UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT
PSYCHOLOGY

MA (Social and Psychological Research)

Research Report

Course code: PSCY7022A

Title

Disparities in access to treatment in relation to Quality of Life in people diagnosed with Parkinson's Disease

By

Simone Harris

Student Number: 1313046

Supervisor: Dr. Aline Ferreira Correia

A research proposal submitted in partial fulfilment of the requirements for the degree of MA (Social and Psychological Research) in the faculty of Humanities, University of the Witwatersrand, Johannesburg, 2023.

Declaration

I declare that this research report is my own, unaided work. It is being submitted for the Degree of Masters of Social and Psychological Research at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any other degree or examination at this or any other university.

_____

Simone Laureen Harris

11th day of April 2023, at Johannesburg.

ABSTRACT

The purpose of this study was to compare the treatment received and the perceived efficacy thereof to manage motor and non-motor symptoms of Parkinson's Disease (PD) between patients who attended either public or private healthcare facilities. The study also examined Quality of Life (QoL) outcomes and its relationship with treatment received, and explored the extent to which sociodemographic variables of household income and internet access moderated the strength and direction of this relationship. Responses to a cross-sectional questionnaire assessing demographic variables and QoL from 80 people with Parkinson's Disease (PwPD) across both healthcare settings in Johannesburg were analyzed using descriptive and correlational statistics, as well as a factorial ANOVA model. Results from this study suggest that PwPD at the private healthcare facility who are members of medical aid schemes have greater access to treatment and higher QoL outcomes than PwPD who received treatment at the public hospital. The study also found that PwPD at public hospitals, of whom the majority use only pharmacological treatment without adjunct therapies, perceive their treatment to be more efficacious than those in the private healthcare facility. Analysis of individual facets of QoL which included Environmental, Physical, Psychological and Social Relationship dimensions revealed that PwPD across both healthcare settings performed the worst in the Psychological domain pertaining to self-esteem, life enjoyment, concentration, acceptance of bodily appearance, having negative feelings and the extent to which they felt their lives to be meaningful. A significant positive moderate relationship was found between treatment and QoL outcomes, where medication with adjunct treatment led to a higher QoL. Household income and internet access did not moderate the relationship between treatment and QoL, however household income was found to be a significant predictor of QoL. Implications of these findings are discussed and recommendations for future research proposed.

Key words: Parkinson's Disease, Quality of Life, treatment, household income, internet access, cross-sectional study.

ACKNOWLEDGEMENTS

This Masters research report would not be possible without the guidance, support, participation and understanding of those either directly or indirectly involved during this process. I would like to take this opportunity to acknowledge the people who contributed in their own way to this often challenging yet rewarding culmination of two years of hard work.

First and foremost, I am grateful to Dr Aline Ferreira Correia, the principal supervisor of this research, for accepting me as her student and guiding me through this process in its entirety. She steered me towards research on Parkinson's Disease which has been life changing. She has been an exemplary supervisor, mentor, role model and friend. I am eternally grateful for all of the time, effort and hard work you have poured into your role as a supervisor. Being able to develop myself professionally and academically under your supervision has been the greatest honor.

To say that I am deeply inspired by Dr Marcelle Smith, Specialist Neurologist at Sandton Mediclinic and Wits Donald Gordon Medical Centre, would be an understatement. I marvel at her professionalism, expert knowledge, rapport with patients and willingness to help other aspiring researchers and healthcare workers. She has been nothing short of exceptional and I am forever indebted to her for allowing me access to her patients.

Dr Zipora Katz, lecturer (University of Witwatersrand) and Neurologist (Chris Hani Baragwanath Academic Hospital [CHBAH]) who unwaveringly assisted me before, during and after data collection. She has been there for me as a mentor and pushed me through difficult times. I've gained so much by observing her incredible work ethic, intellectual capacity and dedication to her area of specialization. Thank you for your constant communication and guidance through this entire process.

I would also like to acknowledge Professor Andre Mochan (University of Witwatersrand) and Senior Neurologist (CHBAH) for his support and commitment towards this study during the data collection process. I would also like to extend a huge thank-you to the rest of the neurologists at CHBH for inviting PwPD to participate in my study on all of my Wednesday visits during the data collection phase.

To Mixo Chuma and Nonhlanhla Yende, your willingness and pleasant attitudes towards assisting me with translations during a few of the participant interviews at Baragwanath has not gone unnoticed. Thank you for your helpfulness and kindness whenever I was in need.

Sincere and heartfelt gratitude must be extended to all the participants from both the private and public healthcare sectors. I appreciate every one of you for dedicating your precious time towards participation in the study, whether in person or telephonically. My wish is for every person with PD to have a better quality of life regardless of sociodemographic circumstances. Hopefully this study will contribute in a meaningful way to the scarcity of literature in this research area.

To my children and extended family, thank you for your unconditional love and support during the many difficult times when I had to lock myself away in the study to give sole attention to the completion of this research report. I value your patience and understanding during this process, keeping me going with words of encouragement and exercising patience during the stressful days and long nights. I hope my academic ambitions will inspire my children to follow their own aspirations one day.

Also to the Institute for Social and Health Sciences (ISHS) where I am doing my research internship. Thank you for allowing me the space to undertake data collection when necessary and for developing me academically and professionally as a researcher. I believe in the work of this Institute and its commitment towards the development of post graduate scholars.

Lastly, this research report is dedicated to my maternal grandfather Charles Andrew Hendricks who passed away from Parkinson's Disease in June 1999. Having watched my late grandmother devote her life to caring for you every single day whilst you never complained as we watched you struggle through your advanced symptoms has inspired me beyond measure. I hope you will be proud of this work.

TABLE OF CONTENTS

LIST OF TABLES

APPENDICES

LIST OF ABBREVIATIONS

PD – Parkinson's Disease

PwPD – People with Parkinson's Disease

STN – Subthalamic nucleus

SN – Substantia nigra

SNpc – Substantia nigra pars compacta

SNpr – Substantia nigra pars reticulata

GABA - Gamma aminobutyric acid

GP – Globus pallidus

GPi – Globus pallidus internal

GPe – Globus pallidus external

L-dopa - Levodopa

Lb - Lewy bodies

EPS - Extrapyramidal system

OT – Occupational therapy

BoNT - Botulinum toxin

CBD - Cannabidiol

LMICs – Lower to middle income countries

1. INTRODUCTION

This chapter will set out to define PD and outline it's associated motor and non-motor symptoms, before approaching the significance of treatment upon QoL outcomes and identifying the major variables being examined by the researcher. Next this chapter will outline the prevalence of PD and address the paucity of literature on PD in South Africa, and then introduce the rationale of the current study. Next, the divide between the private and public healthcare sectors is briefly discussed in relation to treatment and care received before concluding the chapter with the overall aims of the study.

1.1. PD and its symptomology

Parkinson's Disease (PD) is a progressive neurodegenerative disorder of which the precise etiology is still inconclusive. Resulting from the pathophysiologic loss of dopaminergic neurons in the substantia nigra pars compacta (SNpc), functional changes occur that affect the entire basil ganglia network which is responsible for processing signals from the frontal cortex, allowing voluntary movements to be executed correctly (Amod & Bhigjee, 2019; Blandini et al., 2000; Di Filippo et al., 2008; Gibb, 1992). Associated with the ageing process, PD has characteristic motor symptoms that include the primary presence of bradykinesia, tremor, postural instability and rigidity, while non-motor symptoms include sensory abnormalities, autonomic dysfunction, behavioural changes, fatigue, as well as sleep, mood and psychiatric disturbances (Amod & Bhigjee, 2019; Beitz, 2014; Blandini et al., 2000; Öztürk et al., 2011; Pfeiffer, 2016).

1.2. The impact of treatment upon QoL

These symptoms manifest differently in every PwPD and their QoL is often linked to access to a variety of therapeutic approaches with pharmacological treatment the primary intervention (Singh et al., 2007; Tickle-Degnen et al., 2010). The significant impact that various types of

treatment can have on QoL outcomes in PwPD has been widely reported, yet to our knowledge no literature in South Africa (SA) has reported on the moderating effects of sociodemographic variables such as household income and internet access upon the relationship between treatments and their impact on QoL. The assessment of sociodemographic variables is of particular importance in SA given the persistent social disparities, low numbers of healthcare workers, high income inequality, and taking into account how the burden of infectious and noncommunicable diseases preferentially affect people in situations of poverty (Mayosi et al., 2014).

1.3. Prevalence of PD

One of the most comment movement disorders, PD has a global prevalence estimated to be 150-200 per 100,000 (Campani et al., 2022). In SA there are limited prevalence and incidence studies on PD which have been attributed to limited access that patients in impoverished countries have to diagnosis, treatment, and multidisciplinary care (Blanckenberg et al., 2013). The fact that PD is under-studied in Sub-Saharan African (SSA) populations means that prevalence figures are based on a small number of reports which have, so far, estimated the prevalence of PD in SSA to range between 7 to 20 per 100,000 (Blanckenberg et al., 2013). A vast majority of PwPD are undiagnosed due to a lack of awareness about PD, resulting in low QoL outcomes and a poor survival rate (Mokaya et al., 2017). Research about PD and access to treatment is thus critical to promote better QoL outcomes, better access to affordable treatment and medical supervision given the progressive and debilitating characteristics of PD (Mokaya et al., 2017).

1.4. Rationale for current study

The scarcity of literature in SA regarding barriers to treatment needs urgent attention since QoL outcomes are dependent on the proper management of PD-related symptoms

(Blanckenberg et al., 2013). Those who cannot access treatment experience lower survival rates, which contributes to PD's growing impact (Dekker et al., 2020). And still, even PwPD who are able to get the necessary help, often experience progressive difficulties associated with their medical treatment (Anderson et al., 2017). As the country embarks on major health reforms to make public healthcare more available and affordable, especially for disadvantages subgroups, the need for empirical evidence is imperative to help guide and inform policies (Burger & Christian, 2020). This study aimed to contribute to the lack of literature around information accessibility and sociodemographic factors in relation to treatment options and levels of care which directly impact morbidity rates and QoL.

1.5. Healthcare disparities

Whilst there is a group of PwPD, mostly in the private sector, who get diagnosed on time and receive good treatment, there is a larger group of PwPD who are also able to have their PD diagnosed, but aside from the high costs and traveling burdens, treatment is either non-existent or intermittent and therapy services as well as monitoring are limited which frequently forces people to turn to traditional healers first (Dekker et al., 2020). The majority of citizens in SA do not have private healthcare insurance coverage which further prevents affordability of long-term treatment in chronic diseases like PD (Dekker et al., 2020). Good health is dependent on the social, economic and political environments that support the population effectively, thus equitable access to healthcare services is a high priority for most countries and SA is no exception (Benatar et al., 2018). Although healthcare reform has been a priority for government with progressive policies implemented to promote accessible and affordable healthcare, health outcomes remain unequal while the burden of disease remains high (Burger & Christian, 2020).

The country's healthcare system reflects a stark social disparity between those who can afford private health insurance and those who cannot, with the beneficiaries of private healthcare services comprising more affluent, skilled and educated members of medical aid

schemes (Burger & Christian, 2020). With average spending on medical scheme members significantly higher than the uninsured people reliant on public health services, it also equates to a higher spending on medical expertise, specialized facilities and technology as well as more advanced treatments, thus further exposing the inequitable and polarized healthcare system (Burger & Christian, 2020). While the government is still trying to ensure more accessibility to healthcare for the most vulnerable groups, research has shown that this alone will not necessarily improve healthcare access (Burger & Christian, 2020).

1.6. Study Aims

This study aimed to contribute to the dearth of literature on PD in SA by examining treatments being received in both public and private healthcare facilities and report on the perceived efficacy thereof. It also aimed to assess QoL outcomes in both groups and establish the nature of the relationship between treatment and QoL outcomes. Furthermore, the study explored whether sociodemographic factors of household income and internet access moderated the aforementioned relationship. Although PD does not discriminate between patients from either public or private healthcare sectors where there is a huge socioeconomic divide between them, this comparative study aimed to find out whether disparities existed in access to treatment and whether it impacted upon QoL outcomes.

2. LITERATURE REVIEW

2.1. Introduction

This chapter will, firstly, set out to discuss the rationale behind the current study and its relevance to South Africa, before listing the major aims of the research report. Thereafter, an extensive literature review of the neuropathology and clinical presentation of PD is offered, before engaging with the literature on the prevalence of the disease with an overview of global PD rates. The chapter then examines QoL as a key variable in the study before assessing the

different treatment options, all of which are known to impact QoL. Treatment options discussed include pharmacological interventions, Deep Brain Stimulation surgery, physiotherapy and other forms of physical exercise, occupational therapy, speech therapy, light therapy, psychiatry and psychology-related treatments, dietician and nutrition-related treatments, cannabidiol therapy, traditional healing therapy, botox therapy and other alternative therapeutic interventions. The chapter then moves on to discuss access to healthcare in South Africa, particularly examining the divide between the public and private healthcare which may impact the treatment received and levels of care of PwPD. The chapter then motivates for the inclusion of household income and internet access as moderators that potentially impact the relationship between treatment received and QoL of PwPD. Before concluding the chapter, the biopsychosocial model is discussed as the theoretical framework for the study.

2.2. Rationale

Parkinson's Disease (PD) is a chronic and progressive neurogenerative disorder of ageing impacting on the central nervous system and affecting approximately one in 100 people above the age of 65 with difficulties in mobility as a defining feature (Amod & Bhigjee 2019; Singh et al., 2007). People's functional capacity and QoL are affected by the loss of mobility and independence to perform daily life activities (Orcioli-Silva et al., 2014). Mobility problems associated with PD such as tremors, rigidity, freezing, hesitation, festination, turning difficulties, shuffling gait and propulsion significantly affect QoL scores when measured with specific tools to quantify the impact of chronic illness (Rahman et al., 2008). Apart from mobility problems, PD affects other areas of patients' lives, causing autonomic, cognitive and psychological impairments as well as affecting their overall wellbeing, and thus assessing QoL has become an important measure in the management of PD when evaluating the total burden of the illness and not just the motor disabilities (Klepac et al., 2007).

With millions of people affected by PD worldwide, the burden of the disease is increasing as it requires a high level of continuous care which presents a challenge to under-resourced nations such as SA (Blanckenberg et al., 2013). A lack of proper treatment leads to higher morbidity rates and a decreased QoL, especially since the disease progresses rapidly when there is a delay in initiating potential symptom relief agents (Dahodwala et al., 2009). People with advanced symptoms of PD have very low levels of functional capacity and QoL (Orcioli-Silva et al., 2014). Current therapies are aimed at improving patients' functional mobility status but ultimately they cannot modify the progression of the neurogenerative process as there is still no cure for PD (Singh et al., 2007).

There is a low number of prevalence studies on PD from Sub-Saharan Africa (SSA) which is one of the fastest growing regions in the world (Williams et al., 2018). This is problematic because the distribution of health-related resources, although improving around the world, are still scarce in lower-to-middle income countries, and do not meet the standards established by the World Health Organization (WHO) (Williams et al., 2018). In one systematic review carried out in SSA, findings suggested a lack of well-trained medical personnel and multidisciplinary teams to treat people with PD, while treatments themselves were either non-existent or irregular (Williams et al., 2018). A far cry from WHO recommendations (one neurologist per 100,000 of the population), it is estimated that SSA has 3 neurologists per 10 million people alone which in itself has contributed to the low rate of prevalence studies (Blanckenberg et al., 2013; Bower et al., 2014).

South Africa may be in a more fortunate position than other countries in SSA because the Neurology Association of South Africa reports one neurologist per 400,000 people. Still, the quality of care needs urgent attention to improve survival rates by meeting the basic level of requirements to treat PD patients (Williams et al., 2018). Apart from the latter, access to healthcare is also associated with socioeconomic status, race, type of healthcare insurance,

and urban-rural location (Harris et al., 2011). Poor, uninsured, Black African rural respondents experience the greatest barriers (Harris et al., 2011).

Even those who are able to afford treatment, often experience difficult clinical courses either because medications are unavailable or as a result of the continual high costs of purchasing them (Dotchin et al., 2007). In addition to this, patients receive fledgling services in comparison with those in the developed world (Dotchin et al., 2007). Due to the progressive nature of the disease's chronicity and growing disability, there is a considerable socioeconomic burden as the number of patients requiring costly institutionalized care continues to increase (Winter et al., 2010). This also impacts families who need to care for PwPD at home who cannot afford to be institutionalized (Winter et al., 2010). Healthcare policies and programmes need to evaluate cost-driving factors of PD if they intend on reducing the burden of the disease and QoL outcomes (Winter et al., 2010).

To the researcher's knowledge, no literature until now has examined the moderating effect of household income and internet access upon this relationship. This study postulated that a major barrier to proper treatment and care, which ultimately affects QoL and morbidity rates, may be directly impacted by sociodemographic factors, especially in SA where there is an inequitable and vulnerable healthcare system. There is an increased need for empirical evidence to guide and inform policies where diseases like PD are concerned especially in light of the paucity of literature on disparities to treatment access and levels of care received which impact on PwPD QoL outcomes (Burger & Christian, 2020). The exploration of these aims provides valuable insights in terms of how treatment options impact QoL outcomes; particularly in SA where there is a huge social divide between those who can afford medical aid schemes and belong to the private healthcare sector, in comparison with PwPD in the lowest economic sector of the country who rely on public healthcare facilities to access treatment and care for PD.

2.3. Aims

The aim of this study was to explore in a cohort of PwPD,

1. the type of treatment being received by PD patients, either pharmacological, surgical or allied health professional therapies;
2. perceptions about the efficacy of treatments being used to manage PD symptomology;
3. the QoL of PD patients, as measured by the WHOQOL-BREF 26-item questionnaire;
4. the relationship between treatment received and QoL outcomes;
5. whether sociodemographic factors of household income and internet access moderate the relationship between treatment received and QoL outcomes.

2.4. Neuropathology

PD is a disorder of the extrapyramidal system (EPS) which is essential in maintaining posture and involuntary motor functions, thus controlling automatic activities and also influencing voluntary movement (Lee & Muzio, 2020). For the EPS to regulate these mechanisms it involves the processing of centres found in various brain regions such as the cerebral cortex, cerebellum, thalamus, reticular substance and several motor structures of the basal ganglia (Lee & Muzio, 2020). The basil ganglia is critical to the neuropathology of PD since the ability to govern voluntary movements is impacted by the profound changes which take place in the functional organisation of the basil ganglia nuclei (Blandini, 2000). Lesions of the basil ganglia thus lead to motor disorders (Graybiel, 2000).

The basil ganglia is the largest subcortical structure in the forebrain and interacts closely with the frontal cortex (Leisman et al., 2014). There are five interconnected nuclei which make up the basil ganglia, namely the subthalamic nucleus (STN), substantia nigra (SN) which is made up of the substantia nigra pars compacta (SNpc) and substantia nigra pars reticulata (SNpr), putamen, caudate nucleus and globus pallidus which is subdivided into the internal

(GPi) and external (GPe) segments (Blandini, 2000; Graybiel, 2000). The caudate nucleus and putamen, although separate structures, are generally referred together as the striatum because they are fused anteriorly, connected by several bridges of cells which have similar anatomical and functional characteristics (Blandini, 2000; Leisman et al., 2014). The striatum forms the input station of the basil ganglia, receiving input from the cerebral cortex, thalamus and nigrostriatal which is characterised by dopaminergic input from the SN (Waldvogel et al., 2014).

Histopathologically, PD is characterized by the loss of pigmented dopaminergic neurons in the SNpc which project to the striatum through the involvement of the GPi segment of the ventral striatum (Blandini, 2000). Nerve cell loss in PD does not occur without the presence of Lewy bodies (Lb) which are found in the dopaminergic neurons in the SN and usually appear at the early stages of the disease process (DeMaagd & Philip, 2015; Gibb, 1992). Therefore the presence of Lb, which are abnormal aggregations of proteins and lipids signifying neuronal degeneration, is another characteristic feature of PD (Gibb, 1992).

Components of the basil ganglia are parts of larger circuits found in the thalamus and cortex (Leisman et al., 2014). Dopaminergic loss increases activity in the GPi/SNpc circuits which results in gamma aminobutyric acid (GABA) dysfunction and subsequent inhibition of the thalamus (DeMaagd & Phillip, 2015). The ability of the thalamus to activate the frontal cortex is thus decreased, resulting in reduced motor activity which is the main clinical feature of PD (DeMaagd & Phillip, 2015). The loss of these dopaminergic neurons causes functional modifications to the entire basil ganglia circuitry and these changes constitute the neural substrate for the expression of PD's motor symptoms (Blandini, 2000). Why the degenerative process occurs that affects the SNpc is still unknown (Blandini, 2000).

2.5. Clinical Presentation

In 1817 Dr. James Parkinson described PD as a shaking palsy, involving "involuntary tremulous motion, with lessened muscular power, in parts not in action and even when

supported; with a propensity to bend the trunk forwards, and to pass from a walking to a running pace: the senses and intellects being uninjured" (p.441).

The primary diagnostic symptoms of PD include bradykinesia (slowness of movement) with one additional symptom, either muscular rigidity, resting tremor or postural instability (Berardelli et al., 2001; Sveinbjornsdottir, 2016). PD patients often experience motor symptoms only after 50-80% of dopaminergic neurons have already been lost (DeMaagd & Phillip, 2015). Other motor symptoms can emerge such as speech disturbances, swallowing problems, dribbling of saliva and especially dystonia which is prevalent in up to a third of PD patients and defined as a movement disorder that is characterized by persistent or intermittent muscle contractions which causes abnormal, repetitive movements or postures (Jocson & Lew, 2019; Sveinbjornsdottir, 2016).

Non-motor symptoms also occur in PD patients and have the most impact on QoL (Pfeiffer, 2016). These features include sensory abnormalities, sleep problems, behavioural changes, autonomic dysfunction, fatigue, gastrointestinal and bladder dysfunction among others (Parkinson, 2002; Pfeiffer, 2016). Abnormalities of sensation include olfactory (smelling) impairment which is prevalent in up to 90% of patients (Casjens et al., 2013; Pfeiffer, 2016). Visual impairments like dry eye syndrome, convergence insufficiency, impaired colour discrimination and reduced contrast sensitivity are also commonly reported non-motor symptoms (Nowacka et al., 2014). Pain is another sensory abnormality present in about three quarters of PD patients and categorized into musculoskeletal pain which is the most common, nerve pain, dystonia-related pain, akathitic (restlessness) discomfort and primary or central parkinsonian pain (Valkovic et al., 2015).

Behavioural and emotional changes in PD include depression, where one study found the presence of major depressive disorder in up to 17% of PD patients, minor depression in 22% of individuals with PD, and dysthymia in over 10% of individuals with PD (Reijnders et al.,

2018). Anxiety, characterised by either generalized anxiety disorder, panic or phobic disorders, has also been reported to affect 25-40% of PD patients and, like depression, may appear at any stage during the progression of the illness as well as precede motor symptoms (Reijnders et al., 2018). Apathy has also been found in up to 40% of PwPD, and another problem that affects more than 80% of PwPD with a disease duration of over 20 years is the development of dementia (Pfeiffer, 2016; Reijnders et al., 2018).

Autonomic dysfunction occurs at any stage in the trajectory of PD, manifesting in symptoms like constipation, orthostatic hypotension (when the blood pressure drops upon standing) and other blood pressure-related problems such as nocturnal hypertension and post-prandial hypotension (low blood pressure after eating), gastrointestinal dysfunction, urinary dysfunction, sexual dysfunction where sexual satisfaction has reported to be lower in men with PD, and lastly thermoregulatory dysfunction which encompasses sweating problems (Pfeiffer, 2016).

Disturbed or impaired sleep is present in up to 90% of PD patients where sleep fragmentation is the most commonly reported form of insomnia which could be attributed to the inability to turn due to rigidity, bradykinesia, side effects of pharmacological treatment and periodic limb movements (Kurtis et al., 2013). REM sleep disorder (the continuous movement during sleep), has also been reported, and like all other non-motor symptoms it can precede motor symptoms (Kurtis et al., 2013). Lastly, fatigue has gained considerable attention in PwPD who often report the feeling of exhaustion and tiredness to be their most disabling symptom, with a significant impact on their QOL (Dogan et al., 2015).

2.6. Prevalence

Neurological disorders constitute the leading source of disability worldwide, and according to the latest Global Burden of Disease as well as the Risk Factors Study, PD was the fastest growing illness in terms of prevalence, disability and death (Dorsey et al., 2018). Examining

global prevalence rates, the burden of PD has exponentially increased over the last three decades, from 2.5 million in 1990 to over 6 million in 2016 (Dorsey et al., 2018). This could be due to either the ageing of the population, which stems from an increase in life expectancy, or longer disease duration, as well as changes in environmental or social risk factors such as smoking, the use of agricultural pesticides, accessibility to purified water or head trauma (Rocca, 2018). Of the 6 million people living with PD as measured in 2016, 52.5% were men and 47.5% were women, 34.4% of the overall sample were from high sociodemographic index (SDI) countries, almost 51% were from high to middle or middle SDI countries and 15% came from lower to middle income countries (LMIC) or low SDI countries (Dorsey et al., 2018). PD was responsible for 211,296 deaths in 2016 (Dorsey et al., 2018).

The global prevalence and morbidity rate significantly increased between 1990 and 2016 except for southern Latin America, Eastern Europe (particularly Moldova) and Oceania, while the largest increase in prevalence was seen in Norway (Dorsey et al., 2018). The study by Dorsey et al., (2018) indicated that North Africa and Middle East had a prevalence count of 297,861, while Western sub-Saharan Africa and Eastern sub-Saharan Africa came in with similar counts of 44,230 and 46,489 respectively (Dorsey et al., 2018). South sub-Saharan Africa trailed behind all African regions at 20,980 individual counts of PD (Dorsey et al., 2018). Based on population sizes, underdiagnosis, and lack of a PD registry, it would appear that this data does not reflect the actual prevalence of PD in this region, hence the reason rates of PD in Africa have been considered as unreliable (Dorsey et al., 2018; Fereshtehnejad et al., 2014).

The global burden of PD has more than doubled in the past three decades and will continue to increase substantially as populations age and life expectancy increases, and with more patients presenting with advanced PD, primary prevention strategies and effective treatments than are currently available will become an urgent necessity (Dorsey et al., 2018). Under-diagnosis of PD is very common apart from the fact that developing countries face a lack of long-term availability of medication, follow-up treatment plans, health literacy and multi-

disciplinary input (Dotchin et al., 2007). In order to evaluate the burden of PD on the healthcare system and assist decision-making processes for PD management at a gross level, it is vital to record the prevalence of PD in every country because the nature of its effects has a substantial impact on resource utilization and expenditures (Fereshtehnejad et al., 2014; Hirayama et al., 2008).

2.7. Quality of Life of individuals with Parkinson's Disease

At the start of the millennium a paradigm shift occurred in the evaluation of neurological disorders (Rahman et al., 2008). Previously changes in motor symptoms were the focal point of evaluations using such scales like the United PD Rating Scale (UPDRS) (Rahman et al., 2008). There is now more awareness of the full effects of PD, focusing not just on medication or surgical treatment, but also on psychological wellbeing, daily life activities and the capacity for PwPD to carry out social and occupational roles (Rahman et al., 2008). This shift led to the emergence of QoL measures to quantify the accurate impact of chronic illness, and since then, a large body of literature exists illustrating the negative impact that chronic neurological disorders, like PD, has on QoL (Barone et al., 2017; Rahman et al., 2008).

The World Health Organization defines QoL as "an individual's perception of their position in life within the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns" (WHOQOL Group, 1998, p. 551). In other words, it is the discrepancy between one's current level of functioning and their expected state of health, thus affecting people's perceived physical, social and psychological wellbeing (Hirayama et al., 2008).

The aim of medical management is to ameliorate the impact of PD on QoL outcomes. When rehabilitation programmes are implemented to enhance functional mobility, lessen pain and promote physical activity and energy, QoL for PwPD is considerably enhanced (Carr et al., 2001). Such interventions are essential because alterations in the natural aging process and the

progression of chronic illness can lead to a declined ability to perform tasks which enable people to live as independent members of their communities (Graf, 2009). Apart from motor symptoms, PD non-motor symptoms such as depression and cognitive impairment have been demonstrated to be major predictors of QoL outcomes, which will be discussed in more depth when examining therapeutic interventions (Barone et al., 2017).

Quality of Life outcomes inform the rehabilitation need and planning for in-home services such as nursing, meal preparations, financial and medical management as well as supervision (Graf, 2009). Innovative multidisciplinary rehabilitation interventions are warranted when mobility problems like shuffling, falling and turning difficulties are resistant to medical treatment, because they have a significant impact on QoL (Rahman et al., 2008). Assessing QoL is also important in the workplace since PD can occur during middle age which induces a heavy socioeconomic burden for PwPD, their families, caregivers, employers as well as healthcare systems (Fereshtehnejad et al., 2014). In conclusion, QoL is influenced by many facets during the progression of PD, including motor and non-motor symptoms that need to be targeted for intervention either through medication or alternative treatments which could lead to improved QoL (Rahman et al., 2008).

2.8. Therapeutic Interventions

2.8.1. Pharmacological Interventions

Restoring dopamine activity in the striatum with dopaminergic therapies assists with the clinical improvement of motor symptoms (DeMaagd & Phillip, 2015). Many different medications have been developed to relieve PD symptoms, with Levodopa (L-dopa) the most common drug that acts to replenish dopamine levels in the brain (Schulz & Grant, 2000). Sinemet, which is a combination of L-dopa with Carbidopa, is the principle medication used to treat PD because the Carbidopa prevents L-dopa from converting to dopamine before crossing the blood-brain barrier (Schulz & Grant, 2000). Side effects, usually short term, include dyskinesia and other

involuntary movements, nausea and orthostatic hypotension (Schulz & Grant, 2000). Long term use of L-dopa reduces its efficacy due to the prolonged reappearance of symptoms with patients needing to increase their need for medication which is not always possible (Schulz & Grant, 2000).

Despite the medication's eventual reduction of efficacy as well as undesirable side effects, medications like Sinemet are generally the first point of treatment. Despite this, medication intake is significantly lower in SA when compared to Europe, where studies have shown their prevalence in only 12.5% of Africa, mostly in North and South Africa in contrast with 79.1% in Europe (Williams et al., 2018). The procurement of and affordability of PD drugs lead to either irregular or non-existent use, with limited monitoring and access to multidisciplinary staff (Williams et al., 2018). In addition, and given SA's cultural and religious practices, many prefer to resort to traditional healers before going to a medical healthcare facility (Williams et al., 2018).

2.8.2. Deep Brain Stimulation Surgery

While some medications work to improve mobility they can fail after long-term use, so neurologists may advise patients to undergo Deep Brain Stimulation (DBS) surgery, where high frequency electrical stimulation is continuously administered through surgically implanted devices to improve motor symptoms in PwPD who are in advanced stages of the illness (Deuschl et al., 2006). Deep Brain Stimulation surgery targets basil ganglia nuclei such as the STN and GP with the intent to modulate network activity (Strauss et al., 2014). This electrode implantation surgery which has demonstrated its effectiveness for control of symptoms is reversible, programmable and has the ability to be performed bilaterally in a safe manner (Wagle Shukla & Okun, 2014).

DBS surgery is carried out by a neurosurgeon specialising in stereotactic neurosurgery who works as a part of a multidisciplinary team (Bronstein et al., 2011). In order to select appropriate

patients with PD there is a methodical screening process involving a collective of neuropsychologists, neurologists, and neurosurgeons (Wagle Shukla & Okun, 2014). Although there is no specific age limit qualifying potential patients for DBS surgery, most neurologists agree that caution should be exercised with patients above the age of 70, particularly if they have comorbidities and potentially more likely to develop complications such as stroke or haemorrhage (Wagle Shukla & Okun, 2014). Younger age has shown to have lesser risks for any type of surgery, whether patients have PD or not (Wagle Shukla & Okun, 2014).

In one random controlled trial comparing the benefits and risks of DBS with those of best pharmacotherapy treatment, QoL outcomes favoured DBS for 64% of PD pairs randomized to both groups (Weaver et al., 2009). In SA the first DBS surgery was carried out in 2000 by Dr Roger Melvill and these procedures have been performed at mostly private hospitals (Anderson et al., 2017). Although this surgical option has proven itself as an influential therapy to treat motor symptoms, there are risks involved with some patients reporting significant adverse effects in speech, mood and cognitive domains (Wagle Shukla & Okun, 2014). There is no single DBS technique designed to fit every patient perfectly, but technologies are currently being refined to maximize benefits and reduce risks even further (Wagle Shukla & Okun, 2014).

Notwithstanding the growing body of evidence indicating the efficacy of neuromodulation using DBS surgery, this treatment option is still underused in certain patient populations (Chan et al., 2014; Strauss et al., 2014). In Africa, the estimated median number of neurosurgeons is 0.01 per 100,000 people in the population compared to 1.02 in Europe (Williams et al., 2018). The prevailing economic conditions are a major factor in the difficulty of equipping neurology and neurosurgical services (Williams et al., 2018). Addressing this lack of resources would be beneficial to patients and the healthcare system because DBS can alleviate certain motor symptoms which improve QoL, promote independence among patients and potentially lower healthcare costs because DBS reduces medication requirements (Anderson et al., 2017).

Although many patients with PD in SA are eligible for the procedure, the high costs and lack of trained experts still pose great barriers (Anderson et al., 2017).

2.8.3. Physiotherapy and physical exercise

Despite optimal medical management in many cases, the progressive nature of PD is associated with impairments at different levels of body function, typically hindering people when carrying out a wide variety of activities (Bouça-Machado et al., 2018). Although many of the symptoms of PD respond to different therapies, it is clear that functional mobility is directly impacted and correlated with QoL (Anderson et al., 2017). Functional mobility is defined as one's physiological ability to move independently as well as safely in various environments to be able to carry out functional activities as well as perform activities of daily living whether they be inside the home, at work or community (Bouça-Machado et al., 2018). It is important for PD patients to have good functional mobility in everyday life to enable them to move around effortlessly within a reasonable time period (Bouça-Machado et al, 2018).

While pharmacological and surgery treatments target impairments related to dopaminergic lesions, they are only partially effective in controlling the motor symptoms of PD (Radder et al., 2017). As PD progresses to advanced stages, medication is less effective and could cause complications such as disabling dyskinesia, in which case further L-dopa increases are not recommended (Radder et al, 2017). Even with optimal medical management, patients face challenges with daily living activities, such as balance, gait, posture, walking, eating, drinking, transfer activities such as rising and sitting down onto a chair or getting out of bed (Radder et al., 2017; Tomlinson et al., 2013). This results in decreased independence, inactivity and in many cases, social isolation, all of which lead to a reduced QoL (Tomlinson et al., 2013).

Physiotherapy is often recommended as part of a multidisciplinary treatment team to assist PwPD to better carry out their daily living activities because movements, which are normally automatized, are often difficult for patients to perform due to weak limb support against gravity,

a reduction in muscle power or poor timing of velocity (Radder et al., 2017). The aim of physiotherapy is to increase movement quality, functional mobility and general fitness in the hope that secondary complications will be minimized and safety optimized (Radder et al., 2017). Conventional and novel methods of physiotherapy interventions have been widely studied in the literature with one meta-analysis studying the efficacy of conventional methods and newer modalities like resistance and strategy training, treadmill training, dance and martial arts, aerobic exercises, hydrotherapy, balance and gait training, Nordic walking, dual tasking and exergaming (Radder et al., 2020). The aforementioned study by Radder et al. (2020) which included a sample of almost 8,000 participants found that all methods, aside from dual tasking, had a significant impact on either motor symptoms, QoL, gait and balance.

Other newer modalities such as hydrotherapy or aquatic interventions have also demonstrated effectiveness in people living with PD, although land-based exercise programmes have shown better results in group comparison studies (Nowak, 2018). Clinical trials have further suggested that aerobic exercises and stretching techniques could assist motor and non-motor functions although they cannot assist with fall prevention (Li et al., 2016). Intensive training modalities have been found to improve muscle strength and mobility while lower-intensity exercises have a positive impact on gait speed (Li et al., 2016). Exercises such as Tai Chi, the ancient traditional Chinese art has also been shown to reduce balance impairment and falls, whilst also increasing functional mobility (Li et al., 2016).

There are several urban centres around Africa, especially SA, that have comprehensive neurological and auxiliary services available to carry out these kinds of physiotherapies, but access by the general population is limited either due to the high costs involved or other barriers such as having no knowledge of the above available treatments (Dekker et al., 2020). This corroborates study findings which suggest that there is still a low number of patients working with physiotherapists and occupational therapists to help relieve their symptoms (Williams et al., 2018).

2.8.4. Occupational Therapy

As PD progresses, an individual will experience deteriorating manual dexterity due to the worsening rigidity, bradykinesia and tremor, all of which affect even the simplest everyday activity such as dressing, eating food, swallowing a pill or getting out of bed (Rahman et al., 2008). Correlating with poor QoL outcomes, such mobility problems can also cause injury and even lead to hospital admission in cases where symptoms such as shuffling or turning difficulties result in falls (Rahman et al., 2008). PD patients can suffer social stigma and embarrassment from falling, and thus a fear of falling can affect their participation in social activities which further restricts their QoL (Rahman et al., 2008). When an individual's functional independence is affected they become more dependent on caregivers which also requires interventions to assist them both to carry out daily living activities to improve QoL (Rahman et al., 2008).

Recognised as an important adjunct to pharmacological management, occupational therapy (OT), like physiotherapy, focuses on optimizing physical performance, but also includes assisting PD patients to engage in activities and roles which are meaningful in the home and community environment, including self-care, functional mobility, work capacity and leisure activities (Radder et al., 2017; Rao, 2010). Through functional training of motor skills, process skills and psychosocial aspects of performance in different contexts, OT aims to promote overall health and wellness (Rao, 2010). This therapy also extends to caregivers to support their own wellbeing as well as care for patients who need assistance with daily living activities (Radder et al., 2017). It is a relatively low-cost therapeutic intervention which has seen an increase in patient's perceived performance and satisfaction carrying out their daily living activities (Sturkenboom et al., 2015). OT interventions are well tolerated by PD patients, leads to gains in motor function, and has been widely reported to positively influence QoL outcomes for patients as well as caregivers (Rao, 2010; Sturkenboom et al., 2015).

2.8.5. Speech Therapy

Speech disorders can occur in up to 89% of PD patients and lead to communication challenges in social interactions and a subsequent decreased QoL (Wertheimer et al., 2014). Speech production problems caused by PD is commonly known as Parkinsonian/hypokinetic dysarthria, of which the characteristics include a pitch that can either be monotonous, reduced or loud, a change in variable rate, short rushes of speech, imprecise consonants and a harsh, breathy voice (Schulz & Grant, 2000). Dysarthria can emerge and worsen during any stage of PD, resulting in a loss of communication and social isolation (Skodda, 2012). Speech therapy has proven to be useful to address dysfunctions of phonation associated with PD, as well as swallowing difficulties and issues of pitch (Beitz, 2014). Although patients can show improvement after therapy they often revert to the pathological patterns immediately afterwards, thus supporting the evidence that speech therapy should be an ongoing treatment (Schulz & Grant, 2000).

There are also devices available that include voice amplifiers to increase vocal volume, delayed auditory feedback to improve speech intelligibility, a masking device and a wearable intensity biofeedback device to improve vocal loudness, all of which could relieve anxieties of patients with PD who were previously not audible to others (Schulz & Grant, 2000). Laryngeal dystonia, which is a classic feature of PD and characterized by a reduction of voice intensity and audibility of speech has been treated effectively through the use of botox injections which is discussed further down (Schulz & Grant, 2000). Not without side effects, one study reported that patients experienced extreme breathiness, vocal fold edema and even mild bleeding, therefore further research is warranted due to insufficient data to determine appropriate dosage recommendations for various types of botox therapies (Mills et al., 2015).

Speech disturbances have been disabling side effect of DBS surgery in many PwPD (Tripoliti et al., 2014). A study by Wertheimer et al. (2014), examined differential speech profiles

between PD patients with (n=287) and without (n=471) STN-DBS. Findings showed significant differences in perceived speech disturbance severity between both groups, with the DBS group indicating more severe speech symptoms, particularly slurred speech (Wertheimer et al., 2014). It is important for DBS candidate patients to be better informed about possible speech outcomes in order to facilitate adjustment to these conditions post-surgery (Tripoliti et al., 2014).

2.8.6. Light therapy

Sleep disorders are commonly reported by PD patients, and often associated with depression, both of which are caused by a disturbed circadian rhythm and affect individuals' QoL (Rutten et al., 2012; Trotti & Bliwise, 2014). While there is a paucity of large-scale, randomized controlled trials of sleep treatments, bright light therapy (BLT) has been shown to be effective in the treatment of insomnia (Trotti & Bliwise, 2014). Although BLT has been known to restore circadian rhythmicity which assists with mood and insomnia, further research is needed within this specific population (Rutten et al., 2012; Trotti & Bliwise, 2014).

A few studies have also suggested that BLT has a positive influence on motor function and could potentially facilitate a reduction of prescribed dopaminergic medication, but again further studies are needed to illustrate the efficacy and underlying mechanism of BLT in the treatment of motor and non-motor PD symptoms (Ruttem et al., 2012; Trotti & Bliwise, 2014). Reports of damage to skin and eye tissue have been reported after BLT, and patients with photosensitization reactions to light should be monitored by an ophthalmologist or dermatologist when receiving this treatment (Rutten et al., 2012). The paucity of literature around the efficacy of BLT in treating sleep disorders in PwPD warrants further research. In the current study, no participant selected this treatment option.

2.8.7. Psychiatry and Psychology-related treatments

2.8.7.1. Psychiatry-related treatment

Neuropsychiatric disorders are commonly reported in patients with PD, particularly mood disorders (Burn et al., 2012). Hallucinations and other psychotic symptoms which are less prevalent such as delusions are reported complaints that may occur throughout the day in patients with advanced PD symptoms (Varanese et al., 2010). Although hallucinations can involve several sensory modalities, the most common are visual hallucinations and experienced by one in three patients (Fénelon, 2008). Dopaminergic and other pharmacological treatments facilitate the development of these psychotic symptoms, albeit other disease-related factors such as the presence of dementia or cognitive impairments are additional risk factors (Fénelon, 2008). Neurologists often need to evaluate the role of a patient's pharmacological treatment, like decreasing their dose of L-dopa, and trying to balance the effect of psychosis with the worsening of motor function (Varanese et al., 2010). Due to the great susceptibility of PwPD to the motor side effects of several anti-psychotic medications, they should typically be avoided until they are deemed safe in PD (Varanese et al., 2010).

Depression and anxiety can affect 40-60% of PwPD with a significant effect on QoL (Varanese et al., 2010). Regardless of the stage of PD, mood disorders are ranked among the most troublesome non-motor symptoms in PwPD (Beitz, 2014). Factors contributing to the occurrence and severity of depression in PD include nigrostriatal dysfunction, extrastriatal pathology, psychological as well as environmental factors (Schrag, 2006). Anxiety is known to affect one in three patients, while patients also report apathy (loss of motivation) and abulia (loss of ability to think or act) (Beitz, 2014). Drugs are available to control these symptoms but usually doctors will examine patient histories and age to assess the right individual course of action (Varanese et al., 2010). Administering drugs such as low doses of benzodiazepines have been shown to be effective when anxiety is persistent, however it has been known to cause

amnesia and confusion in PwPD with advanced symptoms and also poses a risk factor for falls (Varanese et al., 2010).

2.8.7.2. Psychology-related treatments

Aside from psychiatric treatments, psychological therapies have been effective in improving cognition, assisting affective disorders, and promoting activities and participation (Kampling et al., 2019). Participation in support groups have shown positive improvement, allowing discussion of emotional and psychological concerns for individuals with PD as well as their caregivers (Beitz, 2014). Since patients may be at different stages of the disease it is useful to not only focus on the negative issues but emphasize positivity and a sense of control and social wellbeing since patients in early stages may find it difficult to see those in very advanced stages of the disease (Beitz, 2014).

Mindfulness Based Cognitive Therapy (MBCT) within group settings has benefitted people with PD (Fitzpatrick et al., 2010). Once cross-sectional study comprised of 85 participants with PD found that mindfulness training, which is focused on reducing an escape-avoidance coping style, helped to improve QoL outcomes (Buck et al., 2011). Other therapies include psychodrama, cognitive behavioural therapies, cognitive training, mind-body interventions, cueing, psychodynamic psychotherapy as well as general individual counselling (Kampling et al., 2019).

2.8.8. Dietician / Nutrition

As part of a healthy lifestyle, modern medicine practices focus on reducing inflammation and free radical damage to further protect against neuronal death which could slow PD progression (Li et al., 2016). Certain nutritional supplements, such as vitamins, could decrease the risk of PD. For example, vitamin B6 has been reported to decrease the risk of PD in

patients that smoke, while vitamin D has shown to be inversely associated with the disease (Wang et al., 2015).

A deficiency in vitamin B is particularly known to cause neurological disability and impairment because it is linked to homocysteine which has many neurotoxic pathogenetic effects in neurodegenerative disorders (Lange et al., 2019). Increases in homocysteine levels exacerbate dopaminergic cell death, and elevated levels of homocysteine are normally found in PwPD compared to healthy age-matched controlled groups (Lange et al., 2019). In particular, the substantia nigra contains high levels of vitamin B1 (thiamine), and when it is deficient there is a decreased concentration of striatal dopamine (Lange et al., 2019). A longitudinal study by Costantini and Fancellu (2016) examining the efficacy of intramuscular vitamin B1 (in conjunction with L-dopa) which was administered twice a week over the course of two years to 50 PD patients, found sustained improvement in both motor and non-motor symptoms. Thiamine thus appears to have both a restorative and neuroprotective action in PD, but there are still issues needing to be addressed such as the effect of vitamin B1 in PD patients who are not treated with L-dopa, the optimum dosage levels of thiamine and also the assessment of other dietary components (Costantini & Fancellu, 2016).

Nutraceuticals like coenzyme Q10, fish oils and selenium are known to be potentially therapeutic for PD since they have antioxidant and anti-neuroinflammation properties, but there is still little evidence supporting their clinical usage (Li et al., 2016). While nutritional consultation has been shown to assist in the management of PD-associated conditions, no diet has been proven to alter the course of the disease (Li et al., 2016). Some interventions could potentially address issues like constipation, which is a commonly reported symptom, through increased fibre and water intake, while avoiding large high fat meals can assist with faster gastric emptying (Li et al., 2013). Consulting dieticians can also assist with weight loss and a lack of appetite which are commonly reported symptoms (Beitz, 2013).

Phillips et al. (2018) examined whether diet manipulation influenced motor and non-motor symptoms by dividing a group of 47 PwPD into two groups, one in which participants followed a low-fat diet plan and another allocated to a ketogenic diet plan (high fat, low carbohydrate). Findings indicated that both groups showed significant improvement in motor and non-motor symptoms after 8 weeks, but greater improvements in non-motor symptoms appeared in the ketogenic group (Phillips et al., 2018). It is important to note that the ideal fat-to-carbohydrate ratio of diets is unknown, warranting further investigation in this field based on the scarcity of literature (Lange et al., 2019; Phillips et al., 2018).

2.8.9. Cannabidiol Therapy

Cannabidiol (CBD), one of the main components of cannabis sativa, has been shown to have different effects upon various PD symptoms due to its neuroprotective properties (Chagas et al., 2014). In one study a sample of twenty-one PwPD, without dementia or comorbid psychiatric conditions, were evenly split into three groups who were either treated with placebo, 75mg/day CBD or 300mg/day CBD (Chagas et al., 2014). No statistical differences regarding PD motor symptoms were found but the study revealed improved QoL scores for the group which received 300mg/day CBD (Chagas et al., 2014). It's possible that CBD's antidepressant, anxiolytic, antipsychotic, and sedative properties are responsible for perceived improvements in emotional wellbeing, daily living activities, and overall QoL in patients without psychiatric comorbidities (Chagas et al., 2014).

More individuals with PD have started to use CBD therapy to treat their symptoms, particularly pain, anxiety, bradykinesia and tremor (Cravanas & Frei, 2020). However, adverse effects such as hallucinations have occurred, particularly in patients who use medication associated with an increased risk of psychosis such as certain dopamine agonists (Cravanas & Frei, 2020). Because PD carries an increased risk for the development of hallucinations and psychosis, further research is needed using larger samples and specific objectives before any

definite conclusions can be made about the effectiveness of CBD oil therapy (Cravanas & Frei, 2020).

2.8.10. Traditional Healing Therapy

Traditional healing therapy has been around for centuries. In South Africa, many people do not seek medical help for their PD symptoms, perhaps because they attribute their symptoms to the normal ageing process or associate the disease with a curse or witchcraft for which they may present to traditional healers which is common practice (Mokaya et al., 2017). A survey among a sample of 154 Xhosa speaking Black South Africans (including PwPD, traditional healers and the general public) suggested that only 18% of the participants could identify PD based on a person's symptoms, while everyone else cited mental illness, stress, other diseases, witchcraft and the intake of certain foods or drinks as being responsible for the symptoms (Mokaya et al., 2017).

The aforementioned study also indicated that only PwPD (16% of sample) as well as traditional healers (20% of sample) had a greater knowledge about PD than the general public participants (63% of sample), emphasizing the striking lack of knowledge about PD among general Black South Africans (Mokaya et al., 2017), which leads to undiagnosed and untreated people and ultimately poorer health outcomes and QoL. Mokaya et al. (2017) showed that 51% of participants (N=154) found satisfaction using traditional healing treatments such as the use of plants like aloe vera, tinsel flower, ribbon bush plant, white milkwood, and African potato which provided relaxing effects when they were grounded into powders and smoked, placed into drinks or on small incisions on their skin.

Traditional herbal medicines have been found to have neuroprotective effects in PD in other parts of the world. For example, ginseng is used in Eastern Asian countries for its anti-inflammatory properties, improvement of fatigue and cognition (Li et al., 2016). Ginkgo biloba (also called the maidenhair tree) has been found to contain potential antioxidant and

neuroprotective properties in PD animal models, with one study illustrating an increase in extracellular dopamine levels in the rat prefrontal cortex, while another single case study on a human participant found that a combination of ginkgo biloba with a multivitamin-multimineral supplement led to significant improvement of PD symptoms (Conrad, 2014; Yoshitake et al., 2010). Evidence by the National Toxicology Program in the US suggests that this tree can cause liver cancer in mice and thyroid cancer in rats, and therefore further research is warranted (Conrad, 2014).

Herbs containing high levels of L-dopa like mucuna pruriens and vicia faba have demonstrated neuroprotective effects like recovering dopamine production, which lead to reduced dyskinesia in animal models (Manyam et al., 2004). Yokukansan (YKS), another herbal extract, has shown to be useful in the treatment of neuropsychiatric symptoms like anxiety and hallucinations (Hatano et al., 2014). A study examining the efficacy of YKS in neuropsychiatric symptoms in 25 PD patients who were treated with YKS (7.5g/day) for 3 months yielded significant improvements in hallucinations, anxiety and apathy during treatment, although they worsened after treatment ended (Hatano et al., 2014). Although there have been evidence-based studies reporting on the effectiveness of herbal therapies, there is still a lack of sufficient clinical data and safety profiles to support its clinical usage in the treatment of PD (Li et al., 2016).

2.8.11. Botox Therapy

Botulinum toxin (BoNT), commonly known as botox, has gained notoriety in many neurological conditions and works by hindering the release of acetylcholine at the neuromuscular junction to block neuromuscular conduction and muscle contraction (Mills et al., 2015). Botox therapy is reported to effectively treat a plethora of symptoms such as focal and generalized dystonias, tremor, involuntary spasms, overactive bladder, blepharospasm and lid

apraxia, camptocormia, hyperhidrosis, dysphagia and constipation when pharmacologic treatments are ineffective (Jocson & Lew, 2019; Mills et al., 2015).

A study by Lagalla et al. (2006) investigated the efficacy of BoNT treatment in reducing sialorra, which is related to swallowing disorders which negatively affect QoL outcomes, in a sample of 32 PD patients who complained about excessive drooling. Results showed a reduction in drooling and saliva production, indicating the safety and effectiveness of BoNT injections (Lagalla et al., 2006). One case series study administered BoNT therapy to six PD patients with DBS surgery who had been suffering disabling foot dystonia and found significant improvement after three weeks, including improved pain and lower limb functional outcomes (Gupta & Visvanathan, 2016). Even though BoNT therapy has the potential to improve patients' symptoms, there is still limited data to support its use for gait issues and certain L-dopa induced dyskinesias (Jocson & Lew, 2019; Mills et al., 2015). Further research is needed to advance the understanding of its current and future uses.

2.8.12. Alternative therapeutic interventions

Alternative therapeutic interventions have demonstrated improvements in measures of gait, flexibility, muscle force, fatigue and QoL. Yoga, which combines muscular activity and mindful focus on awareness of the self, the breath and one's energy has been known to reduce or alleviate structural, physiological, emotional and spiritual pain (Woodyard, 2011). One randomized controlled pilot study to investigate the effectiveness of yoga on QoL measures in PwPD found significant improvement in QoL scores as well as a reduction in tremors, improvement in diastolic blood pressure and vital capacity in the group which received the yoga interventions twice-weekly for 12 weeks (Sharma et al., 2015).

Massage therapy, which involves soft tissue manipulation incorporated with relaxation, has positively affected certain PD symptoms such as shoulder stiffness, muscle pain and fatigue, with some patients reporting a higher QoL after long term massage therapy (Donoyama

et al., 2014). Dancing has also been effective in improving both motor and non-motor symptoms like gait and balance (Sharp & Hewitt, 2014). Acupuncture, the traditional Chinese treatment where needles are inserted in specific areas around the body to stimulate nerve receptors, is long known to relieve some motor and non-motor symptoms like sleep and psychiatric disorders as well as gastrointestinal symptoms (Kim et al., 2014). Studies have also illustrated the efficacy of acupuncture in leading to a reduced dose of L-dopa, but this therapy, like the rest described above require further research using larger sample sizes to ascertain their efficacy (Kim et al., 2014; Li et al., 2016).

2.9. Access to healthcare in South Africa

Good health is dependent on the social, economic and political environments that support the population effectively, thus, equitable access to healthcare services is a high priority for most countries (Benatar et al., 2018). That being said, over a billion people from low- to middle-income (LMIC) countries worldwide cannot afford adequate healthcare services (Harris et al., 2011). In SA specifically, disparities in access to healthcare are prevalent largely due to distortions in resource allocation, even though healthcare access for all is enshrined in Section 27 of the Constitution (Coovadia et al., 2009; Harris et al., 2011).

Such barriers exist because of uneven social-power relationships which are largely due to massive inherited inequities in income, access to healthcare and other social services across different race and socioeconomic groups in the country's post-apartheid democracy (Gilson & McIntyre, 2007; Harris et al., 2011). Although healthcare reform is supposed to be a priority for the government with progressive policies implemented to promote accessible and affordable healthcare, considerable inequalities still remain, with policy changes that were initiated in 1994 not yet resulting in expected outcomes (Whitehead et al.,2001). The fragmentation between public and private sectors reflects an unequal healthcare system where health outcomes remain

unfair while the burden of disease remains high (Burger & Christian, 2020; Gilson & McIntyre, 2007).

Based on the huge social divide between those who can afford private health insurance and those who cannot, one study by Burger and Christian (2020) measured access to healthcare by examining the dimensions of availability, affordability and acceptability using data from SA's 2009 and 2010 General Household Surveys in which 190,164 people were included. The study found unequal access to healthcare with findings indicating that only 53% of the population had full access to healthcare, while vulnerable subgroups such as Black South Africans who were less educated, unemployed and poor were less likely to have proper access to healthcare (Burger & Christian, 2020). Beneficiaries of private healthcare services who had full access to healthcare comprised more affluent, skilled and educated members of medical schemes (Burger & Christian, 2020). Moreover, such beneficiaries had access to specialized facilities and technology as well as more advanced medications, further exposing the inequitable and polarized healthcare system, corroborating the literature that, despite policy efforts, there are still disparities in access to healthcare between socioeconomic groups in SA (Burger & Christian, 2020; Gilson & McIntyre, 2007).

The majority of South African citizens do not have healthcare insurance coverage which further prevents affordability of long-term treatment in chronic diseases like PD (Dekker et al., 2020). While the government is still trying to ensure more accessibility to healthcare for the most vulnerable groups, such as poor, lower educated and unemployed Black South Africans, the research has shown that this alone will not necessarily improve healthcare access (Burger & Christian, 2020). For those able to have their PD diagnosed, apart from the high costs and traveling burdens, treatment is either non-existent or intermittent and therapy services as well as monitoring are limited which often forces people to resort to traditional healers first (Dekker et al., 2020).

2.10. Household Income as a moderating sociodemographic variable

The country's societal situation means that QoL is affected in different ways. Essential parts of QoL include work, financial conditions, social relationships, housing problems, leisure activities and travel opportunities amongst others, and these are influences by the larger societal situations (Kuopio et al., 2000). For this reason, this study examined the effects of monthly household income to ascertain its impact upon the relationship between treatment received and QoL outcomes in a comparative analysis between the private and public healthcare sector since the progressive and incurable nature of PD has a high economic burden for the patient, their family and society (Sturkenboom et al., 2015). Costs do vary between countries, with the general consensus that expenditures rise as PD progresses (Sturkenboom et al., 2015). Cost drivers include medication, institutionalization, and in some cases surgeries, while nonmedical costs also begin to increase when there is productivity loss or informal care (Sturkenboom et al., 2015).

Income inequality remains a challenge in SA which is ranked as one of the most unequal societies in the world (Chitiga et al., 2014). Racial undercurrents drive disparities and social stratification in the country which negatively impact on access to employment, adequate healthcare, education and other basic necessities, with such uneven distributions affecting QoL and income earning opportunities (Chitiga et al., 2014). With income inequality having reached extreme levels in SA it was important to study disparities in access to treatment between the private and public healthcare sector particularly in Johannesburg which is the most unequal major city in the country (Alexander et al., 2013). Treatments that are available to PwPD in private healthcare sectors due to their medical aid insurance and higher monthly income are unattainable and unaffordable by PwPD in public healthcare facilities, most of whom are reliant on government grants of below R3,500 which constitute their monthly income (Hirayama et al.,

2008). Assessing this variable's impact on the relationship between treatment and QoL could provide valuable insights into patient outcomes.

2.11. Internet Access as a moderating sociodemographic variable

A body of literature exists indicating the striking lack of information about PD in lower to middle income countries (LMICs) around Africa where preconceived beliefs exist about such neurological conditions (Dekker et al., 2020; Dotchin et al., 2007; Fothergill-Misbah et al., 2021; Mokaya et al., 2017). An ethnographic study in urban and rural Kenya exploring the lived experiences of diagnosis among PwPD indicated that the lack of relevant information about PD often caused delayed interactions with healthcare services for many of the participants, and even after diagnosis the continued lack of information made it difficult for their friends, family and other community members to understand their illness (Fothergill-Misbah et al., 2021). A lack of access to information about PD appears to be a major predictor of delayed diagnoses.

This study theorises that, although the internet is not the only source of information, it is a vital element that assists in obtaining information about PD, treatment options, prognosis and QoL. The internet provides a platform for people to access health information and this is evident by the increase of web-based patient education sites which enable patients, community members and healthcare provides to communicate with each other (Demiris et al., 2008). In fact, internet technologies for disease management has been used in many clinical areas, where frequent monitoring of symptoms can lead to early detection of potentially critical situations (Demiris et al., 2008). For those that do have internet access, in some instances where they feel their doctors are inaccessible due to geographic distances or long waiting periods in-between appointments, they may have interactions with their doctors through electronic communications which allow for effective ways to deliver patient-centred care more conveniently and efficiently (Lim et al., 2017). Diseases like PD may be suited to remote assessment electronically since most features are assessed visually which can be done, for

example, through video calling, or ‘virtual house calls’ as it may, which are increasingly available due to technology, especially for patients who live far, have limited mobility, impaired driving ability and even overburdened caregivers (Lim et al., 2017).

2.12. Theoretical Framework

Neurobiological conceptualisations have dominated the frameworks for understanding psychological and biological difficulties, but it has become critically important to consider social, cultural and economic influences to fully understand how PwPD experience the disease (Simpson et al., 2013). For this reason, the biopsychosocial model of health and illness has been adapted as a conceptual framework in this study. This model, first advocated by Engel (1997) has become an alternative to the biomedical dominance of many healthcare systems because the importance of linking science to humanism was realised. This inter-disciplinary model examines the interconnectedness between biological, psychological and socio-environmental factors, and how the simultaneous interaction between them influences the outcomes of the treatment of a disease (Nowak, 2018). Addressing the biological as well as psychosocial dimensions of patients’ lives could lead to better health outcomes.

Biological factors include the neuropathological and biochemical effects of PD. In other words, it represents the disease and the symptoms accompanying it. Since patients are hyperaware of the progressive nature of PD this affects social and psychological aspects of their lives (Nowak, 2019). Psychological and psychiatric dimensions include challenges like the manifestation of depression, anxiety and sleep disorders which can impact negatively on family dynamics and community participation as PwPD tend to feel inadequate (Nowak, 2019). Social challenges are mostly related to motor symptoms which diminish one’s capacity for work or daily living activities and prevent PD patients from participating in recreational activities, isolating themselves from social settings (Nowak, 2019). These factors may be moderated by

sociodemographic conditions. Based on the above one can see the interconnected nature of the biological, psychological and social elements.

Conceptually, PD's trajectory includes many interrelated biological and psychosocial factors that influence the symptomology experienced by PD patients as the disease progresses (Gibson, 2017). The biopsychosocial model can be applied to assist healthcare professionals to identify suitable interventions for those living with PD because it offers a more holistic model of care practice since it addresses a wider range of factors affecting PD patients (Gibson, 2017). It is patient-centred as opposed to doctor/disease-centred. The more functional patients are leads to a higher QoL, which has a positive effect on their caregivers, family and community at large (Nowak, 2018).

2.13. Conclusion

The scarcity of literature regarding barriers to treatment needs urgent attention since QoL outcomes are dependent on the proper management of PD (Blanckenberg et al., 2013). The burden of this disease is steadily increasing with a reduction in survival rates for those who are not able to access treatment (Dekker et al., 2020). And still, even those who are able to get the necessary help often experience progressive difficulties associated with their medical treatment (Anderson et al., 2017). As South Africa embarks on major health reforms to make public healthcare more available and affordable, especially for the vulnerable subgroups, there is a need for empirical evidence to guide and inform policies (Burger & Christian, 2020).

To our knowledge, no study exists which examines the effect of household income and internet access upon the relationship between treatment received and QoL outcomes. Household income is theorized to affect health outcomes due to the increasing expenditure around PD especially in advanced stages, while internet access is theorized to affect access to information surrounding PD which could result in delayed diagnosis, poorer QoL outcomes, limited knowledge about treatment options and inaccurate preconceived ideas about the

disease. This study aimed to contribute to the lack of literature around the impact of sociodemographic factors such as household income and internet access, in relation to treatments received which impact on QoL outcomes and subsequent morbidity rates.

3. METHODS

3.1. Research Questions

Based on the literature review and rationale for this research proposal, the purpose of this study will be to investigate the following research questions:

i) What are the types of treatments being received by PD patients to manage their PD-related symptoms?
ii) What is the perceived effectiveness of the treatments in managing the PD-related symptoms?
iii) What is the QoL of PD patients as measured by the WHOQOL-BREF questionnaire?
iv) Is there a predictive relationship between treatment received and QoL outcomes?
v) Is the relationship between treatments received and QoL outcomes moderated by household income and internet access?

3.2. Hypotheses

3.2.1. Null Hypothesis

- There are no differences between the treatments being received by PD patients in private healthcare facilities to manage their PD-related symptoms as opposed to those received by patients at public healthcare facilities.
- There are no differences between private and public healthcare patients' perceptions of the effectiveness of the treatments in managing PD-related symptoms.

- There are no mean differences of Quality of Life (QoL) scores, as measured by the WHOQOL-BREF questionnaire, between private and public healthcare PD patients.
- There is no predicted relationship between treatment received and QoL at a level of significance of $p<0.05$.
- The relationship between treatment received and QoL outcomes for PD patients is not moderated by household income at a level of significance of $p<0.05$.
- The relationship between treatment received and QoL outcomes for PD patients is not moderated by internet access at a level of significance of $p<0.05$.

3.3. Sample and sampling method

Purposive homogenous sampling (Etikan et al., 2016) was used to recruit adult participants in both the private and public healthcare sectors who met the clinical diagnostic criteria for PD and under the treatment of a neurologist in the Johannesburg region. Johannesburg was selected as it falls under the province of Gauteng in South Africa, which has the largest population despite it being the smallest area, thus participants would be recruited from the highest population density in the country (Abera Abaerei et al., 2017). Chris Hani Baragwanath Academic Hospital in Johannesburg is the largest public hospital in SA, whilst recruiting PD patients from Sandton meant access to the private sector in an urban area considered the wealthiest square mile of Africa.

Purposive sampling was used to obtain all participants as it allowed for the identification of patients who met the criteria for PD, and thus the conditions for this study. Participants were recruited from the department of Neurology at Chris Hani Baragwanath Academic Hospital, which is classified for the purpose of this study as the ‘public group’ because it is financed and run by provincial health authorities. For the private group, a specialist neurologist at Sandton Mediclinic was approached to participate in this study due to the privatization of healthcare facilities where medical costs are incurred by either the patient themselves or through health

insurance schemes. Both the public and private group possess large repositories of PD patients who were all informed of the study. A total sample of 80 participants (private health care group n=38 and public health care group n=42) consented to voluntary participation in this study.

Data collection took place cross-sectionally from January 2022 to July 2022. Exclusion criteria included a history of any other neurocognitive disorder or illness such as Alzheimer's Disease, traumatic brain injury or stroke, as well as active alcohol or drug use. Patients with a history of psychiatric and/or psychological disorders were not part of the exclusion criteria as it would be difficult to ascertain whether these disorders were nonmotor symptoms of PD which could have preceded the illness. The entire sample met the selection criteria and were required to have a good enough command of English in order to participate. No interpreters were needed for the private group unlike the public group where four face-to-face administrations of the questionnaires needed an interpreter present for participants who were either Zulu or Sotho first language speakers. In all four cases consent was verbally obtained for interpreters, who were administration staff members at the department of Neurology at Chris Hani Baragwanath Academic Hospital, to be present prior to commencing the interviews.

3.4. Research Design

In order to provide a description of the variables such as treatments received by PD patients, the perceived effectiveness efficacy of such treatments as well as QoL outcomes, this study relied on a quantitative research design using a survey method of collecting information through questionnaires, of which items were converted into numerical or quantitative data. This kind of design allows researchers to measure variables, uncover trends and verify measurements made about variables (Watson, 2015). Conducting a quantitative design also enabled the examination of the influence of sociodemographic variables on treatment received and QoL outcomes because such research methodology tests objective theories by assessing relationships among variables which can be measured on instruments, such as the two

questionnaires in this study, which generated numbered data that was analysed statistically to allow for theoretical hypotheses to be tested (Creswell, 2013).

The survey design method used questionnaires which was useful for gathering large amounts of data to describe this particular cohort, as opposed to establishing cause and effect relationships. Survey research allows quantitative or numeric description of trends, attitudes or opinions of a population by studying a smaller sample with the intent of generalizing from the sample to the population (Fowler, 2008). Data was collected cross-sectionally, thus were only carried out at one point in time (Muijs, 2010). Collecting data in this manner thus allowed the study to make inferences about the sample at a particular point in time in the present condition of all participants (Muijs, 2010).

This study is also non-experimental since there is no manipulation of any variable (Creswell, 2013). There are no experimental treatments or interventions administered over time to any participant in either group. This non-experimental form of research is correlational because the study describes and measures the relationship between multiple variables (Creswell, 2013). The primary interest is to explore the degree of associations between variables as they occur naturally without any interference (Creswell, 2013).

The study's quantitative, non-experimental, correlational, cross-sectional design is situated within a post-positivist paradigm which is based on empiricism and challenges the conventional idea of the absolute truth of knowledge by acknowledging that we cannot be absolutely certain about the knowledge claims being made when studying human behaviour (Creswell, 2013). Knowledge through such a lens is based on observation and measurement of an objective reality where numerical measures of these observations are paramount to enquiry (Creswell, 2013).

A post-positivist paradigm also assumes laws or theories which govern the world which need to be tested, verified or refined in order to make inferences about the world, hence a hypothesis, methodology and statistical analysis needed to support or refute theoretical claims

made by researchers (Creswell, 2013). This paradigm presupposes that evidence established is always imperfect and fallible and hypotheses cannot be proven but rather there's an indication to either fail or reject them (Phillips & Burbules, 2000). Secondly, research aims to make claims about particular phenomenon under study and then refine or abandon some of them for other claims which are more strongly warranted (Phillips & Burbules, 2000). Thirdly, all data, evidence and other considerations shape knowledge, and then researchers aim to develop statements that explain the situation of concern or describe the relationships between variables which have been hypothesized (Phillips & Burbules, 2000). Lastly, researchers must be objective and examine methods and conclusions for bias, ensuring validity and reliability of the process (Phillips & Burbules, 2000).

3.5. Instruments

The WHOQOL-BREF (Appendix A) was used to measure QoL in this study. It is the abbreviated version of the WHOQOL-100 instrument that was developed by the World Health Organization (WHO) to measure QoL. This original 100-question survey yields a multi-dimensional profile of scores across different facets of QoL (Physical, Psychological, Social Relationships, Environment and Spiritual/ Religion/ Personal Beliefs). The abbreviated version of this survey contains 26 items, available in 19 languages, and recommended for studies dependent on patient-reported outcomes when QOL is to be measured particularly in patients with PD, Mitochondrial Disease or Spinal Cord injuries when time is restricted or the burden on participants needs to be minimized, as the original 100-item version may be too lengthy for some users (Skevington et al., 2004; Whoqol Group, 1998).

To assess whether the abbreviated instrument was a valid and reliable alternative to measure QOL a confirmatory factor analysis of the WHOQOL-BREF was carried out to test whether it fit the original model (Whoqol Group, 1998). Domains were brought down to four (Physical, Psychological, Social Relationships and Environment) and yielded a comparative fit

index (CFI) of 0.906. Cronbach alpha values for each of the domains ranged from .66 to .84 demonstrating good internal reliability, and it also yielded good discriminant validity in comparison with the WHOQOL-100. To determine whether the contribution made by each domain score explained the observed variance in the general facet from the original instrument, a multiple regression was carried out which indicated significance, concluding that the 26-item version is a valid and reliable alternative to the original instrument (von Steinbüchel et al., 2006). A few studies examining QoL have demonstrated the effective utilisation of both the original (WHOQOL-100) and abbreviated instrument (WHOQOL-BREF) within the South African population (Badenhorst et al., 2018; Lundgren et al., 2006; Phaswana-Mafuya et al., 2013).

Like the original instrument a five-point Likert scale is used to answer each item where the anchor points range from “Not at all” – “An extreme amount”, “Very Poor” – “Very good”, “Very dissatisfied” – “Very satisfied”, “Not at all” – “Extremely”, “Not at all” – “Completely”, “Very poor” – “Very well”, and “Never” – “Always”. The individual domains and items correlating to each of them are depicted in the appendices (Appendix B).

A demographic questionnaire (Appendix C) was specially designed for this investigation and attached in front of the WHOQOL-BREF questionnaire. It included baseline characteristics to measure sociodemographic factors such as gender, age, race, level of education, income bracket, medical aid status, access to internet, present employment status, when diagnosis took place, how long PD symptoms were experienced before diagnosis, type of treatment received, additional recommended treatments, whether treatment was affected by COVID-19 lockdown restrictions, where participants receive their medications, who pays for medications, and whether participants had ever heard about or received DBS surgery. This questionnaire was imperative to include to be able to answer the research questions related to treatment received and the perceived efficacy thereof in PwPD.

3.6. Procedure

Ethical clearance was granted on 23 December 2021 by the Human Research Ethics Committee (HREC Medical) at University of Witwatersrand (Ethics number M210934) (Appendix D). Permission was then obtained from the Medical Advisory Committee (MAC) and Hospital management at Chris Hani Baragwanath Academic Hospital (Appendix E) to carry out data collection at the Department of Neurology. Neurologists at both public and private settings were sent approach letters (Appendix F) informing them about the study and requesting support to facilitate contact with patients living with PD under their care, being aware of the Protection of Personal Information Act (POPI Act) at all times which came into force in 2020 and pertains to respecting the right to informational privacy (Staunton et al., 2020).

After receiving signed consent letters from neurologists in both healthcare settings (Appendix G, Appendix H, Appendix I) different recruitment and data collection strategies were adopted to accommodate for the characteristics in the different settings. In the public healthcare setting I attended the Neurology clinic every Wednesday for a period of six months where PD patients were first informed about the study by the neurologist. If they agreed to participate they were invited to an office space allocated for this study where they were informed of their ethical rights. Patients were asked if they preferred to complete the questionnaires alone or if they would allow a face-to-face administration, as hand tremors and writing problems are widely experienced by PD patients. Where patients did not have sufficient reading capacities they were assisted, keeping in line with the COVID-19 prevention protocols. The questionnaire took an average of 30 minutes to complete.

For the private healthcare setting situated at Sandton Mediclinic, I initially left copies of the questionnaire for the neurologist to invite participants to complete in the waiting room when they attended their visit. They were also allowed to take the questionnaire home and send it back electronically after completion. These strategies were not successful with the recruitment,

therefore, face-to-face invitations were distributed in the neurologist's waiting room, and those who accepted the invitation were either contacted telephonically for the administration of the questionnaire or completed them in person with me at the neurologist's office (January to June 2022). This flexible method allowed the study to adapt to the participants' preferred way to take part in the assessment and to the logistic preferences of each neurologist, creating minimal intrusion to both the clinics and patients in terms of waiting periods. All COVID-19 restrictions and guidelines were observed, ensuring masks were worn, hands and stationery were sanitized and social distancing maintained.

3.7. Ethical considerations

There was steadfast commitment to upholding ethical principles and standards throughout this study, as well as adherence to the POPI act which does not allow access to patients' personal information such as private cellphone numbers unless PD patients first consented, understood the nature of the study and agreed to voluntary participation.

Ethical clearance was granted by the Human Research Ethics Committee (HREC Medical) at University of Witwatersrand (Ethics number M210934) after submitting an application (Appendix Z). An online application was submitted to the Department of Health's website to get permission to commence with the study at Chris Hani Baragwanath Academic Hospital. Part of the application was submitting the research proposal as well as the Hospital Approach Letter (Appendix J) and Ethics clearance certificate from HREC (University of Witwatersrand). Permission was granted on 30 November 2021 by the MAC and Hospital management at Chris Hani Baragwanath Academic Hospital to conduct the study at the public healthcare facility. Permission was also granted by the respective neurologists at both private and public healthcare facilities after the aims and scope of the research were fully disclosed to all the relevant stakeholders.

There was no deceit or benefits associated with participation. Completion of questionnaires were voluntary and PD patients who provided consent were informed about their ethical rights of refusal if they did not want to participate. No identifying information was required thus ensuring the confidentiality of the PD patients. Research identification numbers were assigned to each respondent and only the research team had access to this identification data. Although anonymity was not possible for every questionnaire due to the face-to-face nature of the administration of the instrument, patients were ensured of their confidentiality. Anonymity was also not possible for telephonic interviews since I had access to their cellphone numbers, although they were not saved once the interview was done. No identifying material was used when carrying out statistical analysis or publishing the results. Participants had the right to withdraw from the study at any point in time.

Since the response format was anonymous no individual feedback was possible, however, the entire cohort was given access to my contact information on the participant information sheet (Appendix K) in case they had any concerns about participation or wished to gain access to the study's findings after completion. The neurologists also had access to my personal contact information which was included in the neurologist approach letter. Completed questionnaires were taken as proof of consent by participants. All data was stored indefinitely on a password-protected computer and was only accessed in relation to this particular research report by the research team. All physical copies of the questionnaires have been stored in a locked cupboard with access only by the research team.

3.8. Methods of analysis

The data was captured and coded in Microsoft Excel before being imported to IBM SPSS Statistics (Version 28) predictive analytics software. Before running any type of analysis to answer the research questions the data was checked for missing entries and cleaned. According to the WHOQOL-BREF scoring rules (Appendix L) mean substitutions were made if

no more than one item was missing. Items 3, 4 and 26 of the WHOQOL-BREF were reverse scored. Domain scores were computed and transformed, whilst cases where there were greater than 20 percent of unanswered items of a particular questionnaire were deleted. The final sample included 38 participants from the private healthcare setting and 42 participants from the public healthcare setting.

To answer the first three research questions the data was summarized using descriptive statistics which describe properties of large amounts of data (Muijs, 2010). Frequencies were run to describe all variables from the demographic questionnaire, first as an entire cohort and then secondly as separate groups in cross-tabulations formats. In this way inferences could be made about the differences and similarities between both groups after analysing the descriptive statistics. To assess QoL an independent sample t-test was conducted for the total raw scores to ascertain if differences existed between both groups. Descriptive statistics were used to examine differences or similarities between both groups across each individual domain of QOL.

A Spearman's correlation was carried out to assess the nature and strength of the relationship between treatment received and QoL scores after meeting the non-parametric assumptions to run this type of model, since treatment was categorised into a nominal variable.

To answer the research question about whether socioeconomic factors moderated the relationship between treatment received and QoL outcomes, the study applied a factorial ANOVA (Analysis of Variance) which is a type of linear regression that tests whether more than one independent variable predicts any variation in the outcome variable (Field, 2013). The study aimed to assess whether the relationship between treatment received and QoL was impacted by household income and internet access.

Factorial designs can be used to test for moderation because it assesses the interactions of all independent variables upon the dependent variable, thus this model was able to indicate whether household income and internet access had any impact on the relationship between treatment received and QoL outcome by testing the differences between all possible means

(Field, 2013). A three-way (2x2x2) between-subjects ANOVA was run to represent the independent variables (treatment, household income and internet access) which had two levels of either 0 or 1. For treatments received, 0 represented ‘only medication’ and 1 represented ‘any additional treatments in conjunction with medication’. For household income, 0 indicated ‘income below R10,000’ and 1 indicated ‘income above R10,000’. Internet access was binary-coded such that 0 represented having ‘no internet access’ while 1 meant ‘internet access’. This met the assumptions of a factorial ANOVA where independent variables must be continuous or dichotomous whilst the dependent variable is measured on a continuous scale (Field, 2013).

4. RESULTS

This chapter presents the outcome measures, starting with the results obtained from the demographic questionnaire and QoL assessments of the PD patients. Before carrying out any kind of descriptive or statistical analysis to answer the research questions the sociodemographic data and QoL scores were captured using Microsoft Excel for Microsoft 365 MSO (Version 2208) for management and display purposes. The data was then exported to SPSS (Version 28) predictive analytics software where it was cleaned, checked for missing values, reverse scored where necessary, coded, and labelled to allow for easier identification of items. To analyse the demographic data the categorical variables were described in terms of counts and frequencies, while for QoL where variables were continuous, a summary of statistics were included comprising measures of central tendency (mean, mode and median) and measures of variability (standard deviation, minimum, maximum).

Quality of Life outcomes were assessed using both the raw and transformed domain scores of the WHOQOL-BREF instrument which is the shortened version of the 100-item original scale (WHOQOL). The individual domain scores calculated for the WHOQOL-BREF give a clear indication about the inferences that can be made with respect to Physical Health, Psychological, Social Relationship and Environmental facets of participants.

To investigate the types of treatment received to manage PD symptomology as set out in the aims of this research report this chapter will describe the types of treatments being received by PD patients in both the public and private group based on the responses from the demographic questionnaire. These statistics are used to establish whether any significant differences exist between private and public healthcare facilities. Thereafter in order to answer the research question about PD patients' perceived effectiveness of treatment this study also made inferences based on a particular item from the demographic questionnaire. Regarding information accessibility about available treatment options, items from both the demographic QoL questionnaire were used to make particular observations.

Next, descriptive statistics of the QoL of patients from both groups, as measured by the WHOQOL-BREF questionnaire, are presented; firstly examining the total raw scores and then breaking them up into their specific domains, using a cross-tabulation and independent t-tests to ascertain if there were any similarities or differences among the two groups with regards to each specific domain.

To assess the relationship between treatment received and QoL outcomes a Spearman's correlation was run to establish the nature, strength and direction between the two variables. To test whether the relationship between treatment received (predictor variable) and QoL (outcome variable) was moderated by household income and internet access, a univariate general linear model was run to assess the three-way interaction with the outcome variable, the results of which are discussed in the final section of this chapter.

4.1. Demographic statistics of the sample

Based on the demographic characteristics of the entire sample (Appendix M), 80 PwPD were included in this study, comprised of 42 public PD patients and 38 PD patients from the private healthcare facility. There were more male participants than females (n=50), supporting the literature that PD affects more men than women (Hayes, 2019). When the public and private

group were analysed separately, gender splits reiterated the findings of the collective group statistics as well as broader studies that PD disproportionately affects more men than women (Hayes, 2019).

Collectively, 54% of the sample identified as Black and 32% were White. When analysed individually for both groups the majority of PwPD in the public group were Black (92.9%) while the majority of PwPD from the private group were White (63.2%). English was the most spoken language in the private sector as opposed to Sotho as the most frequently spoken language amongst the public group.

While the private healthcare facility had a mean age of 67.81, echoing the literature that PD is common in people above age 65, the public healthcare setting reported a lower mean (63.12) (Amod & Bhigjee, 2019). Even when a significant outlier was removed this mean shifted to 64 which would indicate that the public healthcare facility had younger PwPD presenting with PD. Concerning employment, most participants were retired either due to age or PD-related symptoms.

Two thirds of the sample had their PD diagnosed within the last decade (66.25%), while one fifth (20%) of participants were diagnosed over a decade ago. Over half of the entire sample (57.5%) experienced symptoms a few months before going to a neurologist and receiving a PD diagnosis. Patients who experienced symptoms for one to five years before going to a neurologist represented 37.5% of the overall cohort, corroborating the literature that people do not always seek help for their symptoms, often associating them with the natural ageing process, or witchcraft or curses, and present with advanced symptoms when they eventually seek clinical help (Mokaya et al., 2017).

Exploration of the education variable revealed that the majority (76.3%) of private PD patients had tertiary education as opposed to only two public PD participants that held an undergrad qualification (4.8%). Examining occupations before retirement, statistics showed polar opposite trends where 81% of participants in the private group fell into the low to senior

management occupation levels in contrast with 7% from the public group. Over 80% of public PD patients had occupied unskilled levels of employment, such as domestic workers, or were semi-skilled service workers like machine operators.

Household income was a critical sociodemographic variable to assess because this study postulated that disparities in access to treatment in relation to QoL outcomes could be impacted by PwPD's monthly household income. In the public healthcare facility the majority (81%) reported an income of below R3,500 per month in comparison with the majority of private PD patients who reported either an income of between R20,000 to R50,000 per month or higher (92.1%). Not one single patient in the private healthcare setting reported a household income of below R3,500 and, inversely, not a single public group participant reported a household income of above R20,000 per month.

Based on these findings the clear distinction between the two groups is apparent. PD patients in public healthcare facilities are mostly Black, lower-educated, non-English first language speakers who are reliant on monthly household incomes of below R3,500, which places them in the lowest socioeconomic sector of the South African population.

4.2. Types of treatments to manage PD symptomology

In order to answer the first research question pertaining to the types of treatments received a multiple response set was run to accommodate for all types of treatments received within each group (Table 4.2).

The entire sample, except for one participant, listed medication as their primary treatment. In the public healthcare setting only three participants had received physiotherapy, and two out of these three patients also went for speech therapy since their PD diagnosis. The results in the private healthcare setting were vastly different with almost one third of participants (31.6%) having undergone DBS surgery which was completely covered by their medical aid schemes, the cost of which is generally around R500,000 for the electrode device alone and

excludes hospital, surgeon, anaesthetist and medication fees. Physiotherapy was the second largest treatment therapy utilised (52.6%) after pharmacological treatment. In the 'other' category, seven private patients listed 'botox injections' (18.4%).

Table 4.2.

Number of treatments received within each group

Treatment received	Private group		Public group		Overall sample	
	n^1	%	n^2	%	*N*	%
Pharmacological (medication)	38	100	41	97.6	79	98,8
DBS Surgery	12	31.6	0	0	12	15
Occupational therapy	4	10.5	0	0	4	5
Physiotherapy	20	52.6	3	7.1	23	28,8
Speech therapy	3	7.9	2	4.8	5	6,3
Light therapy	0	0	0	0	0	0
Psychology/Psychiatry	6	15.8	0	0	6	7,5
Dietician/ Nutritionist	1	2.6	0	0	1	1,3
CBD oil therapy	2	5.3	0	0	2	2,5
Traditional healing	0	0	0	0	0	0
Other	7	18.4	0	0	7	8,8

Note: N = 80 (n^1 = 38; n^2 = 42). Within group comparison.

Answers to item 17 of the demographic questionnaire, which pertains to additional treatment plans recommended by the patient's neurologist revealed that the large majority (91.3%) of the entire cohort listed 'other' to denote that they were not recommended any other treatments by their neurologist apart from their current treatment. Four PwPD reported that they were recommended physiotherapy as an adjunct treatment.

For item 18 which asked 'According to your healthcare insurance status which treatments do you have access to within the next year?', 56.3% of the entire sample indicated that their medical aid or public healthcare facility pharmacy would dispense medication at no extra cost, while 43.8% of the participants had no knowledge about the accessibility of any other treatments listed on the questionnaire. Looking at split group comparisons, 73% of PwPD in the

private group said their medical aid covered their medication while 26% didn't know the extent of their medical aid coverage. In the public group almost 60% had no knowledge about whether additional treatments would be covered by government healthcare facilities.

4.3. Perceived effectiveness of treatments

To assess participants' perceived effectiveness of their current treatment plan, item 13 of the demographic questionnaire, 'Treatment Outcome', addressed this research question (Table 4.3). More public PD patients (54.8%) than private PD patients (39.5%) believed that their treatments worked 'very well' despite them not having adjunct treatments to their pharmacological therapy. More private patients (39.5%) than public patients (19%) believed their treatment(s) worked "well", which alludes to a perception that treatments are fine but could work better to control their symptoms. Based on the descriptive statistics there are differences between private and public healthcare patients' perceptions of the effectiveness of the treatments in managing PD-related symptoms. However, almost the same number of patients in each group (21%) did not believe that their treatment(s) worked as well as they used to.

Table 4.3.

Perceived effectiveness of treatments

Treatment Outcome	Private group		Public group		Overall sample	
	n^1	*%*	*n^2*	*%*	*N*	*%*
Treatment works very well	15	39.5	23	54.8	38	47,5
Treatment works well	15	39.5	8	19	23	28,8
Treatment does not work as well as it used to	8	21.1	9	21.4	17	21,3
Other	0	0	2	4.8	2	2,5

Note: N = 80 (n^1 = 38; n^2 = 42). Within group comparison.

4.4. Quality of Life outcomes

Examining the total raw scores of QoL for the entire cohort a frequency distribution was run which established normality (Appendix N). The lowest and highest scores ranged from 26 to 156 where higher scores represented higher levels of QoL. An independent t-test was run to establish whether there was any significant difference in QoL between the public and private group. As a robust means of analysis the t-test was not sensitive to outliers. The 42 participants from the private group (M = 99.61, SD = 13.54) compared to the 38 participants in the public group (M = 73.74, SD = 12.18) demonstrated significantly higher QoL scores, $t(78) = 8.996$, p = .05 (Appendix M).

To examine each domain pertaining to different facets of QoL the total raw QoL scores for each group were transformed into domain scores to reflect the Physical Health, Psychological, Social Relationships and Environmental facets measured by the WHOQOL-BREF (table 4.4). The transformed scores ranged between 0 and 100 and were computed based on methodology in the WHOQOL-BREG manual. Transformed scores allowed domains to be compared to each other. Higher scores indicated higher QoL within the individual domains.

Table 4.4.

Individual domain scores of QoL

Domain of QoL	Private group (n^1)		Public group (n^2)		Overall sample	
	M	*SD*	*M*	*SD*	*M*	*SD*
Physical Health	66.89	12.55	56.71	13.81	61.55	14.1
Psychological	59.08	14.84	44.60	13.43	51.48	15.8
Social Relationship	79.24	15.91	61.38	14.64	69.75	17.6
Environmental	91.92	9.11	50.83	14.68	70.35	24.02

Note: N = 80 (n^1 = 38; n^2 = 42).

In the Physical Health domain, disparities existed between both groups $t(78) = 3.438$, $p = .05$ (Appendix N) where results showed higher scores for private PD patients, meaning that more public PwPD patients reported dissatisfaction with sleep, energy levels throughout the day, mobility and capacity for work, whilst also exhibiting higher pain levels and struggles with daily living activities.

Statistics for the Psychological domain, which included items pertaining to positive feelings, thinking, self-esteem, body image and spirituality demonstrate that private PD patients scored higher in this facet, $t(78) = 4.583$, $p = .05$ (Appendix Q). The overall mean for the entire cohort was significantly lower than all other domains to denote that PwPD struggled the most with psychological symptoms of PD.

The results of the Social Relationship facet indicate a clear disparity between both groups, with private PD patients reporting a much higher mean to indicate better support structures by family and friends, as well as a better reported sex life, $t(77) = 5.197$, $p = .05$ (Appendix R) .

The Environmental domain illustrated the largest disparity between the means of both groups, $t(78) = 14.853$, $p = .05$ (Appendix S), suggesting that private PD patients felt safer in their daily lives, were happier with their living conditions, had good household incomes and access to information, and experienced ample opportunities for leisure activities, better modes of transportation and healthier physical environments than public PD patients. With such disparities in findings across all respective domains it is clear why private PD patients had a significantly higher overall QoL.

4.5. The relationship between treatment and QoL

In order to run correlational statistics to assess the relationship between treatment received and QoL outcomes, particular assumptions needed to be met. Treatment as the independent variable (IV) was coded as 0 (used only pharmacological treatment) and 1 (used

pharmacological treatment and additional therapies). This met the assumption of running a non-parametric correlation (Spearman's rho) since the IV was categorised as a nominal scale of measure due to its dichotomous nature. The dependent variable (QoL) was measured on an interval scale. Not needing to meet any other assumption, the Spearman's rank-order correlation was run to examine the relationship between treatment received and QoL outcome. The results indicated a positive significant correlation between the two variables, $r_s = .42$, $n = 80$, $p<.001$, with confidence intervals ranging between .213 and .589 (Appendix T). Thus this test statistic indicated that the more treatments received the higher the QoL.

4.6. Effects of sociodemographic variables upon treatment received and QoL

This study postulated that sociodemographic variables of household income and internet access moderated the relationship between treatment received and QoL outcome. A factorial (three-way) ANOVA was conducted to compare the main effects of treatment received, household income and internet access on QoL, and the interaction effect between these independent variables on QoL. In order to run a univariate ANOVA, certain assumptions needed to be met. Firstly the assumption of linearity was met as the results of an inter-correlation between treatment received and QoL was significant (r =.061, p<.05). The assumption of independence was met as the results of the Durbin Watson test was an acceptable 2.0 to indicate that the residuals of the observations in the data are uncorrelated and independent. The Shapiro-Wilk was significant at 0.518 to conclude that the outcome variable of QoL was normally distributed. Skewness and kurtosis values were within accepted ranges (Table 4.6.1) and Q-Q plots across all variables indicated normality. Boxplots, stem-and-leaf plots and histograms did not indicate normality for both household income (Appendix U) and internet access (Appendix V), but according to the Central Limit Theorem for large sample sizes, ideally above 30, the sampling distribution of means is considered normally distributed even if the population distribution is not normal (Chang et al., 2008). Additionally there were no significant

outliers, categorical independent variables and a dependent variable measured on a continuous scale. Finally a non-significant Levene test *F(*6,71) =1.71, *p* = .131 indicated homogeneity of variances.

Table 4.6.1.

Descriptives of outcome variable (QoL) and independent variables

Variables	*Mean*	*SD*	*Min-Max*	*Skewness*	*Kurtosis*
QoL	86.03	18.25	46-122	-.028	-.58
Treatment*	.39	0.5	0-1	0.449	-1.85
Household income (M)	3.34	2.15	1-7	.02	-1.75
Internet access (M)	2.56	1.4	1-4	-.13	-1.89

*Note: M=moderator. *Treatment is binary coded.*

In order to run the factorial ANOVA all independent variables were binary coded. Treatment received, which was entered as the predictor variable in the model, had its 11 categories collapsed into two categories because there was no representation in certain treatment options. Treatment received was thus dummy-coded as 0 (pharmacological treatment only) and 1 (other treatments including pharmacological treatment). Quality of Life was entered as the outcome variable. Household income was not left in its original categorical form because there was no representation on all income levels. It was coded into 0 (income below R10,000) and 1 (income above R10,000). Lastly, internet access was coded in such a way that 0 represented ‘no internet access’ and 1 was used to denote ‘internet access’.

When the univariate ANOVA was run in SPSS to assess the interaction between the variables, results indicated a non-significant three-way interaction effect [*F(*1,71) = .014, *p* = .91]. This showed that the relationship between treatment received and QoL was not influenced/moderated by household income or internet access.

Treatment received did not have a main effect on QoL [*F(*1,71) = .807, *p* = .372], therefore, whether participants used pharmacological treatment only or adjunct therapies in

conjunction with pharmacological treatment, there was no significant differences on how they scored on QoL. When an independent samples t-test was run there was a significant difference between treatment received and QoL (r = .38 , n = 80, $p<.001$,) but this effect fell away when the other independent variables were inserted into the model. It was also important to interpret Partial Eta Squared values, which measure the effect size of different variables in ANOVA models (Field, 2013). Treatment received had a Partial Eta Squared (PES) value of .011 to indicate a small effect size. In other words treatment received only explained 1% of the total variance in QoL after accounting for the variance explained by household income and internet access.

When examining the effect of household income the results indicated that this variable had a main effect upon QoL [$F(1,71) = 25.16$, p = .001] such that participants who reported having an income of above R10,000 had a higher QoL. Even though household income did not moderate the relationship between treatment received and QoL it was found to be a stronger predictor of QoL than internet access and treatment received with a Partial Eta Squared value of .261 to indicate a large effect size..

For the final independent variable of internet access, results showed no main effect upon QoL [$F(1,71) = .23$, p = .633]. This meant that whether participants had internet access or not there were no significant differences on how they scored on QoL (table 4.6.2). Internet access had a very small effect size with a Partial Eta Squared value of .003.

Overall the model found that household income and internet access did not moderate the relationship between treatment received and QoL outcomes. When examining the effects of each independent variable upon the dependent variable, household income was found to be the strongest predictor of QoL outcomes, diminishing the effect of treatment received upon QoL when entered into the factorial ANOVA model. Thus according to the model, the higher the monthly income, the higher the QoL. Based on the demographic and correlational statistics, the majority of PwPD in the private sector had monthly incomes above R10,000 per month and

higher QoL scores across all domains in sharp contrast to the large majority of PwPD in the public sector.

Table 4.6.2

Univariate ANOVA: Test of Between-Subjects Effects (N=80)

Independent Variable	Sig.	Partial Eta Squared	Mean Square
Treatment received	.372	.011	137.93
Household income	<.001	.261**	4293.4
Internet access	.633	.003	39.33
Treatment * Internet access	.279	.016	203.43
Treatment * Household income	.889	.000	3.37
Internet access * Household income	.567	.005	56.55
Treatment * Internet access * Household income	.907	.000	2.37

*Note: Dependent Variable: QoL **p < .05*

5. DISCUSSION

5.1. Overview of study

This study aimed to describe, in a sample of PwPD from public and private healthcare sectors, the types of treatments received and their perceived efficacy, as well as the QoL. The study also explored the nature of the relationship between treatment received and QoL outcomes, and examined the extent to which household income and internet access impacted upon the strength and direction of this relationship, since household income and internet access are important variables linked to health literacy, disability and caregiver burden (Fleisher et al., 2016; Woods & Sullivan, 2019).

Using descriptive and correlational statistics, as well as a three-way factorial ANOVA, this study provided a characterisation of treatment access for PwPD and its impact on QoL, with specific consideration of sociodemographic variables. Demographic statistics were captured

using a 22-item demographic questionnaire and QoL was measured with the 26-item WHOQOL-BREF questionnaire which is the abbreviated version of the original 100-item questionnaire used by the World Health Organisation to measure QoL. The findings illustrated the large social divide between PwPD who can afford medical aid schemes and belong to the private healthcare sector and PwPD in the lowest economic sector of the country who rely on public healthcare facilities to access treatment and care. These results will be briefly summarised and discussed in this chapter.

Firstly this chapter will present some of the demographic characteristics of the entire sample, such as age, timeframe of PD diagnosis and initial symptom presentation. It then moves on to discuss whether Covid-19 had any impact on treatment received, thereafter discussing the sociodemographic variable of household income in relation to treatment access. Next, the results will be organised according to the aims of the study starting with the types of treatments used by each group, followed by the perceptions about the efficacy of their treatment plans used to manage PD symptoms. Thereafter this chapter discusses the QoL of the participants in this study with specific focus on each domain starting with the Physical Health, Psychological, Social Relationship and Environmental facets of QoL. Next the relationship between treatment received and QoL is discussed before moving onto the last aim which was concerned with whether sociodemographic factors of household income and internet access moderated the relationship between treatment received and QoL outcomes. All these findings will be contrasted with the available literature and interpreted within the methodological limitations.

5.2. Demographic characteristics of age

Demographic characteristics of the entire sample indicated that participants ranged in age between 24 and 84 years ($\bar{x}$=65.13, SD=10.86), corroborating findings that PD is a progressive neurodegenerative disorder which is increasingly common as people age,

impacting one in 100 people above age 65 (Amod & Bhigjee, 2019; Dotchin & Walker, 2012). One outlier existed in the public group where the youngest patient was 24 years old. Although older age is the most important risk factor for PD, this particular patient was diagnosed with early onset Parkinson's Disease (EOPD) which is defined as onset between 21-40 or up to age 50 in some cases (Ferguson et al., 2016). Individuals with EOPD are reported to have a more benign progression of PD with less gait disturbances but more pronounced rigidity and bradykinesia as opposed to late-onset Parkinson's Disease (LOPD) (Ferguson et al., 2016).

5.3. Duration of PD and initial symptom presentation

The timeframe of PD diagnosis, as well as the symptoms experienced before diagnosis were variables that did not form part of the research questions in the current study. For the purposes of sample characterization, since they did form part of the demographic questionnaire, it should be noted that the majority of participants across both the public (57.1%) and private (76.3%) groups were diagnosed with PD in the last 10 years. In the public healthcare sector only one person was diagnosed with PD more than 20 years ago, in comparison with 3 participants in the private healthcare sector. More recently, eight participants from the public group were diagnosed within the last few months, as opposed to two patients from the public group. The rest of the participants from the public (19%) and private (10.5%) had their PD diagnosed by a neurologist between 10 and 20 years ago.

In terms of symptoms experienced before diagnosis, the majority of participants across the public (69%) and private (44.7%) experienced PD symptoms for a few months before going to see a neurologist and receiving an official diagnosis. Those who endured symptoms for an entire year before going to a neurologist comprised of 3 participants in the public group and 10 participants from the private group. Participants who experienced symptoms for a period of between two to five years were almost identical across both the public (21.4%) and private

(21.1%) group. One participant in the public group experienced symptoms for more than five years before going to see a neurologist, as opposed to three PwPD from the private group.

5.4. The impact of Covid-19 upon the study

Data collection for the study was carried out in 2022 when the wearing of masks, the use of hand sanitizers and social distancing was still mandatory due to the COVID-19 pandemic. When participants were asked whether COVID-19 had affected their access to treatment, less than a tenth of the entire sample (8.75%) reported being affected. More patients using private health care (10.5%) than those using public health care (7.1%) felt that COVID-19 affected their access to treatment.

This finding challenges a previous report that collateral effects of COVID-19 unequally affected health equity to those in lower power stratas of societies due to factors such as movement restrictions and economic downturns (Shadmi et al., 2020). This would imply that PwPD in the public healthcare sector considered being from lower power stratas of society would be the most negatively affected in terms of accessing healthcare facilities due to COVID-19. It is possible that the reason behind this discrepancy is that the group of PwPD in the public sector did not find that the COVID-19 pandemic further worsened the limited access they have to healthcare options.

This hypothesis could also explain why more private PwPD reported that COVID-19 affected their access to certain treatments. Lockdown and social distancing measures threatened the provision of optimum medical therapy because the first healthcare reaction was to limit access to clinics and neurology wards to prevent PwPD from being infected, whilst a shortage of healthcare workers forced movement disorder neurologists to care for patients infected with COVID-19 (Fisano et al., 2020; Garg & Dhamika, 2020). Standard medical services were overwhelmed with treating COVID-19 patients which resulted in several healthcare services, such as departments of clinical physical and rehabilitation medicine,

closing part of their activities for out-patients which led to a reduction in access to certain treatments (Borg & Slam, 2020).

5.5. The impact of household income in relation to treatment access

Turning now to other sociodemographic variables, household income was dramatically different for patients in the public sector in comparison to those in the private sector. Specifically, there was an almost even split between those who reported a monthly household income of below R3,500 compared to PwPD that reported receiving R20,000 and above. Ninety-two percent of PwPD in the private group earned over R20,000 per month, as opposed to the majority (78.6%) of participants from the public group that received monthly household incomes of R3,500 or less. Income disparities were so wide in fact, that 42.1% of PwPD in the private group had household incomes of over R50,000 per month, more than the large majority of PwPD in the public group each received in a year.

This gap was again transparent when participants were asked whether they had enough money to meet their needs (item 12 of WHOQOL-BREF). While the majority (81.6%) of PwPD in the private group had “completely” enough money to meet their needs, only 2.4% of public PD patients reported the same. Not a single private group participant checked the category “not at all”, in contrast with 64.3% of public group participants. Another outlier existed where one public PD patient voluntarily reported having no existing income, relying solely on family members for financial assistance.

Lower income households rely on strained public healthcare facilities because of inaccessible high-cost private healthcare (Morudu & Kollamparambil, 2020). With the majority of public patients reporting a household income of less than R3,500 per month which mainly goes towards food expenditure, private or out-of-pocket medical expenses are sacrificed because food consumption is already at a bare minimum (Morudu & Kollamparambil, 2020).

Furthermore, out-of-pocket medical expenses such as Psychologists (R1,100 per hour), Psychiatrists (R1,200 per hour), botox injections (R1,200 per unit), occupational therapy (R645 per hour), physiotherapy (R620 per hour), dietician (R850 first session), DBS surgery (R500,000 for electrode device only), and speech therapy (R4,500), are clearly inaccessible to patients earning R3,500 or less per month (www.healthman.co.za; www.discovery.co.za). Access to quality healthcare is a privilege in SA where only a minority of the population are able to afford medical aid schemes and out-of-pocket medical expenses due to higher monthly incomes (Morudu & Kollamparambil, 2020). In summary, the sociodemographic variables characterise two very different subgroups in terms of variables linked to economic capacity and access to treatment, of which the different types of treatment are discussed next.

5.6. Treatment received

The first research question aimed to establish whether the type of treatment(s) being received by PwPD in the public sector differed from the private sector. The null hypothesis was rejected, with results indicating that there was a significant difference between the means of both groups. Participants from the public healthcare sector (n=42) treated their symptoms using only pharmacological therapy except for 3.75% of PwPD that reported having adjunct therapies of physiotherapy and speech therapy. Most PwPD in the private healthcare sector (73.3%) were able to access a host of adjunct therapies including physiotherapy, OT, botox injections (BoNT therapy), speech therapy, CBD oil therapy, psychological and psychiatric related services, as well as surgical options, such as DBS surgery, to treat their motor and non-motor symptoms. Based on descriptive statistics it is evident that there are disparities in access to treatment between private and public healthcare facilities.

Being a member of a medical aid scheme may explain this finding, and corroborates the literature on disparities in access to treatment where therapies, particularly in government healthcare facilities, were either irregular or non-existent, with low availability of multidisciplinary

staff and monitoring services (Benetar, 2013; Williams et al., 2016). Representing the most vulnerable population, yet the largest demographic in terms of race in the country, these results reiterate findings on the huge social divide between those in public versus private healthcare facilities with public healthcare patients mostly comprising Black, uninsured, lower-educated, unskilled and economically disadvantaged members of society (Burger & Christian, 2020).

Given the evidence that supports that treatments such as DBS surgery, physiotherapy, occupational therapy and speech therapy have been found to assist with PD-related symptoms (Habets et al., 2018; Nijkrake et al., 2007; Radder et al., 2017), it would imply that PwPD in the public healthcare sector are not receiving optimal care.

According to Statistics South Africa (StatsSA, 2018), the majority of people in the country depend on public healthcare facilities (71.5%) as opposed to 27.1% of households using private healthcare facilities. Moreover, of the percentage using private healthcare facilities only 9.9% were Black African households (StatsSA, 2018). Using data from the 2018 General Household Survey (GHS), Mhlanga and Garidzirai (2020) investigated whether race still affected access to healthcare in post-apartheid SA, with findings to suggest that race significantly explained the variance in demand for public healthcare. White populations, compared to all other races in the country, had the lowest probability of demand for public healthcare, suggesting that racial differences continue to influence the type of healthcare access (Mhlanga & Garidzirai, 2020). The majority of Black South Africans cannot afford private healthcare and thus make the most use of public healthcare facilities (Mhlanga & Garidzirai, 2020).

5.7. Perceived treatment efficacy

Moving to the second research question, the results also supported the alternate hypothesis that there are differences in perceptions between the public and private group about the effectiveness of treatments to manage PD symptomology. The finding indicated that, in

contrast with the group of PwPD in the private sector, a larger proportion of public healthcare patients felt their treatment plan, almost entirely pharmacological, was more effective. This finding could be attributed to the fact that public PD patients mainly used only pharmacological interventions and had no knowledge about the efficacy of alternative treatment options, the results of which could have manifested differently if they had undergone other treatments. Perceived treatment efficacy for PwPD in the public group is thus largely based on pharmacological treatment (as reported in Table 4.2); while the majority of PwPD in the private group reported on their perceived efficacy of combined therapies

Health literacy is a crucial factor to consider since limited or absent health literacy regarding a neurological disease, such as PD, leads to lower QoL, with many studies advocating for public education (Bhidayasiri et al., 2020; Dekker et al., 2020; Le Blank, 2013; Mokaya et al., 2017; Mshana et al., 2011). Such education, that is accessible, comprehensible, specific to ethnic, geographical or religious needs of a target population, may assist by informing PwPD about other available treatments that are effective to manage motor and nonmotor symptoms of PD (Dekker et al., 2020). The dissemination of medical information has been noted to play an important role in caring for PwPD and a key part of patient education in daily clinical practice (Bhidayasiri et al., 2020; Shimbo et al., 2004).

The ability to obtain, comprehend, and apply health information to make decisions about their daily lives, including healthcare, illness prevention and health promotion, in order to preserve or improve their QoL is known as health literacy (Sørensen et al., 2015). Studies show that low health literacy is linked to lower levels of social status, self-efficacy, social support, older age, and those who are dependent on the government for assistance owing to financial deprivation (Kickbusch et al., 2013; Le Blanc, 2013; Sørensen et al., 2015). Patients with low health literacy also often have lower levels of education and reading, and have trouble using technology which makes it difficult for them to acquire and comprehend healthcare information

(Wittink & Oosterhaven, 2018). Conversely, high levels of health literacy is linked to better health outcomes (Rademakers & Heijmans, 2018; Wittink & Oosterhaven, 2018)

A study examining the relationships between demographic variables, health literacy skills, outcome expectations, efficacy expectations and medication adherence in a sample of 200 patients found that health literacy was significantly associated with age, gender, income and level of education (Bhor, 2006). Health literacy was also found to be a significant predictor of outcome expectations (Bhor, 2006).

Treatment satisfaction, which is related to perceived efficacy, has been linked to an expectation threshold, therefore understanding the expectations of patients is crucial when assessing treatment satisfaction (Leonard et al., 2020; Nisenzon et al., 2011). For example, a study evaluating treatment success and expectations from the perspectives of PwPD (N=148) found that participants believed a 50% reduction in symptoms would be deemed as successful (Nisenzon et al., 2011). Furthermore, the study also found that PwPD did not expect a complete recovery of their functionality after treatment, nor did they set unreasonably high targets for success criteria (Nisenzon et al., 2011). It is possible that the apparent paradox (public patients with lower QoL and less access to treatment reporting higher satisfaction with their treatment plan than private patients with higher QoL scores and more access to treatment) may be explained by patients' expectations of treatment outputs, which were not investigated in this study.

5.8. Differences in QoL outcomes

For the third research question, this study established that there were significant differences of QoL outcomes between private and public PwPD, as measured by the WHOQOL-BREF questionnaire. The findings suggest that QoL outcomes were higher for PwPD in the private sector across all domains.

5.8.1. Physical Health domain of QoL

Private patients reported higher mean scores in the Physical Health domain of QoL ($\bar{x}$=66.89, SD=12.55) to indicate higher satisfaction regarding health, energy levels, mobility, sleep, work capacity and activities of daily living. Treatments such as physiotherapy, adopting an active lifestyle and other forms of physical exercise have been found to improve physical health-related QoL (Bouça-Machado et al., 2020). In the current study 52.6% of private patients listed physiotherapy as an adjunct treatment in contrast with 7.1% of the public group, while 10% of private patients accessed OT services as opposed to no public patients.

Established as a superior treatment option for PD (Bronstein et al., 2011), 31.6% of the private group had undergone DBS surgery which was not offered at the public healthcare facility. Affecting the physical health domain of QoL, PD studies have found that DBS improves motor features such as stride length, posture, and gait speed, improving overall mobility significantly and reducing dyskinesias for certain periods of time (Deuschl et al., 2006; Lozano & Mahant, 2004). Despite the evidence, longitudinal studies have suggested worsening symptoms starting at 18 months postoperatively, but this is also influenced by certain patient characteristics regardless of disease severity (Abboud et al., 2017; Cernera et al., 2020). A study by Abboud et al. (2017) found that the presence of postural instability, a high body mass index (BMI) and poor baseline motor scores led to poorer QoL and functional outcomes after surgery.

Deep brain stimulation surgery is still considered to be among the most important advances in the treatment for neurological diseases like PD (Lozano et al., 2019), and studies have indicated that patients with private healthcare insurance are more likely to undergo surgery (Chan et al., 2014). Such patients have better access to primary care, better skills to negotiate among various treatment options as well as preoperative and postoperative social support (Chan et al., 2014). Patients with reduced monthly incomes have less access to surgeries and

other adjunct treatments which could improve QoL (Chan et al., 2014). Higher access to such alternative treatments have a direct and major implication for this facet of QoL (Li et al., 2013; Ghaffari & Kluger, 2014), hence the differences in the means between both groups for the Physical Health domain.

5.8.2. Social Relationship domain of QoL

The Social Relationship domain of QoL also showed higher mean scores for PwPD in the private sector ($\bar{x}$=79.24, SD=15.91), alluding to better social support by spouses, family members and the community, and better intimate partner relationships. One of the most stressful symptoms of PD is the increasing dependence on others, as well as feeling a sense of isolation which leads many PwPD to withdraw themselves from social activities whilst also causing them to feel lonely (Ghorbani Saeedian et al., 2014). Associated with depression and anxiety, better levels of social support are known to benefit PwPD who suffer from psychosocial symptoms (De Maria et al., 2020; Ghorbani Saeedian et al., 2014). Such support, which usually comes from spouses, partners, family members, co-workers, neighbours, spiritual advisors, healthcare personnel and peer groups, has been associated with improvements in social and emotional functioning, reduction of anxiety and depression, as well as general improvement of QoL (De Maria et al., 2020; Ghorbani Saeedian et al., 2014; Krokavcova et al., 2008). Looking at the means in this domain for the public group ($\bar{x}$=61.38, SD=14.64) it is clear that public patients do not have the same levels of social support as the private sector, which has a major implication for care outcomes and QoL.

5.8.3. Environmental domain of QoL

Private patients reported the highest mean scores ($\bar{x}$=91.92, SD=9.11) in the Environmental domain. This domain also had the biggest difference between both groups. In comparison with the public group ($\bar{x}$=50.83, SD=14.68), private patients reported significantly

higher scores, alluding to better, healthier and safer living conditions, more financial resources, greater participation in and opportunities for leisure activities, satisfaction with transportation and access to healthcare services, as well as more opportunities for acquiring new information and skills.

This finding is directly in line with the data that SA still faces inequitable distribution of environmental quality where Black people suffer widespread social inequities such as mass violence, unemployment and urban decay, while also suffering inferior living environments, poor services, safe water and energy, sanitation and adequate shelter (Ruiters, 2001). The consequences of apartheid's segregated policies along racial, economic and land ownership lines, most White communities were and still are located in more environmentally desirable locations with higher standards of living in stark contrast with the large majority of Black communities (Ruiters, 2001). Characteristic of the private group in this study, most White people have an overall higher environmental QoL which is associated with better and safer living conditions, higher employment rates and higher incomes, leaving the large majority of Black people in the country to remain in the same or similar impoverished conditions. (Greyling & Tregenna, 2017).

5.8.4. Psychological domain of QoL

For the last domain of QoL, namely the Psychological domain, findings showed that participants across both groups struggled the most within this facet (public group: $\bar{x}$=44.6, SD=13.43/ private group $\bar{x}$=59.08, SD=14.84), pertaining to positive feelings, thinking, self-esteem, body image and spirituality. In PD, cognitive and behavioural problems often tend to arise, with dementia commonly occurring in advanced stages of PD, while other symptom manifestations include depression and mood disorders, all of which impact QoL (Opara et al., 2012). Patients with PD tend to suffer with self-image, satisfaction with family life, work and their economic situation, interaction with others and life in general (Opara et al., 2012).

Depression appears to be the most important factor affecting QoL and commonly manifests before the first motor symptoms, often occurring in a bimodal pattern where rates of depression increase at the beginning of PD and peak again during advanced stages (Schrag, 2006). A study by Schrag et al. (2000) aimed at identifying factors determining QoL in a sample of 202 PwPD found that the presence of depression was the most closely associated with lower QoL, followed by cognitive impairment, disability and postural instability. Another study by Behari et al. (2005) which evaluated QoL in 278 PwPD in New Delhi, India, found that female gender, presence of depression, a low degree of independence, and higher L-dopa doses (>400 mg/day) had the most detrimental impact on QoL. Recognising and treating depression-related symptoms is thus necessary to improve QoL outcomes (Behari et al., 2005; Beitz, 2014).

Neuropsychiatric diseases like depression is a leading cause of disability, and in general, there are major problems in SA to access mental health and disability services because such services receive disproportionately smaller proportions of health budgets while most medical aids do not cover it (Burns, 2011). This would support that depression, in both groups, is a symptom that remains ignored and/or untreated for patients across both healthcare settings. The use of medication such as tricyclic antidepressants, selective serotonin and norepinephrine reuptake inhibitors, as well as antiparkinsonian pharmacological treatments are recommended to treat depression in PD for those able to access treatment (Schrag, 2006).

Apart from pharmacological treatment, in this study, the large majority of PwPD in the private sector had adjunct therapies in combination with their prescribed medication. All adjunct therapies selected are known to have a positive effect on QoL outcomes which could explain the findings between both groups in this study where private patients experience significantly higher levels of QoL across all domains (Beitz, 2014; Chagas et al., 2014; Kampling et al., 2019; Mills et al., 2015; Phillips et al., 2018; Radder et al., 2020; Sturkenboom et al., 2015; Weaver et al., 2009).

5.9. Treatment in relation to QoL

A positive and significant correlation was found between treatment and QoL, which suggests that the more adjunct therapies received in conjunction with pharmacological therapy the higher the QoL. This could explain the difference in QoL outcomes between the public and private healthcare groups, where being a member of a medical aid scheme at a private healthcare facility or affording adjunct therapies at private rates enables patients to access a variety of adjunct therapies that are unavailable at public healthcare facilities. (Dotchin & Walker, 2012). To the researcher's knowledge there is a dearth of literature on the relationship between adjunct treatments received and QoL outcomes on the African continent, therefore this finding is an important one to direct future research on QoL.

5.10. Potential moderators affecting the relationship between treatment and QoL

The final hypothesis of this study predicted that sociodemographic variables of household income and internet access would moderate the relationship between treatment received and QoL outcomes, given that internet access and household income have been found to be associated with health-related outcomes (Boz & Karatas, 2015; Greyling & Tregenna, 2017). Although clinical variables, such as the duration of symptoms experienced before official diagnosis and timeframe of PD diagnosis, formed part of the demographic questionnaire, they were not considered as moderators because we specifically examined the relationship between treatment received and QoL outcomes. These variables would not have had an effect on the type of treatment received for patients in the public healthcare sector since the large majority only received pharmacological treatment regardless of the duration of symptoms and timeframe of diagnosis.

This study hypothesised that the relationship between treatment and QoL would be stronger for PwPD who had higher monthly household income and internet access.

Higherhousehold incomes would afford patients the opportunity to pay for adjunct treatments, either through medical aid schemes or out-of-pocket costs, whilst internet access would enable patients to access health-related information that could have a positive effect on their QoL. This hypothesis was not supported as both household income and internet access were not found to moderate the relationship between treatment received and QoL.

5.10.1. Effects of household income as a moderator

Household income had a main effect upon QoL in the factorial ANOVA model, diminishing the relationship between treatment received and QoL. In other words, when household income was inserted into the model, the relationship between treatment received and QoL was weaker. When variables were analysed individually to assess their impact on QoL, treatment had a small effect size on QoL, with a Partial Eta Squared value of .011, while the effect size was large for household income (.261). Partial Eta Squared measures the effect size of different variables in ANOVA models, with values ranging from 0 to 1, where values closer to 0 indicate a lower proportion of variance explained by a particular variable in the model after accounting for variance explained by other variables. Based on the output, household income had a significantly higher Partial Eta Squared value than treatment and internet access, accounting for more of the variance in QoL than the other two independent variables.

In the output of the ANOVA table (table 4.6.2) the p-value for household income (.001) is much smaller than the p-value for treatment (.372) and internet access (.633) to indicate that household income was much more significant at predicting QoL. The latter finding can be expected since PwPD with high monthly incomes would be able to afford a range of adjunct treatments, corroborating the literature on socioeconomic, rural-urban and racial differentials in health outcomes where disparities in access to healthcare between public and private sectors remains wide (Williams et al., 2018; Gordon et al., 2020). The main drivers of inequalities in healthcare utilisation are affordability and ability to pay, and in SA those who are

socioeconomically disadvantaged are discriminated against across the continuum of access (Gordon et al., 2020).

5.10.2. Effects of internet access as a moderator

Although internet access did not moderate the relationship between treatment and QoL, another interesting finding was the lack of information about PD in the public healthcare sector, which was measured by responses to item 13 of the WHOQOL-BREF, and item 7 and 17 of the demographic questionnaire which alluded to the levels of health literacy of patients. Based on treatments recommended to them by neurologists, according to the demographic statistical analysis, the majority of PwPD in the public sector had limited knowledge about adjunct therapies which could better QoL outcomes. Information accessibility could be related to internet access. In this study the majority of public PD patients (71.4%) did not have internet access with the inverse relationship for private PD patients (10.5%). PwPD in the private sector mostly used WiFi at home (81.6%) compared to 7.1% of PwPD in the public sector. More public PwPD used mobile data (21.4%) than private PwPD (5.3%).

The internet is not the only place to access information, however, participants were specifically asked whether they had access to information they needed in their daily life about PD when we went through item 13 of the WHOQOL-BREF questionnaire: “How available to you is the information that you need in your day-to-day life?”. The majority of PD patients in public healthcare facilities had no access to information whatsoever (69%), whereas most private PD patients said they had complete access to information due to internet access (94.7%). The findings above are a clear indication of the lack of information around PD particularly in the public healthcare group. It may explain the lack of information about other therapeutic interventions available to treat motor and non-motor symptoms of PD in public healthcare settings. On the contrary though, these therapies, apart from physiotherapy and speech therapy are likely unavailable at public healthcare settings. Broader PD studies have identified the need

to increase awareness of the disease within the general population as well as educate more healthcare workers about PD, even though there is still an ongoing challenge of a lack of Neurologists (Dotchin et al., 2018).

As the world's population ages, there is an increasing number of older adults overcoming barriers to learn and use information and communication technologies like the internet, which they can access through computers, laptops, smartphones, tablets and other devices (Aggarwal et al., 2020). A study by Boz and Karatas (2015) exploring the impact of internet use on QoL of the elderly found that the use of the computer and internet improved QoL for older people. Another cross-sectional study in the US assessing the relationship between internet use and QoL found that most participants (N=516) with spinal cord injuries who had computers and internet access used it primarily for email, disability and health information, as well as shopping (Drainoni et al., 2004). In the aforementioned study, statistical analysis revealed that socioeconomic factors significantly affected internet access, where participants who were either Black or Hispanic, with lower levels of education experienced the highest barriers (Drainoni et al., 2004). According to Wittink and Oosterhaven (2018) the use of the internet for health information is moderated by education and cognitive decline, which are two variables that were not controlled for in the present study.

With studies finding significant relationships between internet usage and QoL, where advantages include the ability to communicate with family and friends, preserve social networks, have access to information and participate in online leisure activities (Aggarwal et al., 2020; Drainoni et al., 2004), there should be more policies advocating for multidimensional strategies to support internet usage by older populations. These strategies include facilitating free internet access as well as training and education, particularly for those who are economically disadvantaged (Aggarwal et al., 2020).

The divide between public and private healthcare services remains stark, where the large majority of the South African population are disadvantaged across all dimensions of

access (Gordon et al., 2020). This study corroborates the findings that healthcare in SA is associated with sociodemographic status, race and type of healthcare insurance, where poor, uninsured, Black African respondents experience the greatest disparities in access to treatment (Gordon et al., 2020; Harris et al., 2011).

6. CONCLUSION

The aims of this research report were to describe, in a sample of PwPD across both the private and public healthcare sectors, the types of treatment received and their perceived efficacy, as well as QoL. The study also investigated the nature of the relationship between treatment received and QoL outcomes, and additionally explored the extent to which household income and internet access impacted upon the strength and direction of this relationship. This chapter offers a summary of the conclusions arising from the study objectives.

Objective 1: *To report the types of treatments being received by PD patients to manage their PD-related symptoms.*

Both the private and public PD patients used pharmacological interventions. Only a minority (7.1%) of the public PD patients received additional treatments, either physiotherapy (7.1%) or speech therapy (4.8%). On the contrary, the majority (73.7%) of private PD patients reported to receive additional treatments in conjunction with pharmacological treatment, where DBS surgery (31.6%), physiotherapy (52.6%) and botox injections (18.4%) were the most popular. Other listed therapies included OT (10.5%), psychiatry and psychology-related therapy (15.8%), speech therapy (7.9%), CBD oil therapy (5.3%) and dietary changes (2.6%). No participant in either group listed traditional healing therapy or light therapy as an adjunct treatment.

Objective 2: *To assess the perceived effectiveness of the treatments in managing the PD-related symptoms.*

More than half of the public PD patients (54.8%), who only received pharmacological treatment except for three patients who had adjunct treatment, believed their treatments worked “very well”, while 19% of them believed treatments worked “well” and 21.4% believed their treatments worked “as well as they used to”. Private PD patients had a lower perception of their treatments working “very well” (39.5%). The same percentage of participants across both groups believed their treatments “did not work as well as they used” to. Thus more public patients than private patients perceived their treatment plan to be more effective. No differences existed for the perceived efficacy of treatments regarding patients who believed that their treatments did “not work as well as they used to”.

Objective 3*: To examine the Quality of Life (QoL) of the PD patients as measured by the WHOQOL-BREF questionnaire.*

There was a statistically significant indication that QoL scores for private PD patients were higher than participants in public healthcare facilities, suggesting that PwPD in the private sector had a higher QoL than the public group. When QoL individual domains were analysed, findings demonstrated that both groups performed poorest within the psychological facet of QoL. The private group performed highest in the environmental domain, implying a safer, healthier physical environment with more opportunities for leisure activities especially since the majority of them had enough money to meet their needs as opposed to the public group.

Objective 4*: To assess the nature of the relationship between treatment received and QoL outcomes in PwPD.*

A Spearman’s rank correlation was computed to assess the relationship between treatment received and QoL. There was a statistically significant positive correlation between the two variables, $r(78) = .42$, $p = .001$. Statistics indicated that the more adjunct therapies in conjunction with pharmacological treatment, the better the QoL outcome.

Objective 5*: To assess whether household income and internet access moderate the relationship between treatment received and QoL outcomes for PwPD in both private and public healthcare facilities.*

A three-way (2x2x2) factorial ANOVA was run to assess the impact of household income and internet access upon the relationship between treatment received and QoL. Once the independent variables were entered into the ANOVA, findings indicated that the relationship between treatment received and QoL was not moderated by household income nor internet access. However, the model showed that household income had a main effect on QoL, diminishing the effect between treatment received and QoL. Although these sociodemographic variables did not moderate the relationship between treatment received and QoL, the model indicated that household income was a stronger predictor of QoL than treatment and internet access. Further research into the predictive nature of sociodemographic variables upon QoL is warranted in SA and the rest of the African continent where there is a dearth of literature on PD.

The current study concluded that there are disparities in access to treatment in relation to QoL outcomes in PwPD. These disparities are largely a function of those who are members of medical aid schemes treated at private healthcare facilities who have almost complete access to adjunct therapies that are known to affect QoL outcomes. This social divide between the public and private healthcare sector perpetuates inequitable access. Furthermore, PwPD treated at public healthcare settings indicate lower QoL outcomes across all domains. Reliant solely on pharmacological treatment to relieve their symptoms, while they perceive their treatment to be more efficacious, the lack of knowledge and education about PD, and much lower access to adjunct therapies needs urgent attention to improve QoL outcomes.

7. LIMITATIONS

Despite the study meeting its objectives and providing contributions to the literature on PD in SA, there are limitations that should be addressed. Firstly, the sample was not representative of the entire South African population of patients with PD, which affects the power of generalisability (Webb et al., 2005). Only one hospital from each of the healthcare sectors were selected in the Gauteng province, providing only a snapshot of what disparities in access to treatment in relation to QoL might look like on a larger scale in SA, which has eight other provinces. Therefore results may not be generalisable to other hospitals and provinces. Also, the results of this study may not be applicable to other contexts outside SA, particularly considering SA's huge social divide and extreme levels of income inequality, being the country with the highest Gini coefficient in the world (Harmse, 2014).

A second limitation of this study is related to the instrument. There is a limitation in the use of instruments for data collection that are in English. Both questionnaires in this study were administered in English on participants that had different mother tongues. The WHO-QOL BREF should be translated into several widely spoken African languages such as Zulu, Tsonga, Xhosa and Sotho so that there is a better understanding among participants who are not English first-language speakers. Additionally, cognitive decline typically associated with PD may have created difficulties with certain items or with the length of the assessment that were not accounted for (Goldman et al., 2018). Future PD studies examining QoL outcomes must be mindful of possible limited writing, speaking and cognitive abilities which may be affected by the disease.

Thirdly, this study failed to list the particular symptoms of each participant which could have provided deeper insights about their QoL scores. Motor and non-motor manifestations are different in every individual with PD, and as the disease progresses so does disability, physical and mental complications, psychosocial malfunction and potential personal financial loss,

leading to a deteriorating QoL (Martinez-Martin et al., 2020). Consideration of such clinical characteristics should have been included, because comparing groups on perceived treatment efficacy and QoL may be more complex than a linear delineation of private and public healthcare access.

Lastly, the paradoxical finding that public patients perceived their treatment plans to be more efficacious than private patients who had more access to adjunct treatment plans, which subsequently lead to higher levels of QoL, is important to explore for future research. This study failed to investigate patients' expectations of treatment outputs which could have shed more light on this finding.

8. RECOMMENDATIONS

Future research needs to build on the evidence in this study, and therefore future studies in this area should consider the following recommendations:

Greater sample sizes should be used in future research projects and include different provinces to provide data with better power that is representative of the population that it is intending to characterise.

Given that household income predicted QoL outcomes significantly more than treatment received, future studies should explore the impact of various other sociodemographic variables upon QoL.

Future studies examining PD treatment should give BoNT (botox) therapy more priority since it came in as the fourth most utilised treatment for PD after medications, physiotherapy and DBS surgery. Light therapy and traditional healing therapy were not part of any participant's treatment plan across both groups.

With both groups performing the poorest in the psychological domain of QoL it is recommended that further exploration into the psychological factors that affect QoL in PD be researched.

Based on the face-to-face and telephonic nature of the questionnaire administrations, where patients often felt free to voluntarily speak about their various symptoms and daily struggles as well as victories, it is recommended that a mixed method research using semi-structured interview questions should inform future research studies that seek deep, rich data on the lived experiences of PwPD in order to understand the nuances of QoL outcomes in terms of their particular symptoms which manifest differently for every individual.

With findings to suggest that the public sector have limited health literacy in contrast with the private sector, it is recommended that universal health literacy precautions be taken to impart information which is clear and accessible to patients regardless of their literacy or education levels (Wittink & Oosterhaven, 2018). Given this finding, and the link between health literacy and perceptions of therapeutic outcomes, future studies should assess health literacy when investigating treatment access and QoL outcomes.

9. REFERENCE LIST

Abboud, H., Genc, G., Thompson, N. R., Oravivattanakul, S., Alsallom, F., Reyes, D., ... & Fernandez, H. H. (2017). Predictors of functional and quality of life outcomes following deep brain stimulation surgery in Parkinson's disease patients: disease, patient, and surgical factors. *Parkinson's Disease*, *2017*. https://doi.org/10.1155/2017/5609163

Abera Abaerei, A., Ncayiyana, J., & Levin, J. (2017). Health-care utilization and associated factors in Gauteng province, South Africa. *Global Health action*, *10*(1), 1305765. https://doi.org/10.1080/16549716.2017.1305765

Aggarwal, B., Xiong, Q., & Schroeder-Butterfill, E. (2020). Impact of the use of the internet on quality of life in older adults: review of literature. *Primary Health Care Research & Development*, *21*. https://doi.org/10.1017/S1463423620000584

Alexander, P., Ceruti, C., Motseke, K., Phadi, M., & Wale, K. (2013). *Class in Soweto*. University of KwaZulu-Natal Press.

Amod, F. H., & Bhigjee, A. I. (2019). Clinical series of Parkinson's disease in KwaZulu-Natal, South Africa: Retrospective chart review. *Journal of the Neurological Sciences*, *401*, 62-65. https://doi.org/10.1016/j.jns.2019.03.023

Anderson, D. G., Van Coller, R., & Carr, J. (2017). South African guideline on deep brain stimulation for Parkinson's disease. *South African Medical Journal*, *107*(10), 1027-1032. https://doi.org/10.7196/SAMJ.2017.v107i11.12831

Arpey, N. C., Gaglioti, A. H., & Rosenbaum, M. E. (2017). How socioeconomic status affects patient perceptions of health care: a qualitative study. *Journal of Primary Care & Community Health*, *8*(3), 169-175. https://us.sagepub.com/en-us/journals-permissions

Badenhorst, M., Brown, J. C., Lambert, M. I., Van Mechelen, W., & Verhagen, E. (2018). Quality of life among individuals with rugby-related spinal cord injuries in South Africa: a

descriptive cross-sectional study. *BMJ Open*, *8*(6), e020890. http://dx.doi.org/10.1136/bmjopen-2017-020890

Barone, P., Erro, R., & Picillo, M. (2017). Quality of life and nonmotor symptoms in Parkinson's disease. *International Review of Neurobiology*, *133*, 499-516. https://doi.org/10.1016/bs.irn.2017.05.023

Behari, M., Srivastava, A. K., & Pandey, R. M. (2005). Quality of life in patients with Parkinson's disease. *Parkinsonism & Related Disorders*, *11*(4), 221-226. https://doi.org/10.1016/j.parkreldis.2004.12.005

Beitz, J. M. (2014). Parkinson's disease: a review. *Frontiers in Bioscience-Scholar*, *6*(1), 65-74.

Benatar, S. (2013). The challenges of health disparities in South Africa. *SAMJ: South African Medical Journal*, *103*(3), 154-155.

Benatar, S., Sullivan, T., & Brown, A. (2018). Why equity in health and in access to health care are elusive: Insights from Canada and South Africa. *Global Public Health*, *13*(11), 1533-1557. https://doi.org/10.1080/17441692.2017.1407813

Berardelli, A., Rothwell, J. C., Thompson, P. D., & Hallett, M. (2001). Pathophysiology of bradykinesia in Parkinson's disease. *Brain*, *124*(11), 2131-2146. https://doi.org/10.1093/brain/124.11.2131

Bhidayasiri, R., Panyakaew, P., Trenkwalder, C., Jeon, B., Hattori, N., Jagota, P., ... & Fernandez, H. H. (2020). Delivering patient-centered care in Parkinson's disease: Challenges and consensus from an international panel. *Parkinsonism & Related Disorders*, *72*, 82-87. https://doi.org/10.1016/j.parkreldis.2020.02.013

Bhor, M. (2006). *Relationship between health literacy, outcome expectations, efficacy expectations and medication adherence* (Publication No. 11755). [Doctoral dissertation, Purdue University]. ProQuest Dissertations Publishing.

Blanckenberg, J., Bardien, S., Glanzmann, B., Okubadejo, N. U., & Carr, J. A. (2013). The prevalence and genetics of Parkinson's disease in sub-Saharan Africans. *Journal of the Neurological Sciences*, *335*(1-2), 22-25. http://dx.doi.org/10.1016/j.jns.2013.09.010

Blandini, F., Nappi, G., Tassorelli, C., & Martignoni, E. (2000). Functional changes of the basal ganglia circuitry in Parkinson's disease. *Progress in Neurobiology*, *62*(1), 63-88. https://doi.org/10.1016/s0301-0082(99)00067-2

Borg, K., & Stam, H. (2020). Covid? 19 and Physical and Rehabilitation Medicine. *Journal of Rehabilitation Medicine*, *52*(4), 1-1.

Burns, J. K. (2011). The mental health gap in South Africa: A human rights issue. *The Equal Rights Review*, *6*(99), 99-113.

Bouça-Machado, R., Maetzler, W., & Ferreira, J. J. (2018). What is functional mobility applied to Parkinson's disease?. *Journal of Parkinson's disease*, *8*(1), 121-130. http://doi.org/10.3233/JPD-171233

Bouça-Machado, R., Rosário, A., Caldeira, D., Castro Caldas, A., Guerreiro, D., Venturelli, M., ... & J. Ferreira, J. (2020). Physical activity, exercise, and physiotherapy in Parkinson's disease: defining the concepts. *Movement Disorders Clinical Practice*, *7*(1), 7-15. https://doi.org/10.1002/mdc3.12849

Boz, H., & Karatas, S. E. (2015). A review on internet use and quality of life of the elderly. *Cypriot Journal of Educational Sciences*, 182-191. https://doi.org/10.18844/cjes.v1i1.64

Bronstein, J. M., Tagliati, M., Alterman, R. L., Lozano, A. M., Volkmann, J., Stefani, A., ... & DeLong, M. R. (2011). Deep brain stimulation for Parkinson disease: an expert consensus and review of key issues. *Archives of Neurology*, *68*(2), 165-165. http://doi.org/10.1001/archneurol.2010.260

Bucks, R. S., Cruise, K. E., Skinner, T. C., Loftus, A. M., Barker, R. A., & Thomas, M. G. (2011). Coping processes and health-related quality of life in Parkinson's disease. *International Journal of Geriatric Psychiatry*, *26*(3), 247-255. https://doi.org/10.1002/gps.2520

Burger, R., & Christian, C. (2020). Access to health care in post-apartheid South Africa: availability, affordability, acceptability. *Health Economics, Policy and Law*, *15*(1), 43-55. http://dx.doi.org/10.1017/S1744133118000300

Burn, D. J., Landau, S., Hindle, J. V., Samuel, M., Wilson, K. C., Hurt, C. S., ... & PROMS-PD Study Group. (2012). Parkinson's disease motor subtypes and mood. *Movement Disorders*, *27*(3), 379-386. https://doi.org/10.1002/mds.24041

Campani, D., De Luca, E., Bassi, E., Airoldi, C., Barisone, M., Canonico, M., ... & Dal Molin, A. (2022). The prevention of falls in patients with Parkinson's disease with in-home monitoring using a wearable system: a pilot study protocol. *Aging Clinical and Experimental Research*, 1-8. https://doi.org/10.1007/s40520-022-02238-1

Carr, A.J., Gibson, B., Robinson, P.G. (2001). Measuring quality of life: is quality of life determined by expectations or experience? *Br. Med. J.* 322, 1240– 1243. https://dx.doi.org/10.1136%2Fbmj.322.7296.1240

Carr, J., Kies, B., & Fine, J. (2009). Guideline for the treatment of Parkinson's disease. *SAMJ: South African Medical Journal*, *99*(10), 755-758.

Casjens, S., Eckert, A., Woitalla, D., Ellrichmann, G., Turewicz, M., Stephan, C., ... & Pesch, B. (2013). Diagnostic value of the impairment of olfaction in Parkinson's disease. *PLoS One*, *8*(5), e64735. https://doi.org/10.1371/journal.pone.0064735

Cernera, S., Eisinger, R.S., Wong, J.K. *et al.* Long-term Parkinson's disease quality of life after staged DBS: STN vs GPi and first vs second lead. *npj Parkinsons Dis.* **6**, 13 (2020). https://doi.org/10.1038/s41531-020-0115-3

Chagas, M. H. N., Zuardi, A. W., Tumas, V., Pena-Pereira, M. A., Sobreira, E. T., Bergamaschi, M. M., ... & Crippa, J. A. S. (2014). Effects of cannabidiol in the treatment of patients with Parkinson's disease: an exploratory double-blind trial. *Journal of Psychopharmacology*, *28*(11), 1088-1098. https://doi.org/10.1177%2F0269881114550355

Chan, A. K., McGovern, R. A., Brown, L. T., Sheehy, J. P., Zacharia, B. E., Mikell, C. B., ... & McKhann, G. M. (2014). Disparities in access to deep brain stimulation surgery for Parkinson disease: interaction between African American race and Medicaid use. *JAMA Neurology*, *71*(3), 291-299. https://doi.org/10.1001/jamaneurol.2013.5798

Chang, H. J., Wu, C. H., Ho, J. F., & Chen, P. Y. (2008). On sample size in using central limit theorem for gamma distribution. *Information and Management Sciences*, *19*(1), 153-174.

Chitiga, M., Owusu-Sekyere, E., & Tsoanamatsie, N. (2014). Income inequality and limitations of the Gini index: The case of South Africa. *HSRC Review*.

Conrad, G. D. (2014). Is Ginkgo biloba and/or a Multivitamin-multimineral Supplement a Therapeutic Option for Parkinson's Disease? A Case Report. *Global Advances in Health and Medicine*, *3*(4), 43-44. https://doi.org/10.7453%2Fgahmj.2013.096

Coovadia, H., Jewkes, R., Barron, P., Sanders, D., & McIntyre, D. (2009). The health and health system of South Africa: historical roots of current public health challenges. *The Lancet*, *374*(9692), 817-834. https://doi.org/10.1016/S0140-6736(09)60951-X

Costantini, A., & Fancellu, R. (2016). An open-label pilot study with high-dose thiamine in Parkinson's disease. *Neural Regeneration Research*, *11*(3), 406. https://doi.org/10.4103%2F1673-5374.179047

Cravanas Jr, B., & Frei, K. (2020). The effects of Cannabis on hallucinations in Parkinson's disease patients. *Journal of the Neurological Sciences*, *419*, 117206. https://doi.org/10.1016/j.jns.2020.117206

Creswell, J. W. (2013). *Research design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks, CA: Sage.

Dahodwala, N., Xie, M., Noll, E., Siderowf, A., & Mandell, D. S. (2009). Treatment disparities in Parkinson's disease. *Annals of Neurology: Official Journal of the American Neurological Association and the Child Neurology Society*, *66*(2), 142-145. https://dx.doi.org/10.1002%2Fana.21774

De Maria, M., Tagliabue, S., Ausili, D., Vellone, E., & Matarese, M. (2020). Perceived social support and health-related quality of life in older adults who have multiple chronic conditions and their caregivers: a dyadic analysis. *Social Science & Medicine*, *262*, 113193. https://doi.org/10.1016/j.socscimed.2020.113193

Dekker, M. C., Coulibaly, T., Bardien, S., Ross, O. A., Carr, J., & Komolafe, M. (2020). Parkinson's disease research on the African continent: obstacles and opportunities. *Frontiers in Neurology*, *11*, 512. https://doi.org/10.3389/fneur.2020.00512

DeMaagd, G., & Philip, A. (2015). Parkinson’s disease and its management: part 1: disease entity, risk factors, pathophysiology, clinical presentation, and diagnosis. *Pharmacy and Therapeutics*, *40*(8), 504.

Demiris, G., Afrin, L. B., Speedie, S., Courtney, K. L., Sondhi, M., Vimarlund, V., ... & Lynch, C. (2008). Patient-centered applications: use of information technology to promote disease management and wellness. A white paper by the AMIA knowledge in motion working group. *Journal of the American Medical Informatics Association*, *15*(1), 8-13. https://doi.org/10.1197/jamia.M2492

Deuschl, G., Schade-Brittinger, C., Krack, P., Volkmann, J., Schäfer, H., Bötzel, K., ... & Voges, J. (2006). A randomized trial of deep-brain stimulation for Parkinson's disease. *New England Journal of Medicine*, *355*(9), 896-908. https://doi.org/10.1056/NEJMoa060281

Di Filippo, M., Picconi, B., Tozzi, A., Ghiglieri, V., Rossi, A., & Calabresi, P. (2008). The endocannabinoid system in Parkinson's disease. *Current Pharmaceutical Design*, *14*(23), 2337-2346. https://doi.org/10.2174/138161208785740072

Dogan, V. B., Koksal, A., Dirican, A., Baybas, S., Dirican, A., & Dogan, G. B. (2015). Independent effect of fatigue on health-related quality of life in patients with idiopathic Parkinson's disease. *Neurological Sciences*, *36*(12), 2221-2226. https://doi.org/10.1007/s10072-015-2340-9

Donoyama, N., Suoh, S., & Ohkoshi, N. (2014). Effectiveness of Anma massage therapy in alleviating physical symptoms in outpatients with Parkinson's disease: A before-after study. *Complementary Therapies in Clinical Practice*, *20*(4), 251-261. https://doi.org/10.1016/j.ctcp.2014.07.010

Dorsey, E. R., Elbaz, A., Nichols, E., Abbasi, N., Abd-Allah, F., Abdelalim, A., ... & Murray, C. J. (2018). Global, regional, and national burden of Parkinson's disease, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *The Lancet Neurology*, *17*(11), 939-953. https://doi.org/10.1016/S1474-4422(18)30295-3

Dotchin, C. L., Msuya, O., & Walker, R. W. (2007). The challenge of Parkinson's disease management in Africa. *Age and Ageing*, *36*(2), 122-127. https://doi.org/10.1093/ageing/afl172

Drainoni, M. L., Houlihan, B., Williams, S., Vedrani, M., Esch, D., Lee-Hood, E., & Weiner, C. (2004). Patterns of Internet use by persons with spinal cord injuries and relationship to health-related quality of life. *Archives of Physical Medicine and Rehabilitation*, *85*(11), 1872-1879. https://doi.org/10.1016/j.apmr.2004.07.350

Engel, G.L. (1977). The need for a new medical model: a challenge for biomedicine. *Science*, 196(4286): 129-136.

Etikan, I., Musa, S. A., & Alkassim, R. S. (2016). Comparison of convenience sampling and purposive sampling. *American Journal of Theoretical and Applied Statistics*, 5(1), 1-4. https://doi.org/10.11648/j.ajtas.20160501.11

Fasano, A., Antonini, A., Katzenschlager, R., Krack, P., Odin, P., Evans, A. H., ... & Merello, M. (2020). Management of advanced therapies in Parkinson's disease patients in times of humanitarian crisis: the COVID-19 experience. *Movement Disorders Clinical Practice*, *7*(4), 361-372. https://doi.org/10.1002/mdc3.12965

Fénelon, G. (2008). Psychosis in Parkinson's disease: phenomenology, frequency, risk factors, and current understanding of pathophysiologic mechanisms. *CNS Spectrums*, *13*(S4), 18-25. https://doi.org/10.1017/s1092852900017284

Fereshtehnejad, S. M., Shafieesabet, M., Rahmani, A., Farhadi, F., Hadizadeh, H., Shahidi, G. A., ... & LFkk, J. (2014). A novel 6-item screening questionnaire for parkinsonism: validation and comparison between different instruments. *Neuroepidemiology*, *43*(3-4), 178-193. https://doi.org/10.1159/000368167

Ferguson, L. W., Rajput, A. H., & Rajput, A. (2016). Early-onset vs. late-onset Parkinson's disease: a clinical-pathological study. *Canadian Journal of Neurological Sciences*, *43*(1), 113-119. https://doi:10.1017/cjn.2015.244

Field, A. (2013). *Discovering statistics using IBM SPSS statistics*. sage.

Fitzpatrick, L., Simpson, J., & Smith, A. (2010). A qualitative analysis of mindfulness-based cognitive therapy (MBCT) in Parkinson's disease. *Psychology and Psychotherapy: Theory, Research and Practice*, *83*(2), 179-192. https://doi.org/10.1348/147608309X471514

Fleisher, J. E., Shah, K., Fitts, W., & Dahodwala, N. A. (2016). Associations and implications of low health literacy in Parkinson's Disease. *Movement Disorders Clinical Practice*, *3*(3), 250-256. https://doi.org/10.1002/mdc3.12272

Fothergill-Misbah, N., Walker, R., Kwasa, J., Hooker, J., & Hampshire, K. (2021). “Old people problems”, uncertainty and legitimacy: Challenges with diagnosing Parkinson's disease in Kenya. *Social Science & Medicine*, *282*, 114148. https://doi.org/10.1016/j.socscimed.2021.114148

Garg, D., & Dhamija, R. K. (2020). The challenge of managing Parkinson’s disease patients during the COVID-19 pandemic. *Annals of Indian Academy of Neurology*, *23*(Suppl 1), S24. https://doi.org/10.4103%2Faian.AIAN_295_20

Ghaffari, B. D., & Kluger, B. (2014). Mechanisms for alternative treatments in Parkinson’s disease: acupuncture, tai chi, and other treatments. *Current Neurology and Neuroscience Reports*, *14*, 1-11. https://doi.org/10.1007/s11910-014-0451-y

Ghorbani Saeedian, R., Nagyova, I., Krokavcova, M., Skorvanek, M., Rosenberger, J., Gdovinova, Z., ... & van Dijk, J. P. (2014). The role of social support in anxiety and depression among Parkinson’s disease patients. *Disability and Rehabilitation*, *36*(24), 2044-2049. https://doi.org/10.3109/09638288.2014.886727

Gibb, W. R. G. (1992). Neuropathology of Parkinson’s disease and related syndromes. *Neurologic Clinics*, *10*(2), 361-376. https://doi.org/10.1016/S0733-8619(18)30215-9

Gibson, G. (2017). What can the treatment of Parkinson's disease learn from dementia care; applying a bio-psycho-social approach to Parkinson's disease. *International Journal of Older People Nursing*, *12*(4), e12159. https://doi.org/10.1111/opn.12159

Gilson, L., & McIntyre, D. (2007). Post-apartheid challenges: household access and use of health care in South Africa. *International Journal of Health Services*, *37*(4), 673-691. https://doi.org/10.2190%2FHS.37.4.f

Global Parkinson's Disease Survey (GPDS) Steering Committee. (2002). Factors impacting on quality of life in Parkinson's disease: results from an international survey. *Movement Disorders*, *17*(1), 60-67. https://doi.org/10.1002/mds.10010

Goldman, J. G., Vernaleo, B. A., Camicioli, R., Dahodwala, N., Dobkin, R. D., Ellis, T., ... & Simmonds, D. (2018). Cognitive impairment in Parkinson's disease: a report from a multidisciplinary symposium on unmet needs and future directions to maintain cognitive health. *npj Parkinson's Disease*, *4*(1), 19. https://doi.org/10.1038/s41531-018-0055-3

Gordon, T., Booysen, F. & Mbonigaba, J. Socio-economic inequalities in the multiple dimensions of access to healthcare: the case of South Africa. *BMC Public Health 20*, 289 (2020). https://doi.org/10.1186/s12889-020-8368-7

Graf, C. (2009). The Lawton instrumental activities of daily living (IADL) scale. *Medsurg Nurs*, *18*(5), 315-316.

Graybiel, A. M. (2000). The basal ganglia. *Current Biology*, *10*(14), 509-511.

Greyling, T., & Tregenna, F. (2017). Construction and analysis of a composite quality of life index for a region of South Africa. *Social Indicators Research*, *131*(3), 887-930. https://doi.org/10.1007/s11205-016-1294-5

Gupta, A. D., & Visvanathan, R. (2016). Botulinum toxin for foot dystonia in patients with Parkinson's disease having deep brain stimulation: A case series and a pilot study. *Journal of Rehabilitation Medicine*, *48*(6), 559-563. https://doi.org/10.2340/16501977-2094

Habets, J. G., Heijmans, M., Kuijf, M. L., Janssen, M. L., Temel, Y., & Kubben, P. L. (2018). An update on adaptive deep brain stimulation in Parkinson's disease. *Movement Disorders*, *33*(12), 1834-1843. https://doi.org/10.1002/mds.115

Harmse, L. (2014). *South Africa's Gini coefficient: Causes, consequences and possible responses* (Doctoral dissertation, University of Pretoria).

Harris, B., Goudge, J., Ataguba, J. E., McIntyre, D., Nxumalo, N., Jikwana, S., & Chersich, M. (2011). Inequities in access to health care in South Africa. *Journal of Public Health Policy*, *32*(1), S102-S123. https://doi.org/10.1057/jphp.2011.35

Hatano, T., Hattori, N., Kawanabe, T., Terayama, Y., Suzuki, N., Iwasaki, Y., & Fujioka, T. (2014). Yokukansan Parkinson's Disease Study Group. An exploratory study of the efficacy and safety of yokukansan for neuropsychiatric symptoms in patients with Parkinson's disease. *J. Neural Transm*, *121*, 275-281. https://doi.org/10.1007/s00702-013-1105-y

Hayes, M. T. (2019). Gender differences in Parkinson's disease. In *Neurology and Psychiatry of Women* (pp. 213-217). Springer, Cham. https://doi.org/10.1007/978-3-030-04245-5_24

Hirayama, M. S., Gobbi, S., Gobbi, L. T. B., & Stella, F. (2008). Quality of life (QoL) in relation to disease severity in Brazilian Parkinson's patients as measured using the WHOQOL-BREF. *Archives of Gerontology and Geriatrics*, *46*(2), 147-160. https://doi.org/10.1016/j.archger.2007.03.007

*Hollingshead, A. B. (1975). Four factor index of social status. *Yale Journal of Sociology, 8*, 21-51. The Department of Sociology at Yale University.

Jocson, A., & Lew, M. (2019). Use of botulinum toxin in Parkinson's disease. *Parkinsonism & Related Disorders*, *59*, 57-64. https://doi.org/10.1016/j.parkreldis.2018.12.002

Kampling, H., Brendel, L. K., & Mittag, O. (2019). (Neuro) Psychological interventions for non-motor symptoms in the treatment of patients with Parkinson's disease: a systematic umbrella review. *Neuropsychology Review*, *29*(2), 166-180. https://doi.org/10.1007/s11065-019-09409-4

Kickbusch, I., Pelikan, J. M., Apfel, F., & Tsouros, A. (2013). *Health Literacy*. WHO Regional Office for Europe.

Kim, S. N., Doo, A. R., Park, J. Y., Choo, H. J., Shim, I., Park, J. J., ... & Park, H. J. (2014). Combined treatment with acupuncture reduces effective dose and alleviates adverse effect of L-dopa by normalizing Parkinson's disease-induced neurochemical imbalance. *Brain research*, *1544*, 33-44. https://doi.org/10.1016/j.brainres.2013.11.028

Klepac, N., Pikija, S., Kraljić, T., Relja, M., Trkulja, V., Juren, S., ... & Babić, T. (2007). Association of rural life setting and poorer quality of life in Parkinson's disease patients: a cross-sectional study in Croatia. *European Journal of Neurology*, *14*(2), 194-198. https://doi.org/10.1111/j.1468-1331.2006.01604.x

Krokavcova, M., van Dijk, J. P., Nagyova, I., Rosenberger, J., Gavelova, M., Middel, B., ... & Groothoff, J. W. (2008). Social support as a predictor of perceived health status in patients with multiple sclerosis. *Patient Education and Counseling*, *73*(1), 159-165. https://doi.org/10.1016/j.pec.2008.03.019

Kuopio, A. M., Marttila, R. J., Helenius, H., Toivonen, M., & Rinne, U. K. (2000). The quality of life in Parkinson's disease. *Movement Disorders: Official Journal of the Movement Disorder Society*, *15*(2), 216-223. https://doi.org/10.1002/1531-8257(200003)15:2%3C216::AID-MDS1003%3E3.0.CO;2-%23

Kurtis, M. M., Rodriguez-Blazquez, C., Martinez-Martin, P., & ELEP Group. (2013). Relationship between sleep disorders and other non-motor symptoms in Parkinson's disease. *Parkinsonism & Related Disorders*, *19*(12), 1152-1155. https://doi.org/10.1016/j.parkreldis.2013.07.026

Lagalla, G., Millevolte, M., Capecci, M., Provinciali, L., & Ceravolo, M. G. (2006). Botulinum toxin type A for drooling in Parkinson's disease: a double-blind, randomized, placebo-controlled study. *Movement Disorders: Official Journal of the Movement Disorder Society*, *21*(5), 704-707. https://doi.org/10.1002/mds.20793

Lange, K. W., Nakamura, Y., Chen, N., Guo, J., Kanaya, S., Lange, K. M., & Li, S. (2019). Diet and medical foods in Parkinson’s disease. *Food Science and Human Wellness*, *8*(2), 83-95. https://doi.org/10.1016/j.fshw.2019.03.006

LeBlanc, N. D. (2013). Health Literacy of Individuals Living with Parkinson's Disease. (Publication No. 1703). [Masters dissertation, The University of Western Ontario]. Electronic Thesis and Dissertation Repository. https://ir.lib.uwo.ca/etd/1703

Lee, J., & Muzio, M. R. (2020). Neuroanatomy, extrapyramidal system. StatPearls Publishing.

Leisman, G., Braun-Benjamin, O., & Melillo, R. (2014). Cognitive-motor interactions of the basal ganglia in development. *Frontiers in Systems Neuroscience*, *8*, 16. https://doi.org/10.3389/fnsys.2014.00016

Leonard, K. V., Robertson, C., Bhowmick, A., & Herbert, L. B. (2020). Perceived treatment satisfaction and effectiveness facilitators among patients with chronic health conditions: a self-reported survey. *Interactive Journal of Medical Research*, *9*(1), e13029. https://doi.org/10.2196/13029

Li, S., Dong, J., Cheng, C., & Le, W. (2016). Therapies for Parkinson's diseases: alternatives to current pharmacological interventions. *Journal of Neural Transmission*, *123*(11), 1279-1299. https://doi.org/10.1007/s00702-016-1603-9

Lim, S. Y., Tan, A. H., Fox, S. H., Evans, A. H., & Low, S. C. (2017). Integrating patient concerns into Parkinson's disease management. *Current Neurology and Neuroscience reports*, *17*(1), 1-12. https://doi.org/10.1007/s11910-017-0717-2

Lozano, A. M., & Mahant, N. (2004). Deep brain stimulation surgery for Parkinson's disease: mechanisms and consequences. *Parkinsonism & Related Disorders*, *10*, S49-S57. https://doi.org/10.1016/j.parkreldis.2003.12.006

Lozano, A. M., Lipsman, N., Bergman, H., Brown, P., Chabardes, S., Chang, J. W., ... & Krauss, J. K. (2019). Deep brain stimulation: current challenges and future directions. *Nature Reviews Neurology*, *15*(3), 148-160. https://doi.org/10.1038/s41582-018-0128-2

Lundgren, T., Dahl, J., Melin, L., & Kies, B. (2006). Evaluation of acceptance and commitment therapy for drug refractory epilepsy: a randomized controlled trial in South Africa—a pilot study. *Epilepsia*, *47*(12), 2173-2179. https://doi.org/10.1111/j.1528-1167.2006.00892.x

Manyam, B. V., Dhanasekaran, M., & Hare, T. A. (2004). Neuroprotective effects of the antiparkinson drug Mucuna pruriens. *Phytotherapy Research: An International Journal*

Devoted to Pharmacological and Toxicological Evaluation of Natural Product Derivatives, *18*(9), 706-712. https://doi.org/10.1002/ptr.1514

Martinez-Martin, P., Deuschl, G., Tonder, L., Schnitzler, A., Houeto, J. L., Timmermann, L., ... & EARLYSTIM Study Group. (2020). Interpretation of health-related quality of life outcomes in Parkinson's disease from the EARLYSTIM Study. *PloS one*, *15*(8), e0237498. https://doi.org/10.1371/journal.pone.0237498

Mayosi, B. M., & Benatar, S. R. (2014). Health and health care in South Africa—20 years after Mandela. *New England Journal of Medicine*, *371*(14), 1344-1353.

Mhlanga, D., & Garidzirai, R. (2020). The influence of racial differences in the demand for healthcare in South Africa: A case of public healthcare. *International Journal of Environmental Research and Public Health*, *17*(14), 5043. https://doi.org/10.3390/ijerph17145043

Mills, R., Bahroo, L., & Pagan, F. (2015). An update on the use of botulinum toxin therapy in Parkinson's disease. *Current Neurology and Neuroscience Reports*, *15*(1), 1-11. https://doi.org/10.1007/s11910-014-0511-3

Mokaya, J., Gray, W. K., & Carr, J. (2017). Beliefs, knowledge and attitudes towards Parkinson's disease among a Xhosa speaking black population in South Africa: A cross-sectional study. *Parkinsonism & Related Disorders*, *41*, 51-57. https://doi.org/10.1016/j.parkreldis.2017.05.009

Morudu, P., & Kollamparambil, U. (2020). Health shocks, medical insurance and household vulnerability: Evidence from South Africa. *PloS one*, *15*(2), e0228034. https://doi.org/10.1371/journal.pone.0228034

Mshana, G., Dotchin, C. L., & Walker, R. W. (2011). 'We call it the shaking illness': perceptions and experiences of Parkinson's disease in rural northern Tanzania. *BMC Public Health*, *11*(1), 1-8. https://doi.org/10.1186/1471-2458-11-219

Muijs, D. (2010). *Doing quantitative research in education with SPSS*. Sage.

Nijkrake, M. J., Keus, S. H. J., Kalf, J. G., Sturkenboom, I. H. W. M., Munneke, M., Kappelle, A. C., & Bloem, B. R. (2007). Allied health care interventions and complementary therapies in Parkinson's disease. *Parkinsonism & Related Disorders*, *13*, S488-S494. https://doi.org/10.1016/S1353-8020(08)70054-3

Nisenzon, A. N., Robinson, M. E., Bowers, D., Banou, E., Malaty, I., & Okun, M. S. (2011). Measurement of patient-centered outcomes in Parkinson's disease: what do patients really want from their treatment?. *Parkinsonism & Related Disorders*, *17*(2), 89-94. https://doi.org/10.1016/j.parkreldis.2010.09.005

Nowacka, B., Lubiński, W., Honczarenko, K., Potemkowski, A., & Safranow, K. (2014). Ophthalmological features of Parkinson disease. *Medical Science Monitor: International Medical Journal of Experimental and Clinical Research*, *20*, 2243. https://doi.org/10.12659%2FMSM.890861

Nowak, I. (2018). The Effect of Land-Based and Aquatic Exercise Interventions in the Management of Parkinson's Disease Patients. (Doctoral Thesis). Johannesburg: University of Johannesburg (South Africa). Available from ProQuest Dissertations Publishing.

O'carroll, R. E., Smith, K., Couston, M., Cossar, J. A., & Hayes, P. C. (2000). A comparison of the WHOQOL-100 and the WHOQOL-BREF in detecting change in quality of life following liver transplantation. *Quality of Life Research*, *9*(1), 121-124. https://doi.org/10.1023/a:1008901320492

Opara, J. A., Brola, W., Leonardi, M., & Błaszczyk, B. (2012). Quality of life in Parkinsons Disease. *Journal of Medicine and Life*, *5*(4), 375.

Orcioli-Silva, D., Barbieri, F. A., Simieli, L., Rinaldi, N. M., Vitório, R., & Gobbi, L. T. B. (2014). Effects of a multimodal exercise program on the functional capacity of Parkinson's disease patients considering disease severity and gender. *Motriz: Revista de Educação Física*, *20*(1), 100-106. https://doi.org/10.1590/S1980-65742014000100015

Öztürk, A., Şimşek, T. T., Yümin, E. T., Sertel, M., & Yümin, M. (2011). The relationship between physical, functional capacity and quality of life (QoL) among elderly people with a chronic disease. *Archives of Gerontology and Geriatrics*, *53*(3), 278-283. https://doi.org/10.1016/j.archger.2010.12.011

Parkinson, J. (1969). An essay on the Shaking Palsy. *Archives of Neurology*, *20*(4), 441-445.

Pfeiffer, R. F. (2016). Non-motor symptoms in Parkinson's disease. *Parkinsonism & Related Disorders*, *22*, S119-S122. https://doi.org/10.1016/j.parkreldis.2015.09.004

Phaswana-Mafuya, N., Peltzer, K., Chirinda, W., Kose, Z., Hoosain, E., Ramlagan, S., ... & Davids, A. (2013). Self-rated health and associated factors among older South Africans: evidence from the study on global ageing and adult health. *Global Health Action*, *6*(1), 19880. https://doi.org/10.3402/gha.v6i0.19880

Phillips, M. C., Murtagh, D. K., Gilbertson, L. J., Asztely, F. J., & Lynch, C. D. (2018). Low-fat versus ketogenic diet in Parkinson's disease: a pilot randomized controlled trial. *Movement Disorders*, *33*(8), 1306-1314. https://doi.org/10.1002/mds.27390

Phillips, D. C., & Burbules, N. C. (2000). *Postpositivism and Educational Research*. Rowman & Littlefield.

Radder, D. L., Sturkenboom, I. H., van Nimwegen, M., Keus, S. H., Bloem, B. R., & de Vries, N. M. (2017). Physical therapy and occupational therapy in Parkinson's disease. *International Journal of Neuroscience*, *127*(10), 930-943. https://doi.org/10.1080/00207454.2016.1275617

Radder, D. L., Lígia Silva de Lima, A., Domingos, J., Keus, S. H., van Nimwegen, M., Bloem, B. R., & de Vries, N. M. (2020). Physiotherapy in Parkinson’s disease: a meta-analysis of present treatment modalities. *Neurorehabilitation and Neural Repair*, *34*(10), 871-880. https://doi.org/10.1177%2F1545968320952799

Rademakers, J., & Heijmans, M. (2018). Beyond reading and understanding: Health literacy as the capacity to act. *International Journal of Environmental Research and Public Health*, *15*(8), 1676. https://doi.org/10.3390/ijerph15081676

Rahman, S., Griffin, H. J., Quinn, N. P., & Jahanshahi, M. (2008). Quality of life in Parkinson's disease: the relative importance of the symptoms. *Movement Disorders: Official Journal of the Movement Disorder Society*, *23*(10), 1428-1434. https://doi.org/10.1002/mds.21667

Rao, A. K. (2010). Enabling functional independence in Parkinson's disease: update on occupational therapy intervention. *Movement Disorders*, *25*(S1), S146-S151. https://doi.org/10.1002/mds.22784

Reijnders, J. S., Ehrt, U., Weber, W. E., Aarsland, D., & Leentjens, A. F. (2008). A systematic review of prevalence studies of depression in Parkinson's disease. *Movement Disorders*, *23*(2), 183-189. https://doi.org/10.1002/mds.21803

Rocca, W. A. (2018). The burden of Parkinson's disease: a worldwide perspective. *The Lancet Neurology*, *17*(11), 928-929. https://doi.org/10.1016/S1474-4422(18)30355-7

Ruiters, G. (2001). Environmental racism and justice in South Africa's transition. *Politikon: South African Journal of Political Studies*, *28*(1), 95-103. https://doi.org/10.1080/02589340120058120

Rutten, S., Vriend, C., van den Heuvel, O. A., Smit, J. H., Berendse, H. W., & van der Werf, Y. D. (2012). Bright light therapy in Parkinson's disease: an overview of the background and evidence. *Parkinson's Disease*, *2012*. https://doi.org/10.1155/2012/767105

Schrag, A. (2006). Quality of life and depression in Parkinson's disease. *Journal of the Neurological Sciences*, *248*(1-2), 151-157. https://doi.org/10.1016/j.jns.2006.05.030

Schrag, A., Jahanshahi, M., & Quinn, N. (2000). What contributes to quality of life in patients with Parkinson's disease?. *Journal of Neurology, Neurosurgery & Psychiatry*, *69*(3), 308-312. http://dx.doi.org/10.1136/jnnp.69.3.308

Schulz, G. M., & Grant, M. K. (2000). Effects of speech therapy and pharmacologic and surgical treatments on voice and speech in Parkinson's disease: a review of the literature. *Journal of Communication Disorders*, *33*(1), 59-88. https://doi.org/10.1016/S0021-9924(99)00025-8

Shadmi, E., Chen, Y., Dourado, I., Faran-Perach, I., Furler, J., Hangoma, P., ... & Willems, S. (2020). Health equity and COVID-19: global perspectives. *International Journal for Equity in Health*, *19*(1), 1-16. https://doi.org/10.1186/s12939-020-01218-z

Sharma, N. K., Robbins, K., Wagner, K., & Colgrove, Y. M. (2015). A randomized controlled pilot study of the therapeutic effects of yoga in people with Parkinson's disease. *International Journal of Yoga*, *8*(1), 74. https://doi.org/10.4103%2F0973-6131.146070

Sharp, K., & Hewitt, J. (2014). Dance as an intervention for people with Parkinson's disease: a systematic review and meta-analysis. *Neuroscience & Biobehavioral Reviews*, *47*, 445-456. https://doi.org/10.1016/j.neubiorev.2014.09.009

Shimbo, T., Goto, M., Morimoto, T., Hira, K., Takemura, M., Matsui, K., ... & Fukui, T. (2004). Association between patient education and health-related quality of life in patients with Parkinson's disease. *Quality of Life Research*, *13*(1), 81-89. https://doi.org/10.1023/B:QURE.0000015306.59840.95

Simpson, J., McMillan, H., & Reeve, D. (2013). Reformulating psychological difficulties in people with Parkinson's disease: the potential of a social relational approach to disablism. *Parkinson's Disease*, *2013*. https://doi.org/10.1155/2013/608562

Singh, N., Pillay, V., & Choonara, Y. E. (2007). Advances in the treatment of Parkinson's disease. *Progress in Neurobiology*, *81*(1), 29-44. https://doi.org/10.1016/j.pneurobio.2006.11.009

Skevington, S. M., Lotfy, M., & O'Connell, K. A. (2004). The World Health Organization's WHOQOL-BREF quality of life assessment: psychometric properties and results of the

international field trial. A report from the WHOQOL group. *Quality of Life Research*, *13*(2), 299-310. https://doi.org/10.1023/B:QURE.0000018486.91360.00

Skodda, S. (2012). Effect of deep brain stimulation on speech performance in Parkinson's disease. *Parkinson's Disease*, *2012*. https://doi.org/10.1155/2012/850596

Sørensen, K., Pelikan, J. M., Röthlin, F., Ganahl, K., Slonska, Z., Doyle, G., ... & Brand, H. (2015). Health literacy in Europe: comparative results of the European health literacy survey (HLS-EU). *European Journal of Public Health*, *25*(6), 1053-1058. https://doi.org/10.1093/eurpub/ckv043

Statistics South Africa (StatsSA). General Household Survey; Government of South Africa: Salvokop, South Africa, 2018.

Staunton, C., Adams, R., Anderson, D., Croxton, T., Kamuya, D., Munene, M., & Swanepoel, C. (2020). Protection of Personal Information Act 2013 and data protection for health research in South Africa. *International Data Privacy Law*, *10*(2), 160-179. https://doi.org/10.1093/idpl/ipz024

Strauss, I., Kalia, S. K., & Lozano, A. M. (2014). Where are we with surgical therapies for Parkinson's Disease? *Parkinsonism & Related Disorders* 20 (2014): S187-S191. https://doi.org/10.1016/S1353-8020(13)70044-0

Sturkenboom, I. H., Hendriks, J. C., Graff, M. J., Adang, E. M., Munneke, M., Nijhuis-van der Sanden, M. W., & Bloem, B. R. (2015). Economic evaluation of occupational therapy in Parkinson's disease: a randomized controlled trial. *Movement Disorders*, *30*(8), 1059-1067. https://doi.org/10.1002/mds.26217

Sveinbjornsdottir, S. (2016). The clinical symptoms of Parkinson's disease. *Journal of Neurochemistry*, *139*, 318-324. https://doi.org/10.1111/jnc.13691

Tickle-Degnen, L., Ellis, T., Saint-Hilaire, M. H., Thomas, C. A., & Wagenaar, R. C. (2010). Self-management rehabilitation and health-related quality of life in Parkinson's disease: a

randomized controlled trial. *Movement Disorders*, *25*(2), 194-204. https://doi.org/10.1002/mds.22940

Tomlinson, C. L., Patel, S., Meek, C., Herd, C. P., Clarke, C. E., Stowe, R., ... & Ives, N. (2013). Physiotherapy versus placebo or no intervention in Parkinson's disease. *Cochrane Database of Systematic Reviews*, (9). https://doi.org/10.1002/14651858.CD002817.pub4

Tripoliti, E., Limousin, P., Foltynie, T., Candelario, J., Aviles-Olmos, I., Hariz, M. I., & Zrinzo, L. (2014). Predictive factors of speech intelligibility following subthalamic nucleus stimulation in consecutive patients with Parkinson's disease. *Movement Disorders*, *29*(4), 532-538. https://doi.org/10.1002/mds.25816

Trotti, L. M., & Bliwise, D. L. (2014). Treatment of the sleep disorders associated with Parkinson's disease. *Neurotherapeutics*, *11*(1), 68-77. https://doi.org/10.1007/s13311-013-0236-z

United Nations (2021). *United Nations.* Retrieved July 10, 2022d, from United Nations: https://www.un.org/development/desa/youth/what-we-do/faq.html

Valkovic, P., Minar, M., Singliarova, H., Harsany, J., Hanakova, M., Martinkova, J., & Benetin, J. (2015). Pain in Parkinson´ s disease: a cross-sectional study of its prevalence, types, and relationship to depression and quality of life. *PLoS One*, *10*(8), e0136541. https://doi.org/10.1371/journal.pone.0136541

Varanese, S., Birnbaum, Z., Rossi, R., & Di Rocco, A. (2010). Treatment of advanced Parkinson's disease. *Parkinson's Disease*, *2010*. https://doi.org/10.4061/2010/480260

von Steinbüchel, N., Lischetzke, T., Gurny, M., & Eid, M. (2006). Assessing quality of life in older people: psychometric properties of the WHOQOL-BREF. *European Journal of Ageing*, *3*(2), 116-122. https://doi.org/10.1007/s10433-006-0024-2

Wagle Shukla, A., & Okun, M. S. (2014). Surgical treatment of Parkinson's disease: patients, targets, devices, and approaches. *Neurotherapeutics*, *11*(1), 47-59. https://doi.org/10.1007/s13311-013-0235-0

Waldvogel, H. J., Kim, E. H., Tippett, L. J., Vonsattel, J. P. G., & Faull, R. L. M. (2014). Neuropathology in the Human Brain. In G. P. Bates, S. J. Tabrizi & L. Jones (Eds.), *Huntington's Disease* (4th ed., pp. 185-209). New York: Oxford University Press.

Wang, L., Evatt, M. L., Maldonado, L. G., Perry, W. R., Ritchie, J. C., Beecham, G. W., ... & Scott, W. K. (2015). Vitamin D from different sources is inversely associated with Parkinson disease. *Movement Disorders*, *30*(4), 560-566. https://doi.org/10.1002/mds.26117

Watson, R. (2015). Quantitative research. *Nursing Standard (2014+)*, *29*(31), 44. https://doi.org/10.7748/ns.29.31.44.e8681

Weaver, F. M., Follett, K., Stern, M., Hur, K., Harris, C., Marks, W. J., ... & CSP 468 Study Group. (2009). Bilateral deep brain stimulation vs best medical therapy for patients with advanced Parkinson disease: a randomized controlled trial. *Jama*, *301*(1), 63-73. https://doi:10.1001/jama.2008.929

Webb, N. M., & Shavelson, R. J. (2005). Generalizability theory: overview. *Encyclopedia of Statistics in Behavioral Science*.

Wertheimer, J., Gottuso, A. Y., Nuno, M., Walton, C., Duboille, A., Tuchman, M., & Ramig, L. (2014). The impact of STN deep brain stimulation on speech in individuals with Parkinson's disease: the patient's perspective. *Parkinsonism & Related Disorders*, *20*(10), 1065-1070. https://doi.org/10.1016/j.parkreldis.2014.06.010

Whoqol Group. (1995). The World Health Organization quality of life assessment (WHOQOL): position paper from the World Health Organization. *Social Science & Medicine*, *41*(10), 1403-1409. https://doi.org/10.1016/0277-9536(95)00112-K

Whitehead, M., Dahlgren, G., & Evans, T. (2001). Equity and health sector reforms: can low-income countries escape the medical poverty trap?. *The Lancet*, *358*(9284), 833-836. https://doi.org/10.1016/S0140-6736(01)05975-X

Whoqol Group. (1998). Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychological Medicine*, *28*(3), 551-558.

Williams, U., Bandmann, O., & Walker, R. (2018). Parkinson's disease in sub-Saharan Africa: a review of epidemiology, genetics and access to care. *Journal of Movement Disorders*, *11*(2), 53. https://dx.doi.org/10.14802%2Fjmd.17028

Winter, Y., Balzer-Geldsetzer, M., Spottke, A., Reese, J. P., Baum, E., Klotsche, J., ... & Dodel, R. (2010). Longitudinal study of the socioeconomic burden of Parkinson's disease in Germany. *European Journal of Neurology*, *17*(9), 1156-1163. https://doi.org/10.1111/j.1468-1331.2010.02984.x

Wittink, H., & Oosterhaven, J. (2018). Patient education and health literacy. *Musculoskeletal Science and Practice*, *38*, 120-127. https://doi.org/10.1016/j.msksp.2018.06.004

Woods, S. P., & Sullivan, K. L. (2019). Lower neurocognitive functioning disrupts the effective use of internet-based health resources in HIV disease: The mediating effects of general health literacy capacity. *AIDS and Behavior*, *23*(3), 676-683. https://doi.org/10.1007/s10461-018-2350-8

Woodyard, C. (2011). Exploring the therapeutic effects of yoga and its ability to increase quality of life. *International Journal of Yoga*, *4*(2), 49. https://doi.org/10.4103%2F0973-6131.85485

World Health Organization. (1998). *Programme on mental health: WHOQOL user manual* (No. WHO/HIS/HSI Rev. 2012.03). World Health Organization.

Yoshitake, T., Yoshitake, S., & Kehr, J. (2010). The Ginkgo biloba extract EGb 761® and its main constituent flavonoids and ginkgolides increase extracellular dopamine levels in the rat prefrontal cortex. *British Journal of Pharmacology*, *159*(3), 659-668. https://doi.org/10.1111/j.1476-5381.2009.00580.x

10. APPENDICES

Appendix A – WHOQOL-BREF Questionnaire

1

WHOQOL-BREF

June 1997

U.S. Version

Emblem...Soul Catcher: a Northwest Coast Indian symbol of physical and mental well-being. Artist: Marvin Oliver

University of Washington
Seattle, Washington
United States of America

WHOQOL-BREF

About You

Before you begin we would like to ask you to answer a few general questions about yourself by circling the correct answer or by filling in the space provided.

1. What is your gender — Male — Female

2. What is your date of birth? _____ / _____ / _____ (Day / Month / Year)

3. What is the highest education you received?
   - None at all
   - Elementary School
   - High School
   - College

4. What is your marital status?
   - Single
   - Married
   - Living as Married
   - Separated
   - Divorced
   - Widowed

5. Are you currently ill? — Yes — No

6. If something is wrong with your health, what do you think it is? ____ illness/problem

Instructions

This questionnaire asks how you feel about your quality of life, health, or other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks. For example, thinking about the last two weeks, a question might ask:

For office use		*(Please circle the number)*				
		Not at all	**A little**	**Moderately**	**Mostly**	**Completely**
	Do you get the kind of support from others that you need?	**1**	**2**	**3**	**4**	**5**

You should circle the number that best fits how much support you got from others over the last two weeks. So you would circle the number 4 if you got a great deal of support from others. o

For office use		*(Please circle the number)*				
		Not at all	**A little**	**Moderately**	**Mostly**	**Completely**
	Do you get the kind of support from others that you need?	**1**	**2**	**3**	**4** ◯	**5**

You would circle number 1 if you did not get any of the support that you needed from others in the last two weeks. o

For office use		*(Please circle the number)*				
		Not at all	**A little**	**Moderately**	**Mostly**	**Completely**
	Do you get the kind of support from others that you need?	◯ **1**	**2**	**3**	**4**	**5**

Please read each question, assess your feelings, and circle the number on the scale that gives the best answer for you for each question.

For office use			*(Please circle the number)*				
			Very poor	Poor	Neither poor nor good	Good	Very Good
G1 / G1.1	1.	How would you rate your quality of life?	1	2	3	4	5

For office use			*(Please circle the number)*				
			Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
G4 / G2.3	2.	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last two weeks.

For office use			*(Please circle the number)*				
			Not at all	A little	A moderate amount	Very much	An extreme amount
F1.4 / F1.2.5	3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
F11.3 / F13.1.4	4.	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
F4.1 / F6.1.2	5.	How much do you enjoy life?	1	2	3	4	5

For office use		(Please circle the number)				
		Not at all	A little	A moderate amount	Very much	An extreme amount
F24.2 / F29.1.3	6. To what extent do you feel your life to be meaningful?	1	2	3	4	5

For office use		(Please circle the number)				
		Not at all	Slightly	A Moderate amount	Very much	Extremely
F5.2 / F7.1.6	7. How well are you able to concentrate?	1	2	3	4	5
F16.1 / F20.1.2	8. How safe do you feel in your daily life?	1	2	3	4	5
F22.1 / F27.1.2	9. How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

For office use		(Please circle the number)				
		Not at all	A little	Moderately	Mostly	Completely
F2.1 / F2.1.1	10. Do you have enough energy for everyday life?	1	2	3	4	5
F7.1 / F9.1.2	11. Are you able to accept your bodily appearance?	1	2	3	4	5
F18.1 / F23.1.1	12. Have you enough money to meet your needs?	1	2	3	4	5

For office use		(Please circle the number) Not at all	A little	Moderately	Mostly	Completely
F20.1 / F25.1.1	13. How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
F21.1 / F26.1.2	14. To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

For office use		(Please circle the number) Very poor	Poor	Neither poor nor well	Well	Very well
F9.1 / F11.1.1	15. How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how **good** or **satisfied** you have felt about various aspects of your life over the last two weeks.

For office use		(Please circle the number) Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
F3.3 / F4.2.2	16. How satisfied are you with your sleep?	1	2	3	4	5
F10.3 / F12.2.3	17. How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
F12.4 / F16.2.1	18. How satisfied are you with your capacity for work?	1	2	3	4	5

For office use		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
		(Please circle the number)				
F6.4 / F8.2.2	19. How satisfied are you with yourself?	1	2	3	4	5
F13.3 / F17.2.3	20. How satisfied are you with your personal relationships?	1	2	3	4	5
F15.3 / F3.2.1	21. How satisfied are you with your sex life?	1	2	3	4	5
F14.4 / F18.2.5	22. How satisfied are you with the support you get from your friends?	1	2	3	4	5
F17.3 / F21.2.2	23. How satisfied are you with the conditions of your living place?	1	2	3	4	5
F19.3 / F24.2.1	24. How satisfied are you with your access to health services?	1	2	3	4	5
F.23.3 / F28.2.2	25. How satisfied are you with your mode of transportation?	1	2	3	4	5

The follow question refers to **how often** you have felt or experienced certain things in the last two weeks.

For office use		*(Please circle the number)*				
		Never	**Seldom**	**Quite often**	**Very often**	**Always**
F8.1 / F10.1.2	26. How often do you have negative feelings, such as blue mood, despair, anxiety, depression?	**1**	**2**	**3**	**4**	**5**

Did someone help you to fill out this form? *(Please circle Yes or No)* Yes No

How long did it take to fill out this form? _____

THANK YOU FOR YOUR HELP

Appendix B – WHOQOL-BREF Individual Domains and Items

Domain	Facet / Item question	Question number in WHOQOL-BREF
Global items	Overall QOL - “How would you rate your quality of life?”	1
Physical health	General health – “How satisfied are you with your health?”	2
	Pain and discomfort - “To what extent do you feel that pain prevents you from doing what you need to do?”	3
	Dependence on medicinal substances and medical aids – “How much do you need any medical treatment to function in your daily life?”	4
	Energy and fatigue - “Do you have enough energy for everyday life?”	10
	Mobility - “How well are you able to get around?”	15
	Sleep and rest - “How satisfied are you with your sleep?”	16
	Activities of daily living - “How satisfied are you with your ability to perform your daily living activities?”	17
	Work capacity - “How satisfied are you with your capacity for work?”	18
Psychological health	Positive feelings - “How much do you enjoy life?”	5
	Spiritually, religion and personal beliefs - “To what extent do you feel your life to be meaningful?”	6

	Thinking, learning, memory and concentration - “How well are you able to concentrate?”	7
	Bodily image and appearance - “Are you able to accept your bodily appearance?”	11
	Self-esteem - “How satisfied are you with yourself?”	19
	Negative feelings - “How often do you have negative feelings, such as blue mood, despair, anxiety, depression?”	26
Social relationships	Personal relationships - “How satisfied are you with your personal relationships?”	20
	Sexual activity - “How satisfied are you with your sex life?”	21
	Social support - “How satisfied are you with the support you get from your friends?”	22
Environmental QOL	Freedom, physical safety and security - “How safe do you feel in your daily life?”	8
	Physical environment (pollution/ noise/ traffic/ climate) - “How healthy is your physical environment?”	9
	Financial resources - “Have you enough money to meet your needs?”	12
	Opportunities for acquiring new information and skills - “How available to you is the information that you need in your day-to-day life?”	13
	Participation in and opportunities for recreation/ leisure activities - “To what extent do you have the opportunity for leisure activities?”	14

Home environment - “How satisfied are you with the conditions of your living place?”	23
Health and social care: Accessibility and quality - “How satisfied are you with your access to health services?”	24
Transport - “How satisfied are you with your mode of transportation?”	25

Appendix C – Demographic Questionnaire

DEMOGRAPHIC QUESTIONNAIRE

1.HOME LANGUAGE: (Please tick the correct box, you may tick more than one)

English	
Afrikaans	
Zulu	
Xhosa	
Sotho	
Other	

If other, please specify:_____

2.RACE: (Please tick the correct box)

Black	
White	
Coloured	
Indian	
Chinese	
Other	

If other, please specify:_____

3.AGE: (Please tick the correct box)

Under 40	
Between 40 and 50	
Between 50 and 60	
Between 60 and 70	
Between 70 and 80	
Over 80	

4.EDUCATION LEVEL: (Please tick the correct box)

Primary school education only	
High School education without matric	
Matric	
Undergraduate degree / diploma / Technikon/ college	
Postgraduate degree at tertiary institution	
Other	

5.I WAS DIAGNOSED WITH PARKINSON'S DISEASE: (Please tick the correct box)

More than 20 years ago	
Between 15 and 20 years ago	
Between 10 and 15 years ago	
In the last 10 years	
Very recently, in the last few months	
Other	

6.BEFORE I WAS DIAGNOSED WITH PARKSINSON'S DISEASE I HAD FIRST STARTED TO EXERIENCE SYMPTOMS: (Please tick the correct box)

A few months before diagnosis	
A year before diagnosis	
Two years before diagnosis	
Three to five years before diagnosis	
More than five years before diagnosis	
Other	

7.ACCESS TO INTERNET: (Please tick the correct box, you may tick more than one)

I use WIFI at home	
I use WIFI in public spaces such as my work environment	
I rely on data on my phone to access the internet	
I do not have access to the internet	
Other	

8.HEALTH INSURANCE: (Please tick the correct box)

I am on medical aid	
I use government healthcare facilities	
I am a private patient without medical aid	
Other	

9.CURRENT EMPLOYMENT STATUS: (Please tick the correct box)

I am currently employed full-time	
I am currently employed part-time	
I am unemployed	
I am self-employed	
I am retired	
Other	

10.*OCCUPATION: (Please tick the correct box)

Farm labourer	
Unskilled worker, service worker	
Machine operator, semiskilled worker	
Skilled manual worker, craftsman, police and fire services, enlisted military and non-commissioned officer	
Clerical/ sales, small farm worker	
Technician/ semi-professional, supervisor, office manager	
Small business owner, farm owner, teacher, low level manager, salaried worker	
Mid-level manager or professional (Architect, engineer, accountant, attorney), mid-sized business owner, military officer	
Senior manager or professional (Physician, college professor, minister), owner or CEO of large business	
Other	

11.HOUSEHOLD INCOME: (Please tick the correct box)

Less than R3,500 per month	
Between R3,500 and R5,000 per month	
Between R5,000 and R10,000 per month	
Between R10,000 and R20,000 per month	
Between R20,000 and R50,000 per month	
Over R50,000 per month	
Other	

12.CURRENT TREATMENT FOR PARKINSON'S DISEASE: (Please tick the correct box, you may tick more than one)

Pharmacological (Medication)	
Deep Brain Stimulation	
Occupational therapy	
Physiotherapy	
Speech therapy	
Light therapy	
Psychiatry/ Psychology	
Dietician	
CBD Oils	
Traditional healer	
Other	

If you are on medication, please specify the name: _____

13.TREATMENT OUTCOME: (Please tick the correct box)

My treatment works very well to manage the symptoms caused by Parkinson's Disease	
My treatment works well to manage the symptoms caused by Parkinson's Disease	
My treatment does not work as well as it used to to manage the symptoms caused by Parkinson's Disease	
Other	

14.WHO PAYS FOR YOUR TREATMENT? (Please tick the correct box)

It is funded by a governmentinstitution (e.g. hospital pharmacy)	
It is funded by family member(s)	
It is partially funded by the medical aid	
It is fully covered by my medical aid	
I pay for my treatment	
Other	

15.IF TAKING MEDICATION: (Please tick the correct box)

I can get my medication at any pharmacy	
I can only get my medication at hospital pharmacies	
Other	

16.IF YOU PAY CASH FOR TREATMENT, WHAT DOES IT COST?
(Please tick the correct box)

Under R1,000 per month	
Between R1,000 and R5,000 per month	
Between R5,000 and R10,000 per month	
Between R10,000 and R20,000 per month	
Over R20,000 per month	
Other	

17.IN ADDITION TO YOUR CURRENT TREATMENT WHAT OTHER THERAPIES HAS YOUR NEUROLOGIST RECOMMENDED TO YOU (Please tick the correct box, you may tick more than one)

Additional Medication	
Deep Brain Stimulation	
Occupational therapy	
Physiotherapy	
Speech therapy	
Light therapy	
Psychiatry/ Psychology	
Dietician	
CBD Oils	
Traditional healer	
Other	

If other, please specify:_____

18.ACCORDING TO YOUR HEALTHCARE INSURANCE STATUS (PRIVATE/ MEDICAL AID/ GOVERNMENT) WHICH TREATMENTS DO YOU HAVE ACCESS TO WITHIN THE NEXT YEAR? (Please tick the correct box, you may tick more than one)

Pharmacological (Medication)	
Deep Brain Stimulation	
Occupational therapy	
Physiotherapy	
Speech therapy	
Light therapy	
Psychiatry/ Psychology	
Dietician	
CBD Oils	
Traditional healer	
Other	

If other, please specify:_____

19. HAVE YOU CONSIDERED UNDERGOING DEEP BRAIN STIMULATION (DBS) SURGERY AS A TREATMENT FOR PARKINSON DISEASE? (Please tick the correct box)

Yes, I have had Deep Brain Stimulation Surgery	
Yes, I would like to have the surgery sometime in the future	
I have heard about it but I am not able to afford it at the moment	
I have heard about it but I am not willing to undergo brain surgery	
No, I have never heard about it	

20. HAS COVID-19 AFFECTED YOUR ACCESS TO TREATMENT? (Please tick the correct box)

Yes	
No	

21. ARE YOUR TREATMENTS ALWAYS EASILY AVAILABLE? (Please tick the correct box)

Yes	
No	

22.IF YES, PLEASE SPECIFY WHICH TREATMENT WAS AFFECTED BY COVID-19: (Please tick the correct box)

Pharmacological (Medication)	
Deep Brain Stimulation	
Occupational therapy	
Physiotherapy	
Speech therapy	
Light therapy	
Psychiatry/ Psychology	
Dietician	
CBD Oils	
Traditional healer	
Other	

If other, please specify:_____

Appendix D – Ethics Clearance Certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R49 Ms SL Harris

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M210934

NAME: (Principal Investigator)	Ms SL Harris
DEPARTMENT:	School of Human and Community Development Department of Psychology University
PROJECT TITLE:	*Disparities in access to treatment in relation to quality of life in people diagnosed with Parkinson's Disease*
DATE CONSIDERED:	2021/10/01
DECISION:	Approved unconditionally
CONDITIONS:	
NOTE:	If contact information regarding student study participants is required, please contact the Registrar's office - <Nicoleen.Potgieter@wits.ac.za>
SUPERVISOR:	Dr A Ferreira-Correia
APPROVED BY:	CB Penny Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	2021/12/23

This Clearance Certificate is valid for 5 years from the date of approval. An extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office secretariat on the 3rd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to submit details to the Committee. **I agree to submit a yearly progress report**. When a funder requires annual re-certification, the application date will be one year after the date when the study was initially reviewed. In this case, the study was initially reviewed in September and therefore reports and re-certification will be due in the month of **September** each year. Unreported changes to the study may invalidate the clearance given by the HREC (Medical).

Signature of Principal Investigator Date

Appendix E – Approval from Chris Hani Baragwanath Academic Hospital

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

MEDICAL ADVISORY COMMITTEE

CHRIS HANI BARAGWANATH ACADEMIC HOSPITAL

PERMISSION TO CONDUCT RESEARCH

Date: 30th November 2021

TITLE OF PROJECT:

Disparities in access to treatment in relation to Quality of Life in people diagnosed with Parkinson's Disease

UNIVERSITY: Witswatersrand

Principal Investigator: Simone Harris

Department: Neurology

Supervisor : Dr. Aline Ferreira Correia

Permission Head Department (where research conducted): Yes

NHRD No. 202111_014

The Medical Advisory Committee recommends that the said research be conducted at Chris Hani Baragwanath Academic Hospital. The CEO / management of Chris Hani Baragwanath Academic Hospital is accordingly informed and the study is subject to:-

- **Permission having been granted by the Committee for Research on Human Subjects of the University of the Witwatersrand.**
- The Hospital will not incur extra costs as a result of the research being conducted on its patients within the hospital
- The MAC will be informed of any serious adverse events as soon as they occur
- Permission is granted for the duration of the Ethics Committee Approval.

.....
Recommended
(On behalf of the MAC)
Date: 30/11/2021

.....
Approved/Not Approved
Hospital Management
Date: 30/11/2021

Appendix F – Neurologist Approach Letter

Psychology

School of Human & Community Development

University of the Witwatersrand

Private Bag 3, Wits, 2050

Tel: 011 717 4503 Fax: 086 553 4913

November 2021

Dear Dr _____ (name),

My name is Simone Harris. I am currently completing my Masters in Social and Psychological Research at the University of the Witwatersrand. As part of the degree, I am conducting research on disparities in access to treatment in relation to Quality of Life (QoL) in individuals diagnosed with Parkinson's Disease. I will be looking at whether any socioeconomic factors influence the relationship between treatment received and quality of life outcomes. The study aims to contribute to the lack of literature in this area, as very few reports have studied access and availability to treatment for Parkinson's Disease in Johannesburg. I would like to invite patients with Parkinson's Disease under your care to participate in my study and would appreciate your assistance in facilitating this.

I have obtained ethical clearance from the Human Research Ethics Committee (HREC Medial) at University of Witwatersrand (Provisional Clearance number M210934) and I have also obtained clearance from the department of Health to conduct the study at Chris Hani Baragwanath Hospital in Gauteng.

I will make use of the WHOQOL-BREF (World Health Organization Quality of Life questionnaire) which is a reliable measure of QoL. Attached to this is a socioeconomic questionnaire asking for information such as treatments received, knowledge about treatments offered, household income, access to internet, whether they are private, governmentor medical aid members, treatment accessibility and availability, the impact of COVID-19 on treatment etc. The questionnaire will take approximately 30 minutes to complete and it will be dropped off at your consulting rooms or I will be there personally to introduce myself while your patients are waiting for their consultation. I will seek formal consent by providing participant information sheets to all potential participants to explain my study and ethical considerations.

This PIS assures them of their confidentiality and right to withdraw at any time. Patients will be asked to fill in the questionnaire on site and leave it with me or at your offices if I am not present. Completed questionnaires will be collected once a week to keep track of the data collection when I am not there. I require the voluntary participation of approximately 30 patients and I am hoping that you will consider participating in my study. I am also able to do surveys telephonically if patients cannot come in themselves.

There are low risks associated with participation in this study. The questionnaires require no identifying information thus maintaining the confidentiality of the patients. Given the anonymous response format, individual feedback cannot be given. Upon completion of the study, I will be able to provide you with a summary of the findings if requested. If patients also request findings of the study or if they have any concerns or queries about their participation, or wish to withdraw they will be provided with my personal contact details which form part of the participant information sheets. They will also be given the contact details of Dr Penny, the chair of the Human Research Ethics Committee (HREC) if they have any queries. All of the questionnaires will be captured electronically and this information will only be accessible to the research team. The electronic database will be stored indefinitely on a password-protected computer that only the research team will have access to. No identifying information will link any patients to the study or your affiliated practice, ensuring confidentiality at all times.

It would be much appreciated if you could assist me by informing your patients of this study and facilitate the handout and collection of questionnaires at your consulting room unless I could be there personally to assist in this process. Should you wish to participate in this study, please complete the attached consent form and email it to either my supervisor Dr. Aline Ferreira Correia or myself. Alternatively I can come and collect it at your office. All contact details appear below. I look forward to hearing from you.

Kind regards,

Ms. Simone Harris
Cell: 082 505 1110
E-mail: 1313046@students.wits.ac.za

Dr Aline Ferreira Correia
Cell: 072 200 9292
E-mail: aline.ferreiracorreia@wits.ac.za

Dr CB Penny, Chair of HREC
Tel: 011 717 2301
E-mail: Clement.Penny@wits.ac.za

Appendix G – Signed Neurologist Consent Form

CONSENT FORM

Psychology

School of Human & Community Development

University of the Witwatersrand

Private Bag 3, Wits, 2050

Tel: 011 717 4503 Fax: 086 553 4913

I, _____ (name and surname) working at _____ (name of hospital), agree to assist Ms. Harris by informing the patients of her study and facilitating the handing out and collection of questionnaires. Information about the study and contact details of the researcher and supervisor has been provided to me in writing. I understand that patients' participation in this study is voluntary and that all details will be kept confidential at all times. My name and institutions you are affiliated with will be kept confidential further preserving the anonymity of responses. I may request a copy of the final research report by contacting the researcher.

Name and Surname: _____

Signed: _____

At: _____

Date: _____

Appendix H – Signed Neurologist Consent Form

CONSENT FORM

Psychology

School of Human & Community Development

University of the Witwatersrand

Private Bag 3, Wits, 2050

Tel: 011 717 4503 Fax: 086 553 4913

I, [illegible] MECHAN (name and surname) working at [illegible] (name of hospital), agree to assist Ms. Harris by informing the patients of her study and facilitating the handing out and collection of questionnaires. Information about the study and contact details of the researcher and supervisor has been provided to me in writing. I understand that patients' participation in this study is voluntary and that all details will be kept confidential at all times. My name and institutions you are affiliated with will be kept confidential further preserving the anonymity of responses. I may request a copy of the final research report by contacting the researcher.

Name and Surname: [illegible] MECHAN

Signed: _____

At: Soweto 6/8/2021

Date: _____

Appendix I – Signed Neurologist Consent Form

CONSENT FORM

Psychology

School of Human & Community Development

University of the Witwatersrand

Private Bag 3, Wits, 2050

Tel: 011 717 4503 Fax: 086 553 4913

I, Marcelle Smith (name and surname) working at Soweto Medical & Wits Donald Gordon (name of hospital), agree to assist Ms. Harris by informing the patients of her study and facilitating the handing out and collection of questionnaires. Information about the study and contact details of the researcher and supervisor has been provided to me in writing. I understand that patients' participation in this study is voluntary and that all details will be kept confidential at all times. My name and institutions you are affiliated with will be kept confidential further preserving the anonymity of responses. I may request a copy of the final research report by contacting the researcher.

Name and Surname: Marcelle Smith

Signed: _____

At: Soweto Medicine

Date: 02/02/2012

Appendix J – Hospital Approach Letter

Psychology

School of Human & Community Development

University of the Witwatersrand

Private Bag 3, Wits, 2050

Tel: 011 717 4503 Fax: 086 553 4913

November 2021

Att: Chris Hani Baragwanath Hospital

26 Chris Hani Rd, Diepkloof 319-Iq, Johannesburg, 1864

To whom it may concern,

My name is Simone Harris. I am currently completing my Masters in Social and Psychological Research at the University of the Witwatersrand. As part of the degree I am conducting research on disparities in access to treatment in relation to Quality of Life (QoL) in people diagnosed with Parkinson's Disease. I will be assessing whether socioeconomic factors mediate the relationship between access to treatment and QoL outcomes, as measured by the World Health Organization QoL questionnaire (WHOQOL-BREF). The study aims to contribute to the lack of literature in this area, as very few reports have studied access and availability to treatment for Parkinson's Disease in Johannesburg. I would like to approach neurologists at Chris Hani Baragwanath Hospital to invite patients with Parkinson's Disease under their care to participate in my study and would appreciate your assistance in facilitating this.

I have obtained ethical clearance from the Human Research Ethics Committee (HREC Medical) at University of Witwatersrand (Provisional Clearance number M210934) and I have also obtained clearance from the department of Health to conduct the study at public hospitals in Gauteng (will be attached upon approval).

My study will make use of the WHOQOL-BREF (World Health Organization Quality of Life questionnaire) which is a reliable measure of QoL. Attached to this is a demographic questionnaire asking for information such as treatments received, knowledge about treatments offered, household income, access to internet, health insurance status, internet access and the impact of Covid-10 on their

treatment access. The questionnaire itself will take approximately 30 minutes to complete while 5 minutes will be used beforehand to explain the study and obtain consent, fulfilling all ethical requirements first and informing participants of their rights to confidentiality and the right to withdraw at any given time. Patients will also have the right of not answering specific questions if they wish so.

Questionnaires will be left at the offices of the neurologists and I will be liaising with them on the best method of data collection with the least amount of intrusion at their practice. On certain days, with the permission of the neurologist, I will be there personally to introduce myself and the study while patients are waiting for their consultation. I will explain my study and all ethical considerations and ask them if they would like to volunteer as a participant. Patients will be asked to fill in the questionnaire on site and leave it with me or at the neurologists' office if I am not present. Completed questionnaires will be collected weekly to keep track of the data collection. I require the voluntary participation of approximately 30 patients and I am hoping that you will consider granting me permission to approach neurologists at Baragwanath Hospital.

There are low risks associated with participation in this study. The questionnaires require no identifying information thus maintaining the confidentiality of the patients. The data will be captured and stored electronically on a password-protected computer that only the research team will have access to. Given the anonymous response format, individual feedback cannot be given to patients. I will be giving them my contact details if they have any follow up concerns or questions about the study itself or if they wish to withdraw their participation. Participants will also be given the contact details of Dr Penny, the chair of the Human Research Ethics Committee (HREC) if they have any queries.

Upon completion of the study, I will be able to provide you with a summary of the findings if requested. Should you wish to participate in this study, please complete the attached consent form and email it to either my supervisor Dr. Aline Ferreira Correia or myself. Alternatively I can come and collect it at your office. My contact details and those of my supervisor appear below. I look forward to hearing from you.

Kind regards,

Ms. Simone Harris
Cell: 082 505 1110
E-mail: 1313046@students.wits.ac.za

Dr Aline Ferreira Correia
Cell: 072 200 9292
E-mail: aline.ferreiracorreia@wits.ac.za

Professor CB Penny, Chair of HREC
Tel: 011 717 2301
E-mail: Clement.Penny@wits.ac.za

Appendix K – Participant Information Sheet

Psychology

School of Human & Community Development

University of the Witwatersrand

Private Bag 3, Wits, 2050

Tel: 011 717 4503 Fax: 086 553 4913

January 2022

Dear Sir/Madam

Study title: *Disparities in access to treatment in relation to quality of life in people diagnosed with Parkinson's Disease*

My name is Simone Harris. I am currently completing my Masters in Social and Psychological Research at the University of the Witwatersrand. As part of the degree, I am conducting research on access to treatment for Parkinson's Disease in relation to Quality of Life (QoL). This study will look at socioeconomic factors to see whether they influence access to treatment and subsequent quality of life outcomes for those in public and private healthcare settings. I would like to invite you to participate in my study.

Participation will involve completion of two questionnaires. They should take approximately 30 minutes to complete. You can either fill in a hard copy of the questionnaires or it can be administered telephonically where I will call you directly and assist you to fill it in. Hard copies can be filled in at the department of Neurology and left with the neurologist or myself when I am there in person. All COVID-19 restrictions will be adhered to in terms of social distancing, wearing of masks and sanitizing of hands and stationery.

Your participation is voluntary. Refusal to participate will have no effect whatever on any ongoing medical treatment you may be having. There are low risks associated with participation in this study and I have obtained ethical clearance from the Human Research Ethics Committee (HREC Medical) at University of Witwatersrand (Provisional Clearance number M210934).

A few of the questions are sensitive in nature and may evoke distress. Should you experience any psychological distress please contact Dr Aline Ferreira Correia if you require free counseling services. I have included her contact information below.

The questionnaires contain no identifying information, so your responses will remain strictly confidential. To ensure your anonymity there is no way of linking you to your completed questionnaire and you have the right to withdraw from the study at any point. Once the study is complete I will be able to provide you with a summary of the general findings, although I cannot give you individual feedback on your questionnaire because there is no identifying information since we are hiding your identity. There is neither cost nor payment involved in taking part in the project.

Completion and return of the questionnaire will be taken as consent for me to use your responses in the context of my study. Questionnaires will be stored electronically on a password-protected computer which only the research team will have access to. If you have any further questions or would like feedback on the results of this study, please feel free to contact me. My details appear on the next page. Thank you for considering taking part in my research project. Please detach and keep this sheet.

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg ("Committee"). A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research. If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Dr Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

Thank you for reading this Study Information Sheet.

Kind regards,

Ms. S. Harris
Cell: 082 505 1110
E-mail: 1313046@students.wits.ac.za

Dr. Aline Ferreira Correia
Cell: 072 200 9292
E-mail: aline.ferreiracorreia@wits.ac.za

January 2022

Appendix L – WHOQOL-BREF Scoring Rules

DOMAIN SCORES

Domains	WHOQOL-100 Facets	Raw domain score	Raw score range
Domain 1: Physical	Facet 1 + Facet 2 + Facet 3	12 - 60	48
Domain 2: Psychological	Facet 4 + Facet 5 + Facet 6 + Facet 7 + Facet 8	20 – 100	80
Domain 3: Level of Independence	Facet 9 + Facet 10 + Facet 11 + Facet 12	16 – 80	64
Domain 4: Social relationships	Facet 13 + Facet 14 + Facet 15	12 – 60	48
Domain 5: Environment	Facet 16 + Facet 17 + Facet 18 + Facet 19 + Facet 20 + Facet 21+ Facet 22 + Facet 23	32 – 160	128
Domain 6: Spirituality / Religion / Personal beliefs	Facet 24	4 – 20	16

TRANSFORMATION OF SCALE SCORES

The next step involves transforming each raw scale score to a 0-100 scale using the formula shown below:

$$\text{Transformed Scale} = \left[\frac{(\text{Actual raw score} - \text{lowest possible raw score})}{\text{Possible raw score range}}\right] \times 100$$

where "Actual raw score" is the values achieved through summation, "lowest possible raw score" is the lowest possible value that could occur through summation (this value would be 4 for all facets), and "Possible raw score range" is the difference between the maximum possible raw score and the lowest possible raw score (this value would be 16 for all facets: 20 minus 4).

This transformation converts the lowest and highest possible scores to zero and 100, respectively. Scores between these values represent the percentage of the total possible score achieved. The WHOQOL-100 scores from other Centers may not be transformed to the 0-100 scale. The U.S.WHOQOL instruments and scoring programs have used this transformation to provide comparative data for interpretation.

Example: A Facet 1 "Pain and discomfort" raw score of 15 would be transformed as follows:

$$\text{Transformed Scale} = \left[\frac{(15 - 4)}{16}\right] \times 100 = 68.75$$

WHOQOL-BREF Scoring

The WHOQOL-Bref, still in field trials, is a subset of 26 items taken from the WHOQOL-100. The same steps for the scoring WHOQOL-100 should be followed to achieve scores for the Bref. Although scoring the Bref is identical to scoring the WHOQOL-100, there are some differences that need to be addressed:

- The WHOQOL-Bref does not have facet scores
- Mean substitutions are recommended for Domain 1 *Physical Health* and Domain 4 *Environment* if no more than one item is coded missing
- Only three items need to be reversed before scoring

The WHOQOL-Bref (Field Trial Version) produces a profile with four domain scores and two individually scored items about an individual's overall perception of quality of life and health. The four domain scores are scaled in a positive direction with higher scores indicating a higher quality of life. Three items of the Bref must be reversed before scoring. They can be seen in Table 9, indicated by the "- (reverse)" denotation in the *Direction of scaling* column.

TABLE 9. Scoring Domains of the WHOQOL-BREF

Domains and questions 236/BREF		Direction of scaling	Raw domain score	Raw item score
Overall Quality of Life and General Health			....(2-10)	
G1.1/B1	How would you rate your quality of life?	+		....(1-5)
G2.3/B2	How satisfied are you with your health?	+		....(1-5)
Domain 1	**Physical Health**		....(7-35)	
F1.2.5/B3	To what extent do you feel that physical pain prevents you from doing what you need to do?	-(reverse)		....(1-5)
F13.1.4/B4	How much do you need any medical treatment to function in your daily life?	-(reverse)		....(1-5)
F2.1.1/B10	Do you have enough energy for everyday life?	+		....(1-5)
F11.1.1/B15	How well are you able to get around?	+		....(1-5)
F4.1.1/B16	How satisfied are you with your sleep	+		....(1-5)
F12.2.3/B17	How satisfied are you with your ability to perform your daily living activities?	+		....(1-5)
F16.2.1/B18	How satisfied are you with your capacity for work?	+		....(1-5)
Domain 2	**Psychological**		....(6-30)	
F6.1.2/B5	How much do you enjoy life?	+		....(1-5)
F29.1.3/B6	To what extent do you feel your life to be meaningful?	+		....(1-5)
F7.1.6/B7	How well are you able to concentrate?	+		....(1-5)
F9.1.2/B11	Are you able to accept your bodily appearance?	+		....(1-5)
F8.2.1/B19	How satisfied are you with yourself?	+		....(1-5)
F10.1.2/B26	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	- (reverse)		....(1-5)
Domain 3	**Social relationships**		....(3-15)	
F17.1.3/B20	How satisfied are you with your personal relationships?	+		....(1-5)
F3.2.1/B21	How satisfied are you with your sex life?	+		....(1-5)
F18.2.5/B22	How satisfied are with the support you get from your friends?	+		....(1-5)

Domains and questions 236/BREF		Direction of scaling	Raw domain score	Raw item score
Domain 4	Environment		....(8-40)	
F20.1.2/B8	How safe do you feel in your daily life?	+		....(1-5)
F27.1.2/B9	How healthy is your physical environment?	+		....(1-5)
F23.1.1/B12	Have you enough money to meet your needs?	+		....(1-5)
F25.1.1/B13	How available to you is the information that you need in your daily-to-day life?	+		....(1-5)
F26.1.2/B14	To what extent do you have the opportunity for leisure activities?	+		....(1-5)
F21.2.2/B23	How satisfied are you with the condition of your living place?	+		....(1-5)
F24.2.1/B24	How satisfied are you with your access to health services?	+		....(1-5)
F28.2.2/B25	How satisfied are you with your transport?	+		....(1-5)

If no more than one item from the *Physical Health* or *Environment* domains has been coded as missing, we recommend that a domain score be calculated by substituting a person-specific average across the completed items in the same scale. For example, if a respondent does not have a value for item B16 *How satisfied are you with your sleep?* in the Physical Health domain, but has answered all of the other items in that domain, then the value for item B16 would be the average of the remaining 6 items. If two or more items are coded missing in these two domains, the domain score should not be calculated, likewise if any items are coded missing in the *Psychological* and *Social Relationships* domains, a domain score for that respondent would not be calculated.

After item recoding and handling of missing data, a raw score is computed by a simple algebraic sum of each item in each of the four domains. Once complete, check the frequencies of each domain to be sure that the scores are within the correct range indicated in Table 9 *Raw domain score* column. The next step is to transform each raw scale score using the formula on page 32. The possible raw score ranges for each domain are as follows: *Physical Health*=28, *Psychological*=24, *Social Relationships*=12, and *Environment*=32.

Scoring Exercise and Test Dataset for the WHOQOL-BREF Instrument

The purpose of this scoring exercise is to help WHOQOL-Bref users to evaluate results from each step in the process of calculating the Domain summary scores of the instrument. This exercise was created for SPSS users, but with minor modifications, can be adapted for other computer programs or can be useful for those scoring the survey manually.

A test dataset and SPSS code for scoring the WHOQOL-Bref a computer disk in this packet. The test dataset, which is called "**WQ_BREF.TXT**" on the disk, contains data from 64 administrations of the WHOQOL-BREF. The data can be seen in *Appendix F*. The enclosed diskette also provides the user with the SPSS syntax used to:

- import raw data into SPSS format [**WQ_B_DL.SPS**]
- derive the WHOQOL-BREF domain summaries [**WQ_BREF.SPS**]

The SPSS code (called "**WQ_BREF.SPS**") on the disk begins by labeling all items and checking for out-or-range values. It then recodes the 3 negatively stated items so that a higher score indicates better health. The 4 domains are then scored, labeled, and transformed to a 0 to 100 scale used to interpret and compare to other validated instrument tools such as the WHOQOL-100. A copy of the SPSS syntax is reproduced in Appendix F.

Table 10 presents statistics for the transformed domains for the WHOQOL-Bref. After scoring the test dataset, the means, standard deviations, and minimum and maximum observed values should agree with those presented in Table 10

TABLE 10. Test Dataset Descriptive Statistics: WHOQOL-BREF

Descriptive Statistics

	N	Minimum	Maximum	Mean	Std. Deviation
Physical (TRANSFORMED)	64	32.14	92.86	66.7969	14.5480
Psychological (TRANSFORMED)	64	37.50	95.83	73.5026	13.7165
Social Relations (TRANSFORMED)	64	25.00	100.00	73.1771	17.0891
Environment (TRANSFORMED)	64	28.13	100.00	72.8027	14.1592
Valid N (listwise)	64				

Appendix M – Demographic Characteristics of Sample

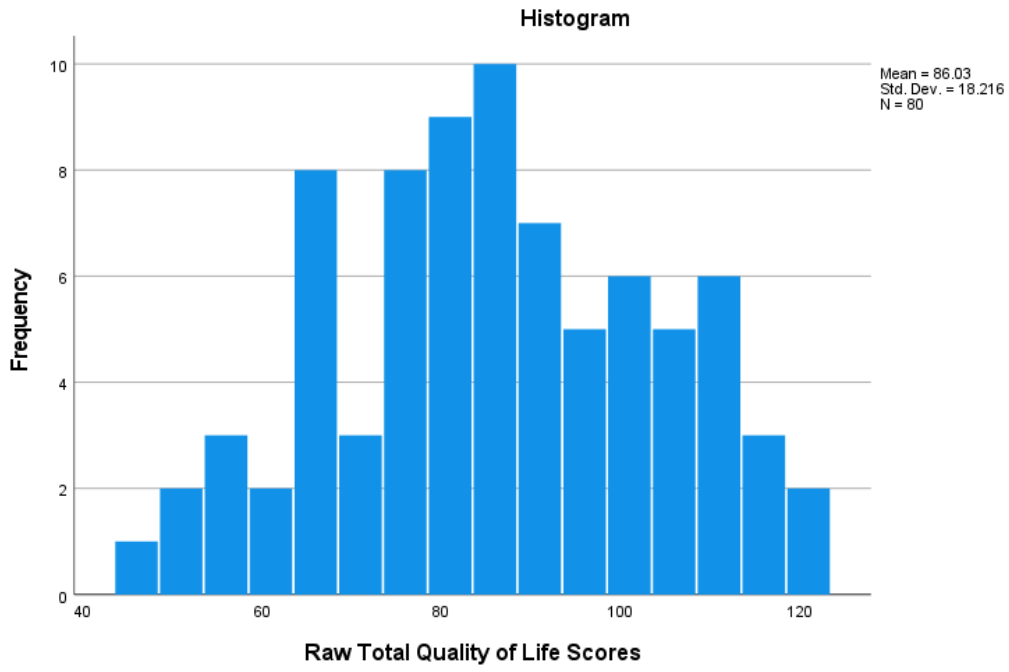
Variables	Private group		Public group		Overall sample	
	n[1]	%	*n*[2]	%	*N*	%
Gender						
Female	16	42.1	14	33.3	30	37,5
Male	22	57.9	28	66.7	50	62,5
Race						
Black	4	10.5	39	92.9	43	53,8
White	24	63.2	2	4.8	26	35,5
Coloured	1	2.6	0	0	1	1,3
Indian	9	23.7	1	2.4	10	12,5
Other	0	0	0	0	0	0
Home language						
English	27	71.1	2	4.8	29	36,25
Afrikaans	8	21.1	1	2.4	9	11,3
Zulu	2	5.3	10	23.8	12	15
Xhosa	0	0	3	7.1	3	3,8
Sotho	0	0	12	28.6	12	15
Other	1	2.6	13	31	14	17,5
Marital status						
Single	3	7.9	11	26.2	14	17,5
Married/ Living as married	28	73.7	19	45.3	47	58,8
Divorced/ Widowed	7	18.5	12	28.6	19	23,8
Employment						
Employed	10	26.3	5	11.9	15	18,8
Unemployed	28	73.7	37	88.1	65	81,3
Education level						
Primary school	0	0	11	26.2	11	13,8
High school (without Matric)	1	2.6	23	54.8	24	30
Matric	8	21.1	6	14.3	14	17,5
Undergrad qualification	12	31.6	2	4.8	14	17,5
Postgrad qualification	17	44.7	0	0	17	21,3
Household income (per month)						
Below R3,500pm	0	0	34	81	34	42,5
R3,500-R10,000 pm	2	5.3	5	11.9	7	8,8
R10,000- R20,000pm	1	2.6	3	7.1	4	5
R20,000-R50,000pm	19	50	0	0	19	23,8
Over R50,000pm	16	42.1	0	0	16	20
Internet access						
Access	34	89.5	12	28.6	46	57,5
No access	4	10.5	30	71.4	34	42,5
Health insurance						
Medical aid	35	92.1	1	2.4	36	45

No medical aid	3	7.9	41	97.6	44	55
Diagnosed with PD						
Over 20 years ago	3	7.9	1	2.4	4	5
Between 15-20 years	0	0	4	9.5	4	5
Between 10-15 years ago	4	10.5	4	9.5	8	10
In the last 10 years	29	76.3	24	57.1	53	66,3
Recently, in the last few months	2	5.3	9	19	11	13,8
Other	0	0	1	2.4	1	1,3
Treatment for PD symptoms						
Medication	38	100	41	97.6	79	98,8
DBS surgery	12	31.6	0	0	12	15
Occupational therapy	4	10.5	0	0	4	5
Physiotherapy	20	52.6	3	7.1	23	28,8
Speech therapy	3	7.9	2	4.8	5	6,3
Light therapy	0	0	0	0	0	0
Psychiatry/Psychology	6	15.8	0	0	6	7,5
Diet/Nutrition	1	2.6	0	0	1	1,3
CBD therapy	2	5.3	0	0	2	2,5
Traditional healing	0	0	0	0	0	0
Other	7	18.4	0	0	7	8,8

Note: N = 80 (n^1 = 38; n^2 = 42). Participants were on average 65.1 years old (SD = 10.9).

Appendix N – Normality checks for raw QoL scores

Histogram



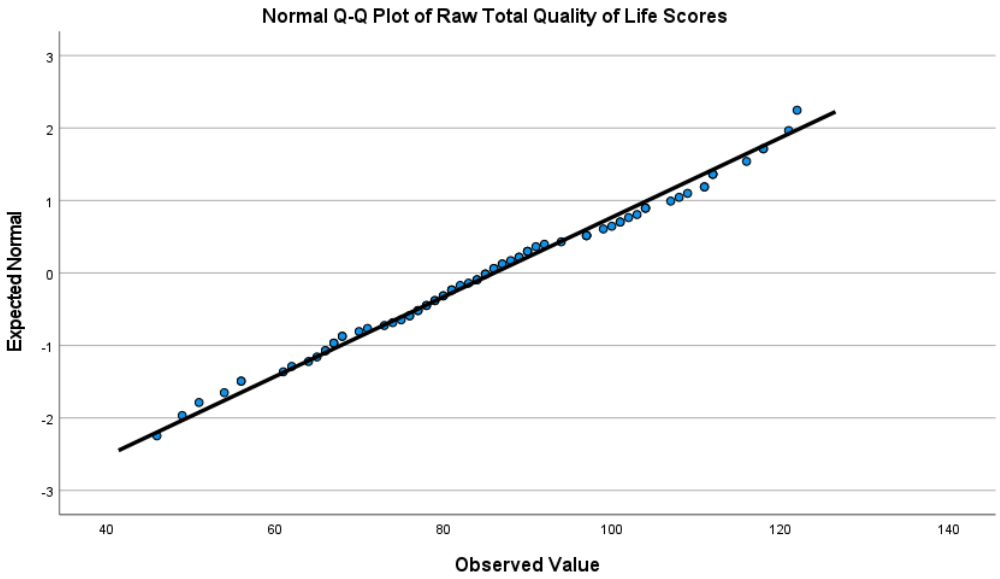
(i) Stem-and-Leaf Plot

Raw Total Quality of Life Scores Stem-and-Leaf Plot

Frequency	Stem &	Leaf
2,00	4 .	69
4,00	5 .	1466
10,00	6 .	1245667788
13,00	7 .	0134566778899
19,00	8 .	0011123445556677899
11,00	9 .	00012477779
11,00	10 .	01123444789
8,00	11 .	11222688
2,00	12 .	12

Stem width: 10
Each leaf: 1 case(s)

(ii) Normal Q-Q Plot



Appendix O – T-Test statistics for raw QoL scores

(i) Group Statistics

Group Statistics

	Private_Public	N	Mean	Std. Deviation	Std. Error Mean
Raw Total Quality of Life Scores	Private	38	99.61	13.542	2.197
	Public	42	73.74	12.178	1.879

(ii) Independent samples T-Test

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means							
						Significance				95% Confidence Interval of the Difference	
		F	Sig.	t	df	One-Sided p	Two-Sided p	Mean Difference	Std. Error Difference	Lower	Upper
Raw Total Quality of Life Scores	Equal variances assumed	.176	.676	8.996	78	<,001	<,001	25.867	2.875	20.143	31.592
	Equal variances not assumed			8.948	74.809	<,001	<,001	25.867	2.891	20.108	31.626

(iii) Effect sizes

Independent Samples Effect Sizes

		Standardizer[a]	Point Estimate	95% Confidence Interval	
				Lower	Upper
Raw Total Quality of Life Scores	Cohen's d	12.843	2.014	1.469	2.550
	Hedges' correction	12.968	1.995	1.455	2.526
	Glass's delta	12.178	2.124	1.483	2.752

a. The denominator used in estimating the effect sizes.
Cohen's d uses the pooled standard deviation.
Hedges' correction uses the pooled standard deviation, plus a correction factor.
Glass's delta uses the sample standard deviation of the control group.

Appendix P – T-Test statistics for Physical Health Domain of QoL

(i) Group Statistics

Group Statistics

	Private_Public	N	Mean	Std. Deviation	Std. Error Mean
Domain1 - physical	Private	38	66.89	12.552	2.036
	Public	42	56.71	13.806	2.130

(ii) Independent samples T-Test

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means							
						Significance				95% Confidence Interval of the Difference	
		F	Sig.	t	df	One-Sided p	Two-Sided p	Mean Difference	Std. Error Difference	Lower	Upper
Domain1 - physical	Equal variances assumed	.268	.606	3.438	78	<,001	<,001	10.180	2.961	4.285	16.076
	Equal variances not assumed			3.455	77.997	<,001	<,001	10.180	2.947	4.314	16.047

(iii) Effect sizes

Independent Samples Effect Sizes

		Standardizer[a]	Point Estimate	95% Confidence Interval	
				Lower	Upper
Domain1 - physical	Cohen's d	13.226	.770	.312	1.223
	Hedges' correction	13.355	.762	.309	1.211
	Glass's delta	13.806	.737	.267	1.200

a. The denominator used in estimating the effect sizes.
Cohen's d uses the pooled standard deviation.
Hedges' correction uses the pooled standard deviation, plus a correction factor.
Glass's delta uses the sample standard deviation of the control group.

Appendix Q – T-Test statistics for Psychological domain of QoL

(i) Group Statistics

Group Statistics

	Private_Public	N	Mean	Std. Deviation	Std. Error Mean
Domain2 - psychological	Private	38	59.08	14.839	2.407
	Public	42	44.60	13.429	2.072

(ii) Independent samples T-Test

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means							
						Significance				95% Confidence Interval of the Difference	
		F	Sig.	t	df	One-Sided p	Two-Sided p	Mean Difference	Std. Error Difference	Lower	Upper
Domain2 - psychological	Equal variances assumed	1.028	.314	4.583	78	<,001	<,001	14.484	3.160	8.192	20.775
	Equal variances not assumed			4.560	74.992	<,001	<,001	14.484	3.176	8.156	20.811

(iii) Effect sizes

Independent Samples Effect Sizes

		Standardizer[a]	Point Estimate	95% Confidence Interval	
				Lower	Upper
Domain2 - psychological	Cohen's d	14.115	1.026	.556	1.491
	Hedges' correction	14.253	1.016	.550	1.476
	Glass's delta	13.429	1.079	.577	1.570

a. The denominator used in estimating the effect sizes.
Cohen's d uses the pooled standard deviation.
Hedges' correction uses the pooled standard deviation, plus a correction factor.
Glass's delta uses the sample standard deviation of the control group.

Appendix R – T-Test statistics for Social Relationship domain of QoL

(i) Group Statistics

Group Statistics

	Private_Public	N	Mean	Std. Deviation	Std. Error Mean
Domain3 - social relationships	Private	37	79.24	15.907	2.615
	Public	42	61.38	14.637	2.259

(ii) Independent samples T-Test

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means							
						Significance				95% Confidence Interval of the Difference	
		F	Sig.	t	df	One-Sided p	Two-Sided p	Mean Difference	Std. Error Difference	Lower	Upper
Domain3 - social relationships	Equal variances assumed	.055	.815	5.197	77	<,001	<,001	17.862	3.437	11.018	24.706
	Equal variances not assumed			5.169	73.721	<,001	<,001	17.862	3.455	10.977	24.748

(iii) Effect sizes

Independent Samples Effect Sizes

		Standardizer[a]	Point Estimate	95% Confidence Interval	
				Lower	Upper
Domain3 - social relationships	Cohen's d	15.244	1.172	.690	1.647
	Hedges' correction	15.394	1.160	.683	1.631
	Glass's delta	14.637	1.220	.700	1.729

a. The denominator used in estimating the effect sizes.
Cohen's d uses the pooled standard deviation.
Hedges' correction uses the pooled standard deviation, plus a correction factor.
Glass's delta uses the sample standard deviation of the control group.

Appendix S – T-Test statistics for Environmental domain of QoL

(i) Group Statistics

Group Statistics

	Private_Public	N	Mean	Std. Deviation	Std. Error Mean
Domain4 - environment	Private	38	91.92	9.113	1.478
	Public	42	50.83	14.680	2.265

(ii) Independent samples T-Test

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means							
						Significance				95% Confidence Interval of the Difference	
		F	Sig.	t	df	One-Sided p	Two-Sided p	Mean Difference	Std. Error Difference	Lower	Upper
Domain4 - environment	Equal variances assumed	7.340	.008	14.853	78	<,001	<,001	41.088	2.766	35.580	46.595
	Equal variances not assumed			15.190	69.410	<,001	<,001	41.088	2.705	35.692	46.483

(iii) Effect sizes

Independent Samples Effect Sizes

		Standardizer[a]	Point Estimate	95% Confidence Interval	
				Lower	Upper
Domain4 - environment	Cohen's d	12.356	3.325	2.640	4.002
	Hedges' correction	12.477	3.293	2.614	3.963
	Glass's delta	14.680	2.799	2.046	3.539

a. The denominator used in estimating the effect sizes.
Cohen's d uses the pooled standard deviation.
Hedges' correction uses the pooled standard deviation, plus a correction factor.
Glass's delta uses the sample standard deviation of the control group.

Appendix T – Spearman's rho correlation between QoL and treatment received

(i)

Correlations

			Raw Total Quality of Life Scores	Rx_recoded
Spearman's rho	Raw Total Quality of Life Scores	Correlation Coefficient	1.000	.418**
		Sig. (2-tailed)	.	<,001
		N	80	80
	Rx_recoded	Correlation Coefficient	.418**	1.000
		Sig. (2-tailed)	<,001	.
		N	80	80

**. Correlation is significant at the 0.01 level (2-tailed).

(ii)

Confidence Intervals of Spearman's rho

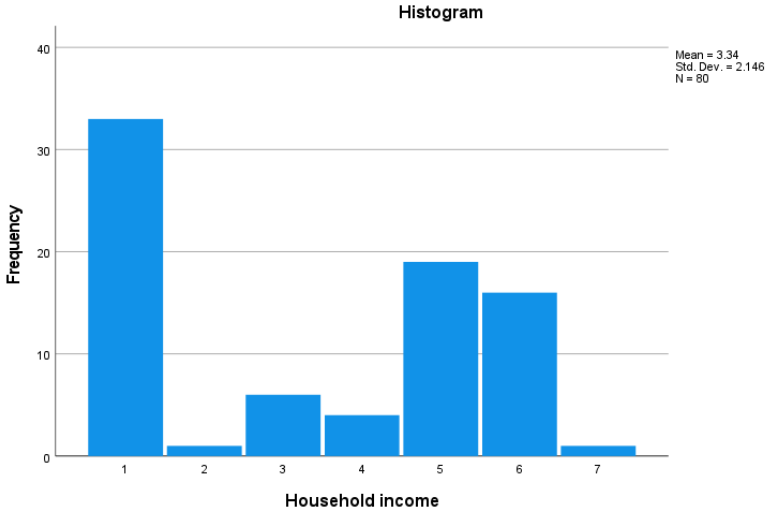
	Spearman's rho	Significance(2-tailed)	95% Confidence Intervals (2-tailed)[a,b]	
			Lower	Upper
Raw Total Quality of Life Scores - Rx_recoded	.418	<,001	.213	.589

a. Estimation is based on Fisher's r-to-z transformation.

b. Estimation of standard error is based on the formula proposed by Fieller, Hartley, and Pearson.

Appendix U - Normality checks for Household Income (Independent variable)

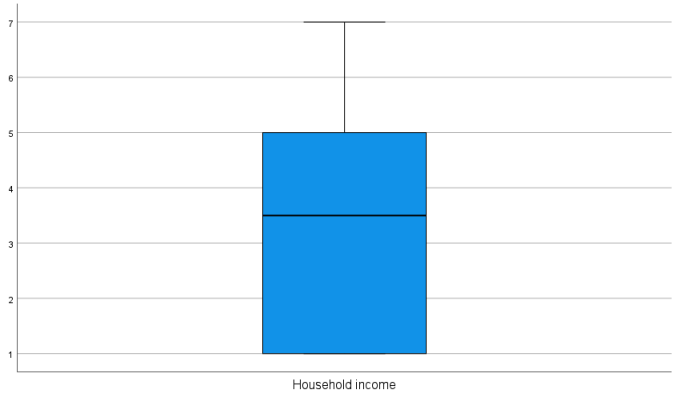
(i) Histogram



(ii) Stem-and-Leaf plot

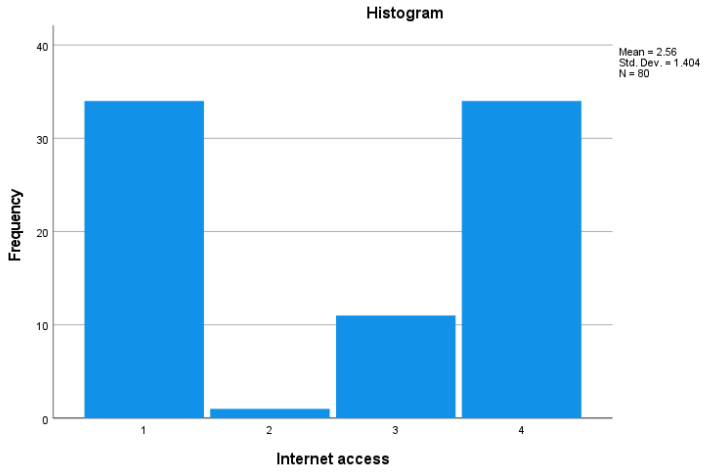
```
 Frequency     Stem &  Leaf

    33,00        1 .  000000000000000000000000000000000
     1,00        2 .  0
     6,00        3 .  000000
     4,00        4 .  0000
    19,00        5 .  0000000000000000000
    16,00        6 .  0000000000000000
     1,00        7 .  0

Each leaf:        1 case(s)
```

(iii) Boxplot



Appendix V – Normality checks for Internet Access (Independent variable)

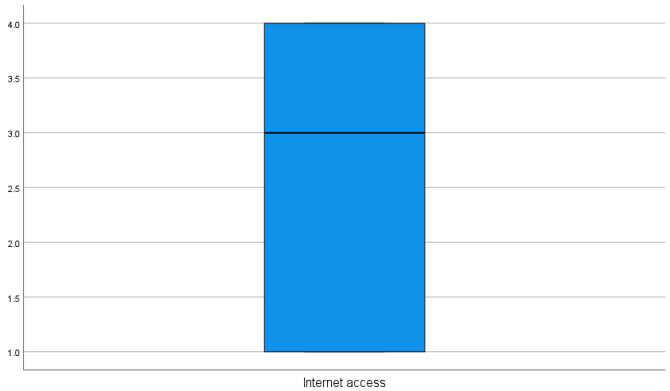
(i) Histogram



(ii) Stem-and-Leaf plot

```
 Frequency     Stem &  Leaf

    34,00        1 .  0000000000000000000000000000000000
      ,00        1 .
     1,00        2 .  0
      ,00        2 .
    11,00        3 .  00000000000
      ,00        3 .
    34,00        4 .  0000000000000000000000000000000000

Each leaf:        1 case(s)
```

(iii) Boxplot



Appendix W – Neurologist Consent Form

Psychology

School of Human & Community Development

University of the Witwatersrand

Private Bag 3, Wits, 2050

Tel: 011 717 4503 Fax: 086 553 4913

I, _____ (name and surname) working at _____ (name of hospital), agree to assist Ms. Harris by informing the patients of her study and facilitating the handing out and collection of questionnaires. Information about the study and contact details of the researcher and supervisor has been provided to me in writing. I understand that patients' participation in this study is voluntary and that all details will be kept confidential at all times. My name and institutions you are affiliated with will be kept confidential further preserving the anonymity of responses. I may request a copy of the final research report by contacting the researcher.

Name and Surname: _____

Signed: _____

At: _____

Date: _____

Appendix X – TREE Ethics Course Certificate Module 1

TREE

Zertifikat Certificado
Certificat Certificate

Promouvoir les plus hauts standards éthiques dans la protection des participants à la recherche biomédicale
Promoting the highest ethical standards in the protection of biomedical research participants

Clinical Trials Centre
The University of Hong Kong

Certificat de formation - Training Certificate

Ce document atteste que - this document certifies that

Simone Harris

a complété avec succès - has successfully completed

Introduction to Research Ethics

du programme de formation TRREE en évaluation éthique de la recherche
of the TRREE training programme in research ethics evaluation

Release Date: 2021/05/13
CID : 2ddbb8d.rg

Professeur Dominique Sprumont
Coordinateur TRREE Coordinator

FMH Continuing Education Program (5 Credits)
Programme de formation continue (5 Crédits)

fédération Pharmaceutica Helvetiae

FPH Programmes de formation continue

Continuing Education Programme
Programme de formation continue

Ce programme est soutenu par - This program is supported by :

European and Developing Countries Clinical Trials Partnership (EDCTP) (www.edctp.org) - Swiss National Science Foundation (www.snf.ch) - Canadian Institutes of Health Research (http://www.cihr-irsc.gc.ca/e/29801.html) - Swiss Academy of Medical Science (SAMS/ASSMS/SAMW) (www.samw.ch) - Commission for Research Partnerships with Developing Countries (www.kfpe.ch)

[REV : 20170310]

Appendix Y – TREE Ethics Course Certificate Module 2

Zertifikat Certificado
Certificat Certificate

TREE

Promouvoir les plus hauts standards éthiques dans la protection des participants à la recherche biomédicale
Promoting the highest ethical standards in the protection of biomedical research participants

Certificat de formation - Training Certificate

Ce document atteste que - this document certifies that

Simone Harris

a complété avec succès - has successfully completed

Research Ethics Evaluation

du programme de formation TREE en évaluation éthique de la recherche
of the TREE training programme in research ethics evaluation

Release Date: 2022/04/05

CID : MEXGDEEMJC

Professeur Dominique Sprumont
Coordinateur TREE Coordinator

Clinical Trials Centre
The University of Hong Kong

APPROVED BY
SIWF ISFM FMH
Programmes de formation continue (2 crédits)
Continuing Education Programs (2 credits)

Foederatio Pharmaceutica Helvetiae
FPH
Programmes de formation postgraduée et continue
Programmes de formation continue
Continuing Education Programms

Ce programme est soutenu par - This program is supported by :

European and Developing Countries Clinical Trials Partnership (EDCTP) (www.edctp.org) - Swiss National Science Foundation (www.snf.ch) - Canadian Institutes of Health Research (http://www.cihr-irsc.gc.ca/e/2891.html) - Swiss Academy of Medical Science (SAMS/ASSMS/SAMW) (www.samw.ch) - Commission for Research Partnerships with Developing Countries (www.kfpe.ch)

[REV : 20220217]

Appendix Z – TREE Ethics Course Certificate Module 3

Zertifikat Certificado
Certificat Certificate

TREE

Promouvoir les plus hauts standards éthiques dans la protection des participants à la recherche biomédicale
Promoting the highest ethical standards in the protection of biomedical research participants

Certificat de formation - Training Certificate

Ce document atteste que - this document certifies that

Simone Harris

a complété avec succès - has successfully completed

Informed Consent

du programme de formation TREE en évaluation éthique de la recherche
of the TREE training programme in research ethics evaluation

Clinical Trials Centre
The University of Hong Kong

Release Date: 2022/04/05
CID: L34030VaPd

Professeur Dominique Sprumont
Coordinateur TREE Coordinator

APPROVED BY
SIWF ISFM EMH
Programmes de formation continue (2 crédits)
Continuing Education Programs (2 credits)

FPH
Programmes de formation continue
Continuing Education Programs
Foederatio Pharmaceutica Helvetiae
Programmes de formation postgraduée et continue

Ce programme est soutenu par - This program is supported by :
European and Developing Countries Clinical Trials Partnership (EDCTP) (www.edctp.org) - Swiss National Science Foundation (www.snf.ch) - Canadian Institutes of Health Research (http://www.cihr-irsc.gc.ca/e/2891.html) - Swiss Academy of Medical Science (SAMS/ASSM/SAMW) (www.samw.ch) - Commission for Research Partnerships with Developing Countries (www.kfpe.ch)

[REV : 20220217]

Appendix 1 – Ethics Application Form

University of the Witwatersrand, Johannesburg

Ethics Application Form* for *Human Research Ethics Committee (HREC Non-Medical)

(SCHOOL ETHICS COMMITTEES: Revised January 2020)

Instructions

1. This form must be completed by Honours (4th year) and Masters by Coursework and Research Report students who require ethics clearance, or for ethics clearance for coursework activities as part of a taught degree. Note that staff non-degree applications, PhD and research Masters students must complete the online form.
2. Completed applications must be submitted to the relevant School Ethics Committee.
3. Applications may be submitted as hard or soft (electronic) copies, but the first page of the application must contain the signatures of the student and supervisor. Final revised versions must be in soft (electronic) copy as all documentation will be archived.
4. Incomplete or handwritten applications will **NOT** be considered, including where signatures are missing.
5. Necessary supporting documents (e.g. *Participant Information Sheet, Consent Form*, copies of instruments, permission letters), must be provided.

SECTION A

Complete this checklist to show what documents you have submitted and that you agree with the conditions of application.

x	Completed ***Ethics Application Form***.
x	Copy of the ***Research proposal***.
x	Copy of proposed ***Research instruments*** (e.g. questionnaires/interview schedules).
x	***Participant Information Sheets*** (for each different sample group and/or instrument used).
x	***Consent forms*** (for each different sample group and/or instrument used).
	Relevant permission letters if required (from, e.g. company's HR department, National authorities such as Government departments, etc.) - consult the ***Guidance on the Use of Permission Letters*** document.

SIGNATURES (REQUIRED)

Declaration: We, the signatories, declare that all information on this form is correct and that we will strive to maintain the highest ethical standards in this research at all times, according to disciplinary and university expectations, recognising that ethical practice in research is always a continuing process.

I recognise that it is my responsibility to conduct my research in an ethical manner according to Guidelines of the University of the Witwatersrand, according to any laws and/or legal frameworks that may apply, and according to the norms and expectations of my discipline. In preparing this Application for Ethics Clearance form, I have consulted the ***Guidelines for Human Research Ethics Clearance Application/Non-Medical*** (available on this website https://www.wits.ac.za/research/researcher-support/research-ethics/ethics-committees/). In receiving ethics clearance, I agree to abide by the conditions of data collection as outlined in the *Guidelines* document.	x Yes	No

By signing this form, the researcher and supervisor of this project undertake to ensure that any amendments to this project that are required by the Human Research Ethics Committee (Non-Medical) and School Ethics Committees are made before the project commences.

	Date	Name	Signature*	
Applicant	3 November 2021	Simone Harris		
Supervisor		Dr Aline Ferreira-Correia		

*electronic signatures are permitted but there are requirements governing this – please see *Guidelines* document.

SECTION B

1. Summary of risk categories of this research project

1.1 Does this project involve human participants? [x] Yes [ ] No

1.2 I have read and understood the risk categories table [x] Yes [ ] No
Applicants must have read the table of risk level category definitions on the final page of this document. This table is also available on the University Ethics Committee webpage.

1.3 The applicant must tick the box for the category that best applies to this project:

Risk category	**Tick the appropriate box**
No risk	
Minimal risk	
Low risk	x
Medium risk	
High risk	

Medium or high risk applications must be submitted the School ethics committee to the University HREC

1.4 Are participants selected as **experts**? [ ] Yes [x] No

1.5 Will human participant research involve **vulnerable categories**? [x] Yes [ ] No

If **YES** state which ones:
Parkinson's Disease may have caused cognitive decline in some patients.

If **YES**, how will **existing vulnerabilities** among research participants be addressed? They will be able to get assistance in answering questions by their caretakers or family members who are generally with them most of the time especially if they are in the advanced stages of Parkinson's Disease. Alternatively they will answer to the best of their ability.

1.6 Does this research expose either the participant(s) or the researcher(s) to any **potential risks or harm** to which they would not otherwise be exposed? [x] Yes [ ] No

If **YES**, how will **potential risks or harm** be addressed?
Participants will receive a referral letter for counseling should the need arise. This letter will be attached to all questionnaires which participants can tear off and take with them.

NB: Vulnerability is context specific. The term 'vulnerable categories' includes, among others, children under 18, orphans, prisoners, persons with cognitive or communication disorders, people who are traumatised or currently in traumatic situations. Vulnerable categories do not necessarily include poor or marginalised communities, older people, women, people with disabilities (unless it results in diminished capacity to give informed consent). Not all research involving 'vulnerable categories' is Medium or High Risk research: here vulnerability must be considered in terms of the nature of the research and the context in which the research is carried out. Where necessary, include details of steps to be taken to facilitate data collection across language barriers (e.g. interpretation or translation).

2. Researcher's personal data	
Your family name: Harris	Your first name: Simone x
Title: ☐ Mr ☒ Ms ☐ Other : _____	
School:	Humanities, Psychology Department
Your student number:	1313046
Your email:	1313046@students.wits.ac.za / sim1magic@gmail.com
Your tel number:	082 505 1110
Name of supervisor(s):	Dr Aline Ferreira Correia
Your supervisor's Wits email:	Aline.FerreiraCorreia@wits.ac.za
Your supervisor's Wits tel number:	072 200 9292

3. Research project

3.1 Title of research project:

Disparities in access to treatment in relation to Quality of Life in people diagnosed with Parkinson's Disease

3.2 Is this research for degree purposes? ☒ Yes ☐ No

If so, for what degree?

☐ Honours ☒ Masters (research report) ☐ Other (specify) _____

3.3 Has it been **approved** by the relevant School or Faculty higher degrees committee or other relevant unit?

☒ Yes ☐ No ☐ Submitted and pending

3.4 Will any **additional researchers** be covered by this ethics protocol (including translators/interpreters, research assistants, etc. but not including supervisors)?

☐ Yes ☒ No

If yes, please specify their names, affiliations and roles:

3.5 What are the **aims and objectives** of the research? (Please be specific)

To establish whether there are socioeconomic variables which affect the relationship between access to treatment and quality of life outcomes for Parkinson's Disease patients.

3.6 Summary or abstract of the research (give a brief outline of the research plan such that reviewers can understand what will be done, 100 words maximum)

There is a scarcity of literature in this area where access to treatment for Parkinson's Disease is concerned in relation to quality of life outcomes, especially in South Africa in particular, so this study will contribute to the literature. I will be administering a questionnaire measuring quality of life outcomes (WHOQOL-BREF) to patients with Parksinson's Disease. There will be an accompanying page asking for socioeconomic data. Upon collection of the data after it has been completed I will run statistical analysis to test the relationship between the variables.

3.7 Do you have any **financial or material interests or a familial relationship** associated with your research participants or with the organisations that you will be involved with in your research?

[ ] Yes [x] No

If yes, please explain how you will **manage any existing or potential conflicts of interest**, if applicable:

4. Formal permission

4.1 Where will the research be carried out? (Please give a specific location and /or the names of specific organisations or institutions)
I will be writing to neurologists in private practice and I will be writing to Baragwanath Hospital with the help of my supervisor, who has already established contact with neurologists who have shown interest in assisting with data collection should we received ethical clearance.

4.2 Has appropriate **formal permission been obtained**, if required (e.g. employer, governmentdepartment, land owner, etc.)?

[ ] Yes (attached) [ ] Not required [x] Pending (must be supplied before ethics clearance car

NB: Obtaining permission is often necessary when conducting research *within the premises* of a particular site such as an ethnographic study of the functioning of a supermarket or a school, or the way staff interact with clients in a clinic or how members of a closed social media group interact/post on a specific topic. Permission is also required to use data from personal communication with participants or experts. Please note that any research done on Wits University campuses with employees or students of the University requires formal permission from the Registrar. Please read the detailed guidelines on Permission Letters from the Ethics website https://www.wits.ac.za/research/researcher-support/research-ethics/ethics-committees/

5. How will data on human research participants be collected (instruments, methods, procedures)? (tick all applicable boxes) (**NB:** All applicable instruments must be attached to the application)

x	Hard copy questionnaires or diagnostic tests, etc.
	Online instruments (e.g. questionnaires, surveys)
	Individual interviews (e.g. structured, semi-structured, etc.)
	Personal communication (e.g. email or informal conversation with experts)
	Group interviews (e.g. seminar/discussion groups, focus groups, etc.)
	Ethnographic observation, participant observation, other informal descriptive, and/or interactive methods (you must specify ethnographic methods in the box below)
	Autoethnography
	Community-based methods or techniques such as drama workshops, community theatre, training workshops, participant rural appraisal, rapid rural appraisal, etc. (you must specify in the box below)
	Research on/in therapeutic or counselling contexts
	Putting on your own exhibition / public performance
	Observation of other public performances, and/or public behaviour observation
	Photography
	Video recording
	Audio recording (e.g. of interviews)
	Use of data from social media
	Other research methods or techniques (you must specify in the box below)

Explanation of **research methods** specified above, and / or explanation of any other **research methods that are not listed** above:
I will be administering the questionnaire either myself, or they will be handed out in my absence at neurologists' consulting rooms. I will also offer patients the opportunity to do the questionnaire telephonically.

6. Who will the research participants be?

6.1 List the **different** participant groups (e.g. experts, community members, key informants) that you will be working with in your project:
Patients who have been diagnosed with Parkinson's Disease and are under neurological care.

6.2 Description of these participant groups, including **age range** and **sample size**, for **each group**:
I'm looking at recruiting patients over age 50, both men and women and hoping to get at least 30 completed questionnaires from the private sector, and 30 completed questionnaires from Baragwanath Hospital.

7. How will informed consent be obtained?

7.1 How will **potential participants** be **identified / selected / recruited**?
Through the help of the neurologists patients will be informed of the study. Patients are given an information sheet to take with them. Participation/ filling in the questionnaire constitutes as consent. All of their ethical rights will be explained to them at the start by myself as the primary investigator.

7.2 Will any **incentives** be offered to participants? [ ] Yes [x] No
(**NB**: it is NOT compulsory to offer any incentives. Please note for any curricula incentives, permission is required from the Registrar's

office and DVC. Fiscal incentives are limited to R150 – see *Guidelines* document) If **YES**, please explain:
7.3 How will informed consent be obtained? [ ] Formal (Signed form) [x] Informal (e.g. verbal) [ ] Other (e.g. online survey)
If you cannot obtain **formal written consent**, explain why: Patients will first be approached by their neurologist who will explain the study. If they agree I will follow up afterwards either with a phone call or be there physically onsite. I will explain the study to them again, inform them of their rights, and should they wish to participate their filled-in questionnaire is taken as informed consent.
NB: Attach *Participant Information Sheets* and *Consent Forms* for each sample group (please label these carefully), and/or other related materials. It is essential that participants in research be fully informed (irrespective of the method used) and then be able to agree on this basis to participate in the research.

8. Protecting participant identities		
8.1 Can **confidentiality** of participants' responses be guaranteed throughout the **data collection** process?	[x] Yes	[ ] No
8.2 Can **anonymity** be guaranteed throughout the **data collection** process?	[ ] Yes	[x] No
8.3 Can **anonymity** be guaranteed in **resulting research reports** or publications?	[x] Yes	[ ] No
8.4 Explain how you will manage issues of **anonymity and confidentiality** in your project (What will participants be told in this regard?): No identifying information is asked on the questionnaire and they are allowed to withdraw from the study at any time. Once the data has been collected it will be put into a spreadsheet where every questionnaire is given an identifying number. This number will not be able to identify the participant who filled in the questionnaire. It is only for statistical purposes when conducting analysis. Participants' consent forms will be kept separate from the raw data and stored in a locked cabinet in the supervisor's office at the University of the Witwatersrand.		
Definitions: ***Confidentiality***: that any information considered confidential by the participant or researcher will not be disclosed to others. ***Anonymity throughout the data collection process:*** that you as the researcher will not be able to identify the participant. ***Anonymity in the resulting reports***: that the participant's name/identifying data will not be disclosed and that anyone reading your results will not be able to identify the participant. **NB**: While confidentiality may be desirable, it cannot be guaranteed in, for example, focus groups, or ethnographic observations. Similarly, anonymity should be preserved in questionnaires, but cannot be offered in workshop methodologies, focus group research, etc. Participants should have the right to remain anonymous in the final report and this must be respected in handling of all data relating to them. Participants need to be informed about these issues through the *Participant Information Sheet*.		

9. Protection of data during and after the research

9.1 How will the data be protected while the research is **in progress**? (This includes how the identities of participants will be protected).
There will be no identifying information on the questionnaire. When the data has been captured into Excel and SPSS, only I will have access to the data, as well as my supervisor if requested. The data will be stored securely in a password-protected computer.

9.2 What is to be done with the research data **after completion** of the project? Please note that usage of data should be consistent with what is indicated to participants in the *Participant Information Sheet* and *Consent Form*.

	Stored in archives (specify below)		Stored in online database (specify below)
x	Stored in password protected computer	x	Stored in digital form with all identifying features removed
x	Stored for future secondary analysis		Destroyed after … years (insert numbers of years, if applicable)

Please specify which **archives or online databases** will be used (if applicable):

NB: 'Raw' or unprocessed data, especially **where the identity or personal data of research participants is included, must be safeguarded** and preserved from unauthorised access. Data may be destroyed after use, but **preservation in an archive or personal collection** may also be appropriate, desirable or even essential. For instance, datasets that contain **historically important information** or information that relates to **national heritage** must be preserved and should be placed in a public archive where possible and appropriate. All data should be preserved in a way that **respects the nature of the original participants' consent**. If you are unsure about the procedure of data management and storage, please contact the Data Services Librarian.

<table>
<tr><td colspan="3">10. Summary CV of applicant
ALL boxes in the following table must be completed by the applicant. Do not attach a formal CV to your application.</td></tr>
<tr><td>10.1 List your academic qualifications. Include dates or current registration status</td><td colspan="2">BA (Journalism) – University of Johannesburg
BA Honours (Psychology) – University of Witwatersrand
MA (Social and Psychological Research) – University of Witwatersrand</td></tr>
<tr><td>10.2 Describe any ethics <u>content</u> training you have previously received in the previous 3 years (e.g. ethics short courses; online courses; ethics CPD courses; ethical input as part of a research methods course)</td><td colspan="2">Complete Ethics online course: Introduction to Research Ethics of the TRREE Training Programme in research ethics evaluation.</td></tr>
<tr><td rowspan="2">10.3 List of instruments or methods used in this project, as listed in Section 5 of the application form (Tick the appropriate boxes and describe these specific instruments if necessary)</td><td>x</td><td>Hard copy questionnaires or diagnostic tests, etc.</td></tr>
<tr><td></td><td>Online instruments (e.g. questionnaires, surveys)</td></tr>
<tr><td></td><td>Individual interviews (e.g. structured, semi-structured, etc.)</td></tr>
<tr><td></td><td>Personal communication (e.g. email or informal conversation with experts)</td></tr>
<tr><td></td><td>Group interviews (e.g. seminar/discussion groups, focus groups, etc.)</td></tr>
<tr><td></td><td>Ethnographic observation, participant observation, other informal descriptive, and/or interactive methods (you <u>must specify</u> ethnographic methods in the box below)</td></tr>
<tr><td></td><td>Autoethnography</td></tr>
<tr><td></td><td>Community-based methods or techniques such as drama workshops, community theatre, training workshops, participant rural appraisal, rapid rural appraisal, etc. (you <u>must specify</u> in the box below)</td></tr>
<tr><td></td><td>Research on/in therapeutic or counselling contexts</td></tr>
<tr><td></td><td>Putting on your own exhibition / public performance</td></tr>
<tr><td></td><td>Observation of other public performances, and/or public behaviour observation</td></tr>
<tr><td></td><td>Photography</td></tr>
<tr><td></td><td>Video</td></tr>
<tr><td></td><td>Audio recording (e.g. of interviews)</td></tr>
<tr><td></td><td>Use of data from social media</td></tr>
<tr><td></td><td>Other research methods or techniques (you <u>must specify</u> in the box below)</td></tr>
<tr><td colspan="2">Explanation of research methods specified above, and / or explanation of any other research methods that are not listed above: I am only going to be administering a questionnaire, keeping all Covid restrictions and regulations in place at all times.</td></tr>
</table>

10.4 Describe your previous **experience** in deploying the instruments or methods of research which you are applying here (refer to Section 5 and table in Section 10.3)	I administered questionnaires in my Honours year. We surveyed teachers in private as well as public schools. We left questionnaires for teachers in the front office. Once they were completed they were placed inside a box left at the front reception and collected after 2 weeks from each respective school. Permission from schools, department of education and teachers were all granted.

HREC (Non-Medical) Risk level categories definitions (January 2020)

This table identifies broad categories of risk. Schools/Departments can provide specific examples of these categories that are specific to that particular discipline, or the types of data collection methods or participant groups that are most common in that discipline. Please note that any study involving minors cannot be considered by Schools irrespective of the risk level.

Risk category	Definition	Example	Notes
No risk	No contact with human participants	Document analysis or literature review Studies based on theoretical or secondary analysis alone Use of non-human, quantitative datasets (e.g. economic data) Use of previously-collected human datasets (where permission from previous participants have been explicitly granted) Use of anonymized and aggregated human datasets (e.g. census data)	These studies do not require ethics clearance A waiver may be given, however, if required by a university faculty or external body These studies may require ethics clearance, dependent on the type of study and faculty requirements A waiver may be given, however, if required by a university faculty or external body Applications deemed No Risk can be considered at School level
Minimal risk	Where the likelihood and magnitude of possible harm are no greater than those imposed by daily life in a stable society, or routine educational or psychological tests	Questions about people's everyday lives, activities and opinions rather than detailed biographical information No sensitive questions or topics Review of privileged information (e.g. documentation not publically available)	Applications deemed Minimal Risk can be considered at School level
Low risk	Where the only foreseeable risks is that of discomfort, or where there may be some sensitivity involved in terms of the questions asked	Questions about people's everyday lives, activities and opinions – may include biographical information and some potentially sensitive questions and/or topics May include some vulnerable contexts	Applications deemed Low Risk can be considered at School level
Medium risk	Where there is a likely risk of some harm for participants and/or the researcher, but where appropriate steps can be taken to mitigate or reduce risk	Sensitive topics and/or questions that may have potential for trauma and emotional distress May include vulnerable categories or marginalized groups, may include some types of low-level illegal activities, such as artisanal mining	Applications deemed Medium Risk cannot be considered at School level and must be referred to the main committee

High risk	Where there is a real and foreseeable risk of harm which may lead to serious adverse consequences if not managed in a responsible manner	Research locality itself may contain potential risks to the participants and/or researcher There is a clear justification to undertake the research using this participant group and/or using the proposed instruments, despite the potential risks Highly sensitive topics, e.g. experiences of violence, rape, illegal activities Vulnerable or marginalized groups, or where multiple vulnerabilities exist Research involving deception of the participants Research involving serious illegal and criminalized activities, such as violence, fraud Where the participants place themselves at risk of harm if they participate Where the researcher may place themselves at risk of harm Where the researcher may place themselves at risk of breaking the law Where the research may reveal information that may place the participant or others at risk (e.g. victims of abuse, violence), requiring intervention from government, university or other institutions There is a clear justification to undertake the research using this participant group and/or using the proposed instruments, despite the potential risks	Support/counselling services must be provided for participants, if appropriate A distress protocol should be given, if appropriate Applications deemed High Risk cannot be considered at School level and must be referred to the main committee Remedial interventions by external professionals can be taken should harm occur Support/counselling services must be provided for participants and/or for the researcher A distress protocol and debriefing strategy should be given, if appropriate

NOTES:

(1) Definitions of terms

Discomfort refers to a sensation of uneasiness, disturbance or mild pain.

Harm refers to damage incurred (which may include physical, psychological/emotional, social, economic or legal harm) as an outcome of an action, or through emotional distress.

Risk refers to (i) the likelihood of exposure to a particular negative consequence, and/or (ii) the magnitude of the possible consequences of exposure, and/or (iii) the possibility that research could result in harm.

(2) Discussion of risk

Individuals that may be at increased risk include:

• Those who are dependent/reliant on the institution/person who provides/mediates access to researchers;

• Those who are involved in illegal activities or who are criminalized by the state, e.g. drug dealers, sex workers, undocumented migrants.

NB: it is essential to consider the individual – not an aggregated group – when assessing risk.

(3) Discussion of vulnerability

Vulnerability can stem from: a lack of capacity or impaired ability to provide voluntary informed consent; health status; social pressures that may impact on the ability to make a free and informed decision; an inability to protect one's interests in research. Vulnerability may be considered as dynamic and specific to a particular context, and may arise as a result of power asymmetries between participants and researchers/institutions. There may be layers of vulnerability that function and interact within a

participant's circumstances. Being vulnerable does not necessarily imply that harm or exploitation will occur, but it does increase the risk of harm or exploitation through research.

In addition to those in vulnerable categories, vulnerability may also include individuals whose ability to provide informed consent may be reduced where:

• Their decision-making capacity is limited due to individual mental health status;

• Their decision-making capacity is limited due to the environment in which they live/work, e.g. prisoners/detainees, residents of drug rehabilitation centres;

• They are under 18 years of age;

• They are dependent on the state to maintain a legal status, e.g. documented asylum seekers, documented refugees.

NB: it is essential to consider the individual – not an aggregated group – when assessing vulnerability.

The researcher needs to minimise the risk of harm, ensure that the consent process supports a truly informed decision, and put in place additional measures to ensure ethical involvement of vulnerable groups. Where necessary, include details of steps to be taken to facilitate data collection across language barriers (e.g. interpretation or translation) and/or in cases of illiteracy.

Useful references:

Bracken-Roche, D., Bell, E., Macdonald, M.E. and Racine, E. (2017). The concept of 'vulnerability' in research ethics: an in-depth analysis of policies and guidelines. *Health Research Policy and Systems*, 15 (1), 8, doi:10.1186/s12961-016-0164-6.

Horn, L., Sleem, H. and Ndebele, P. (2014). Research vulnerability. In: M. Kruger, P. Ndebele and L. Horn (Eds.), *Research ethics in Africa: A resource for research ethics committees*. Stellenbosch: SUN Press, pp. 81-90.

(4) Distress protocol

A 'distress protocol' is a procedure to follow in emergency situations where, for example, a participant becomes clearly distressed during an interview. Under such situations, the interview is terminated and the distress protocol is enacted. Researchers may need to consider:

1. The possible distress experienced by the participant: e.g. questions that address issues of abuse, abandonment, previous negative sexual experiences, or traumatic memories that may induce distress. A distress protocol must include the name and contact details of an appropriate provider who can provide support, at no cost to the participant. This may include counselling services or access to NGOs/law clinics;

2. The possible distress experienced by the researcher: this may include provisions for how the safety of the researcher will be supported, and should be discussed with supervisor and the name and contact details for counselling services provided if needed.