigue scores compared to the PD group (59.42 versus 48.03, p=0.015).

TABLE 4 – SF-36 item health survey

	HD (n=78) Mean (SD)	CI (95%)	PD (n=33) Mean (SD)	CI (95%)	p-value
Physical functioning *n=76;33	66.9 (23.2)	61.5-72.2	63.2 (26.0)	54.0-72.4	0.471
Role–limitations due to physical health	44.3 (38.8)	35.5-53.1	28.8 (34.3)	16.6-41.0	0.050
Less time	52.0 (50.9)	40.5-63.4	42.4 (50.2)	24.6-60.2	0.365
Do less	32.9 (47.3)	22.0-43.7	18.2 (39.2)	4.3-32.1	0.120
Limit kind of work *n=75;33	44.0 (50.0)	32.5-55.5	27.3 (45.2)	11.2-43.3	0.102
Difficulty	46.1 (50.2)	34.6-57.5	27.3 (45.2)	11.2-43.3	0.067
Pain †	77.5 (25.7)	71.7-83.3	65.3 (31.7)	54.1-76.6	0.036
Amount	76.1 (27.0)	70.0-82.2	61.3 (33.7)	49.1-73.4	0.017
Limiting activity	78.9 (28.4)	72.5-85.3	68.9 (32.5)	57.4-80.5	0.110
General health	51.4 (22.4)	46.4-56.5	49.5 (21.5)	41.9-57.5	0.683
Emotional well-being	72.9(20.7)	68.2-77.6	62.5 (22.1)	54.7-70.4	0.020
Nervous *n=76;33	77.6 (28.7)	71.1-84.2	62.4 (38.3)	48.8-76.0	0.024
Down	72.0 (31.0)	64.9-79.0	64.2 (29.9)	53.6-74.8	0.230
Calm *n=75;33	67.2 (31.3)	60.0-74.4	53.3 (32.7)	41.8-64.9	0.039
Blue *n=76;33	71.6 (26.2)	65.6-77.6	69.7 (32.1)	58.3-81.1	0.748
Happy	77.4 (25.8)	71.5-83.3	63.0 (35.0)	50.6-75.5	0.018
Role limitations due to emotions	55.0 (46.4)	44.4-65.5	41.4 (44.1)	25.8-57.1	0.157
Social functioning	68.3 (30.4)	61.5-75.2	59.5 (32.1)	48.1-70.9	0.171
Energy/fatigue	59.4 (20.3)	54.8-64.0	48.0 (25.6)	39.0-57.1	0.015
Vibrant	59.0(31.1)	51.9-66.0	54.5 (30.5)	43.8-65.4	0.494
Amount * n=76;33	60.5 (31.9)	43.2-57.8	37.6 (33.8)	25.6-49.6	0.059
Wornout * n=76;33	69.5 (26.2)	63.5-75.5	55.2 (5.8)	43.4-66.9	0.019

Tired	57.9 (26.7)	51.8-64.0	44.9 (36.1)	32.06-57.6	0.038

* Denominator varies due to missing values

† The pain score reflects the QOL experienced due to pain, where a higher score reflects a better QOL due to less pain.

Abbreviations: HD, haemodialysis; PD peritoneal dialysis; SD, standard deviation; CI (95%), 95% confidence interval

Table 5 reports the ESRD specific domains. There was no significant difference in overall symptom score between the cohorts (78.2 versus 71.7 respectively, p=0.068). Only shortness of breath was significantly different between groups (HD 84.4 ±23.3 versus PD 62.1±34.3, p=0.0001). Both groups experienced a high burden of kidney disease symptoms and sleep disturbance.

TABLE 5 – ESRD-targeted items

	HD (n=77) Mean (SD)	CI (95%)	PD(n=33) Mean (SD)	CI (95%)	p-value
Symptoms/problems	78.2 (17.1)	74.3-82.1	71.7 (16.8)	65.7-77.6	0.068
Soreness	77.3 (28.3)	70.8-83.8	72.7 (28.9)	62.5-83.0	0.449
Chest pain	89.5 (21.3)	84.6-94.3	80.3 (29.8)	69.7-90.9	0.072
Cramps	68.4 (32.8)	60.9-75.9	70.5 (30.3)	59.7-81.2	0.761
Pruritus	66.9 (36.4)	58.6-75.1	53.8 (41.5)	39.1-68.5	0.100
Dry skin	65.6 (39.1)	56.7-74.5	53.0 (39.4)	39.1-67.0	0.127
SOB	84.4 (23.3)	79.1-89.7	62.1 (34.3)	50.0-74.3	0.0001
Faintness	81.2 (28.7)	74.7-87.7	80.3 (27.1)	70.7-89.9	0.883
Loss of appetite	83.1 (24.9)	77.5-88.8	72.7 (37.7)	49.4-86.1	0.090
Feeling drained	74.0 (31.7)	66.8-81.3	39.7 (33.5)	57.8-81.6	0.523
Paresthesia	82.8 (30.2)	76.0-89.6	73.4 (36.4)	60.3-86.6	0.169
Nausea	77.6 (29.9)	70.8-84.5	78.8 (30.7)	67.9-89.7	0.854
Effects of kidney disease	64.1 (23.9)	57.6-69.6	65.5 (22.4)	57.6-73.5	0.776
Burden of kidney disease	41.4 (30.6)	34.5-48.3	44.3 (32.0)	33.0-55.7	0.651
Work status	33.8 (45.5)	23.4-44.1	33.3 (42.7)	18.2-48.5	0.963
Cognitive function	79.8 (21.9)	74.9-84.8	78.4 (16.9)	72.4-84.4	0.737
Quality of social interaction	78.8 (19.7)	74.3-83.3	73.3 (22.6)	65.3-81.4	0.206
Sexual function *	83.6 (23.6)	75.1-92.1	80.6 (19.9)	65.3-95.8	0.727
Sleep	66.1 (21.1)	62.3-71.9	58.9 (21.9)	51.2-66.7	0.691
Social support	81.2 (25.4)	75.4-86.9	76.8 (31.2)	65.7-87.8	0.439
Dialysis staff encouragement	88.5 (18.2)	84.3-92.6	89.8 (18.6)	83.2-96.4	0.734
Patient satisfaction	65.4 (26.6)	59.4-71.5	72.7 (24.2)	64.1-81.3	0.179

*n equals 32 for HD group and 9 for PD group.

Abbreviations: HD, haemodialysis; PD peritoneal dialysis; SD, standard deviation; CI (95%), 95% confidence interval

Discussion

This cross-sectional study compared the quality of life between HD and PD patients in a public-sector hospital with a PD-First policy in South Africa. This study adds to limited literature regarding HRQOL for patients dialyzing in middle-income countries.

This study highlights the challenges that our cohort of dialysis patients face, particularly with regards to their poor socio-economic circumstances. A large proportion of our dialysis patients rely on disability grants for income, have food insecurity and live in informal housing. The concern regarding safety was profound. These challenges are likely to affect patient's quality of life and their experience on dialysis. Although there was no significant symptom difference overall this study demonstrated that the HD patients reported less pain, shortness of breath, fatigue and better energy scores with an overall improvement in emotional wellbeing. However, the degree of kidney disease burden and emotional impact of the illness was marked in both cohorts.

In our cohort, PD patients experienced more pain than HD patients. An Iranian study reported similar findings, with PD patients having more pain.[18] However, two studies from South Africa found no difference in the pain experienced between modalities.[19, 20] Furthermore, numerous studies showed more pain in patients on HD than PD.[21-23]

HD was also superior to PD in a further 3 domains. Firstly, The HD patients in our cohort scored slightly better in ESRD specific symptom categories, although this was not significant. When subgroup analysis was done on individual symptoms, PD patients experienced significantly more "shortness of breath". In a previously reported outcome study from our unit, the commonest cause of death was fluid overload.[24] Unfortunately, due to resource constraints we have limited access to automated peritoneal dialysis [APD] and icodextrin, which may contribute to the high degree of fluid overload.

Secondly, HD patients scored better in the domain of “energy/fatigue”, feeling less worn-out and tired. This has been previously reported in a study from our Cape Town dialysis centre,[20] and in a study in Turkey.[25] Thirdly, HD patients had better emotional well-being scores and felt less nervous, and were calmer and happier compared to the PD patients. Two local studies previously reported no difference in emotional wellbeing between dialysis modalities.[19, 20] The difference in our findings may reflect a worsening in socio-economic circumstances within our catchment area over recent years. Having the additional regular emotional support from fellow patients and nursing staff may be assisting with this improved feeling of wellbeing in the HD cohort.

The socio-economic status of our patients is very poor and this creates an extremely challenging environment in which to live with a chronic illness or thrive on RRT. This may have profound effect on quality of life. Table 6 describes the socio-economic circumstances of the study cohort compared to Western Cape (WC) province and South Africa census data.[3] This information confirms that our dialysis study cohort has worse social challenges than the average WC population. The unemployment rate in the dialysis cohort is higher. They have a much lower reported household income, a higher percentage reporting hunger and more patients live in informal dwellings. Access to running water and flushing toilets is also more limited in our cohort than the average population. This is concerning as lack of running water likely places PD patients at an increased risk of peritonitis.

Education was similarly low within both cohorts for primary and secondary school completion. Those on HD had a higher rate of completing tertiary education (38%) compared to PD (18%), p=0.044. Even though level of education has been shown not to affect HRQOL in PD patients in Brazil,[26] a low level of education was shown to increase the risk for first peritonitis events independent of socio-economic factors.[27]

TABLE 6 – Comparison of socio-demographic data between study cohort and populations of the City of Cape Town, the Western Cape Province, and South Africa [3]

	Dialysis cohort	City of Cape Town (n=4 005 016)	Western Cape (n=6 279 730)	South Africa (n=55 653 654)
Female	57%	51.6%	50.7%	---
Race				
African	48%	42.6%	35.7%	80.4%
Mixed	48%	39.9%	47.5%	7.2%
White/Asian	4%	17.6%	16.8%	12.4%
Married (pop. Aged >18)	38%	41.1%	40.2%	30.7%
Education (pop. Age 20+)				
primary school	7,3%	4.2%	5.1%	---
secondary school	45%	35.0%	33.8%	---
tertiary	32.7%	14.8%	12.7%	---
Employed	31.7%	---	---	**42.4**% *
Household income per month †	R 3750	---	R 18 580	R 11 514
Reporting hunger	21.8%	12.7%	13.2%	19.9%
Dwelling				
Formal	70%	81.6%	82.4%	79.2%
Informal	30%	17.6%	16.6%	13.0%
Traditional/Other	---	0.7%	1.0%	7.8%
Home occupants		3.2	3.2	---
Water	79,1%	93.7%	93.2%	84.5%
Electricity	95,4%	97.8%	97%	---
Flushing toilet	81,3%	92.8%	93.4%	63.4%

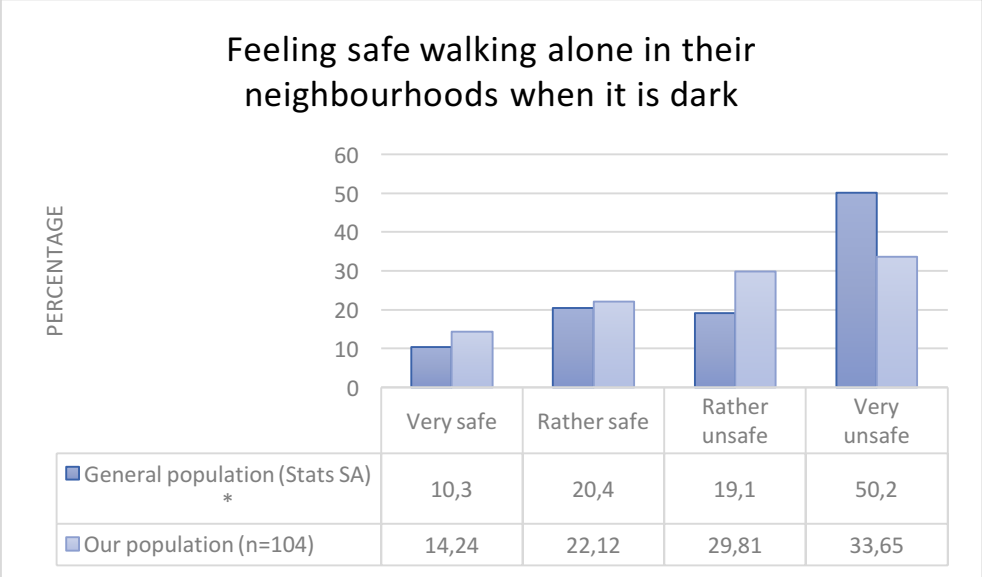
*[2]

† [28]

Abbreviations: pop, population; R, South African Rand

Figure 2 describes the perception of safety of the dialysis cohort. The majority of the cohort (>60%) felt unsafe walking around their neighbourhood at night. This is comparable to reported data.[29] This is not surprizing, given that out of all metro's in SA, Cape Town has one of the highest reported murder rates (63/100 000 population). This is extremely high compared to the global average of only 6,04 per 100 000 population.[30] This lack of security could be contributing to the high levels of insomnia, anxiety and low energy experienced by the entire cohort.

FIGURE 2 demonstrates distribution of feeling of safety in ones environment in our cohort vs Stats SA [29]



Limitations

This study has several limitations. Firstly, the sample size is small with small numbers of PD patients in comparison to HD. We have fixed numbers of patients that are able to access chronic dialysis due to resource constraints. This could be improved by a **multicentre** analysis in the future. Secondly, 32 patients from the cohort were not interviewed, this may be explained due to the variability in the timing of their dialysis shift or clinic attendance. Thirdly, bio-chemical measure of dialysis adequacy, which could affect quality of life, was not reported. However, despite this we know from previously published data that the overall adequacy and outcomes of our PD cohort was comparable to the other larger, PD programmes in high income countries.[31] Fourthly, this study is limited to a public sector dialysis unit, without a cohort from the private sector, with patients from better socio-economic circumstances. Therefore this study could not prove a link between poor socio-economic circumstances and HRQOL. Lastly a depression score between cohorts was not analyzed and the peritonitis rate was not reported. This may be relevant given the low socio-economic status of this cohort.

Conclusion

In a PD-First programme in a poor socio-economic setting, PD HRQOL was inferior to HD in 4 categories related to symptoms of ESRD and psychological wellbeing and may relate to our patients' lack of autonomy in choosing an appropriate dialysis modality. It would therefore be important to institute interventions to offer additional support. The socio-economic status of our cohort overall is particularly poor and perhaps having regular contact with dialysis staff and patients for support may be important.

A PD-First programme in our setting is essential to be able to offer a higher number of patients RRT. Possible interventions to improve HRQOL would be ongoing repeated educational interventions, especially in PD patients where there is less frequent contact with the nursing staff,[32] patient support groups and a more intensive pre-dialysis education programme preparing patients for dialysis which we hope would reduce patient anxiety and improve emotional well-being.

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APPENDICES

Questionnaires

Consent form

Ethics approval

Instructions to Author by chosen Journal “SAMJ South African Medical Journal”