Living with Parkinson's disease in Kenya: sociality, improvisation and hope

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Dedications

This thesis is dedicated to all the people with Parkinson's disease and their families living in Kenya – to those who continue to battle with their condition and to those who are no longer with us.

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Not many people can say they finished their PhD in a global pandemic; I can.

Abstract

This thesis explores the lived experiences of Parkinson's disease (PD) in Kenya, sub-Saharan Africa, using ethnographic research. PD is the second most common neurodegenerative disease globally and results in motor and non-motor complications that progress over time, despite effective symptomatic drug therapy. PD increases in prevalence with age, which raises concerns as the population of Africa undergoes demographic transition. To date, most research on PD has focussed on high-income country contexts, so we know very little about how people with PD (PWPD) and their families manage in more resource-constrained settings where medical facilities and information may also be lacking.

Based on ten months of fieldwork across multiple sites in urban and rural Kenya, including observations and interviews with 55 PWPD, 23 family members, 23 healthcare professionals and three healers, this thesis makes empirical, theoretical and policy-related contributions. Empirically, it became very clear that awareness about PD is low among both the general population and among healthcare professionals; basic medication and services are unavailable and unaffordable for the majority; the number of neurologists is very low; and palliative care is virtually non-existent.

Theoretically, the thesis contributes to debate across three main areas. First, it highlights the importance of sociality and biosociality in navigating care for PWPD and their families, and connections, which sometimes endured beyond death through a form of 'necrosociality'. Second, uncertainty, improvisation and innovation emerged as defining features of PD management, although structural constraints on agency acted as limits on improvisation. The third theme concerns the importance of hope and faith, which could sometimes be at odds with knowing about PD and preparing for death.

This thesis ends with some reflections on policy and practice, including the need for PD awareness efforts, increased speciality neurology training, earlier diagnoses and the registration of effective, affordable medication.

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Abbreviations

APDF	Africa Parkinson's disease Foundation
ART	Antiretroviral therapy
HIC	High-income country
HIV/AIDS	Human immunodeficiency virus/acquired immune deficiency syndrome
KEMRI	Kenya Medical Research Institute
LIC	Low-income country
LMIC	Lower-middle-income country
NCDs	Non-communicable diseases
NGO	Non-governmental organisation
NHIF	National Hospital Insurance Fund
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NMSQ	Non-motor symptoms questionnaire
PD	Parkinson's disease
PSG	Parkinson's support group
PWPD	Person/people with Parkinson's disease
SSA	Sub-Saharan Africa
UK	United Kingdom
USA	United States of America
WHO	World Health Organization

Chapter 1. Introduction

On my first day of fieldwork in Nairobi, I attended a support group meeting for people with Parkinson's disease (the day after World Parkinson's Day). These support groups became one of the main focuses of my research and this initial meeting, which by chance had a visiting nurse from the UK, provided me with an insight into some of the problems faced by people living with Parkinson's disease in Kenya. I sat down on one of the wooden school chairs in the church classroom along with 28 other people: people living with the disease, family members, pharmacists, a neurologist and the visiting nurse. One of the group's founders gave a brief history for the new attendees. The group then discussed what medication was available – which they determined was "not much". Some talked about how they had given up seeing neurologists, while none saw physiotherapists or occupational therapists. There was a discussion of challenges of affording medication and having to 'make do' in the face of worsening symptoms.

1.1 Background

This thesis explores the progressive, debilitating neurological disorder, Parkinson's disease (PD), as experienced by people living with the condition in Kenya, East Africa. PD is the second most common neurodegenerative disease globally and is associated with a host of motor and non-motor complications (Connolly, 2014). Motor symptoms include tremor (involuntary shaking of particular parts of the body), akinesia (loss of spontaneous voluntary movement) or bradykinesia (slowness of movement), muscular rigidity (stiffness) and postural instability (balance issues) (DeMaagd and Philip, 2015). Non-motor complications can include mood changes (depression, anxiety and apathy), cognitive dysfunction, sleep disturbances, constipation, incontinence and loss of sense of smell (DeMaagd and Philip, 2015) among others; some of these can present years before the onset of motor symptoms. Cognitive and mood changes can lead to a decline in wellbeing and quality of life for both those suffering from PD (Massano and Bhatia, 2012) and their families/caregivers (Carter *et al.*, 2008; de-Graft Aikins, 2016). Symptomatic drug therapy is effective in improving motor symptoms (Dotchin *et al.*, 2011). Levodopa has been the 'gold standard' PD treatment since the 1960s (Hornykiewicz, 2010) but, like other medications, cannot alter the course of the disease – symptoms will progress at a similar rate even with medication (NICE, 2017). This

progression varies from person to person and most people with Parkinson's disease (PWPD) survive many years; although with increasing care requirements.

PD is a condition that primarily affects older people and increases in prevalence with age (Pringsheim *et al.*, 2014). There are estimated to be 6.2 million people worldwide living with PD (Dorsey *et al.*, 2018; Feigin *et al.*, 2019), with 96% diagnosed after the age of 50. Dorsey and Bloem (2018) propose that the "Parkinson Pandemic" requires immediate action as they predict the number of people living with PD will rise to 12.9 million by 2040. This is due to an increase in total world population, increased longevity, population ageing and declining smoking rates (smoking is associated with reduced risk) (Dorsey and Bloem, 2018). A substantial number of PD prevalence studies have been carried out globally, yet few have been conducted in sub-Saharan Africa (SSA), the focus of this thesis. Available research in SSA has found generally low levels of knowledge resulting in under-diagnosis; even when diagnosis happens, treatment is typically unavailable or too expensive (Dotchin and Walker, 2012; Mokaya *et al.*, 2016). There are very few studies exploring people's experiences of living with, and managing, PD in the continent, none of which are ethnographic; existing research comes from Tanzania (Mshana *et al.*, 2011), Uganda (Kaddumukasa *et al.*, 2015), South Africa (Mokaya *et al.*, 2017) and Ethiopia (Walga, 2019).

As PD is primarily associated with later life, for many, experiences need to be understood in the context of ageing and older peoples' resources for care. However, research on the experience of ageing in Africa remains limited (Hoffman and Pype, 2016), and especially the experience of ageing with chronic disease. Some earlier work suggests that growing "modernisation" (Apt, 2001) and "material constraints" (Aboderin, 2004a) have made it harder for extended families to care for older people; a particular challenge when provision of health and social care within the formal sector may be limited.

To my knowledge, this study is the first piece of ethnographic research to explore people's experiences of living with PD in a low- or middle-income country context. It contributes to the small but growing literature on ageing in Africa, seeking to understand how older people living with chronic illness, and their families, negotiate care. This chapter outlines the study's research questions, thesis structure, key discussion points and contextualises the thesis.

1.2 Research questions

The overarching aim of this study was to understand the lived experiences of people with Parkinson's disease and their families in Kenya, with the following specific research questions:

(a) How does the process of diagnosis work and what challenges are experienced?

(b) How do PWPD, their families and healthcare professionals navigate care and treatment?

(c) How do PWPD and their families negotiate PD in the home and society?

(d) How do families negotiate care at the end of life?

In order to address these research questions, a questionnaire survey, in-depth biographical interviews, informal interviews and continuous ethnographic observations were carried out over nine months (April to December 2018), and for an additional month in May 2019, across various locations in Kenya.

1.3 Thesis structure

This thesis is structured into eight chapters. **Chapter One** (this chapter) presents background information about PD, introduces the research questions and provides context for the study. **Chapter Two** presents a review of the literature relevant to this study including: an introduction to PD; the management and experience of PD in SSA; an exploration of the lived experiences of PWPD globally; theoretical approaches to chronic disease management in SSA; and an exploration of ageing in SSA and older people's resources for care. **Chapter Three** provides a theoretical and methodological framework for this study, outlines the details of recruitment, ethics, data collection and analysis and provides a reflection on positionality and the emotion of ethnography. **Chapters Four** to **Seven** present an analysis of ethnographic data and discussion of the lived experiences of PWPD in Kenya, including: PWPDs' diagnostic journeys; experiences of navigating therapeutic landscapes; experiences of living with PD and PWPDs' resources for care; and finally, experiences of end-of-life care. Each of these chapters is foregrounded with narrative accounts from interview material, field notes and observations. The narratives illustrate examples of a range of experiences of PWPD with different social, educational, and financial resources. Finally, **Chapter Eight**

brings empirical findings and theoretical ideas together to understand and answer the study's research questions. The chapter provides a critical reflection of the study's strengths and limitations, summarises the empirical findings and draws together core themes that thread through the thesis, including: (bio)sociality, personhood and interdependence; intergenerational care and reciprocity; improvisation, self-management, uncertainty and hope; and labelling and legitimacy. The chapter outlines the policy implications of the study, provides directions for further research and a final conclusion.

1.4 Research context and positioning

This study was conducted across multiple sites in Kenya. Situated on Africa's east coast, Kenya is one of 54 countries in sub-Saharan Africa, one of the world's poorest regions (Farmer *et al.*, 2013a), despite significant improvements in gross domestic product (World Bank, 2019a) and life expectancy over the last 15 years (World Bank, 2019b). I chose Kenya as the setting for this research because of already established in-country contacts through one of my supervisors, but also because I grew up in the coastal city of Mombasa until the age of 13. I hold dual nationality (British and Kenyan), speak conversational Kiswahili, Kenya's national language, and I regard Kenya as my "home". As others have observed, and I personally experienced, carrying out fieldwork 'at home' presents both challenges and opportunities (van Ginkel, 1994). As a white Kenyan, my position has always been hard for some people to understand, but participants responded to me openly and genuinely.

Before embarking on this PhD project, I had no direct link to, or experience of, PD in my life. However, through the research I became deeply drawn into the experiences and lives of those with whom I worked. This was often emotionally – and sometimes ethically – challenging, and it was not always easy to maintain boundaries between the roles of researcher, friend, and advocate. At times, I found myself getting emotional and angry at the awful situations and suffering I encountered, driven by external forces. As Bourgois (2002) states, ethnographers can become very involved with the people they study. Throughout the research, I reflected on my own objectivity , while recognising that ethnographic study is always also subjective and personal (Hegelund, 2005).

1.5 The Kenyan healthcare system and demographic change

Healthcare in Kenya prior to 1888 (before British rule) largely involved what is known today as traditional, complementary and alternative medicine (Kareru *et al.*, 2006). Under British rule, the first 'modern' hospital was built in Mombasa (1891). In 1901, another was built in Nairobi, which became the main national referral hospital of Kenya and an important site of observations and recruitment within this study. The British established ten further hospitals across the country. In 1963, after independence, provision of public healthcare was centralised and governed by the Ministry of Health; life expectancy was then 48 years (United Nations, 2019). The government proposed to provide free healthcare for all and abolished public clinic fees by 1965. The following year, the government-run National Hospital Insurance Fund (NHIF) was established. By 1984, life expectancy had increased to 59 years (United Nations, 2019). However, in the same year, the first HIV/AIDS case was identified in Kenya. In 1989, fees were reintroduced into public clinics to generate additional revenue as a response to economic constraints, donor pressure and structural adjustment requirements (Chuma *et al.*, 2009). Life expectancy in Kenya continued to reduce, reaching a low of 51 years by 2000 (United Nations, 2019). DelVecchio Good *et al.* (1999) refer to an *"overcrowding of death"* that occurred in the national referral hospital in Kenya because of the HIV/AIDS epidemic.

In 2018, the government established new laws to address 'universal health coverage', although Kenya's health system is below the threshold for all service capacities and access (WHO, 2019a). For example, as of 2013, there were 0.2 physicians per 1,000 population in Kenya (the UK has 2.8). However, Kenya has seen improvements in life expectancy since the turn of the century (66 years as of 2017) (United Nations, 2019) aligning with targets set within the Millennium Development Goals (United Nations, 2008) and international aid focus on infectious diseases (malaria, tuberculosis, HIV) and reducing child and young-adult mortality. Crucially, no global health efforts at the time addressed older people or non-communicable diseases (NCDs).

As of 2018, Kenya's population had reached 51.4 million people and is predicted to reach 95.5 million by 2050 (United Nations, 2019). In 1980, Kenya had the world's youngest population with a median age of 15 – this increased to 18.9 by 2015 and is predicted to

reach 25.7 by 2050 (United Nations, 2015a), a pattern common across SSA attributed to increased life expectancy. In 2015, 4.5% of Kenya's population was aged over 60, while 0.4% were aged over 80 – these proportions are expected to double by 2050 to 9.6% and 0.8% respectively (United Nations, 2015b). However, Kenya, like much of the world, has experienced an epidemiological transition resulting in an increased incidence and prevalence of NCDs. In 2018, NCDs accounted for 50% of inpatient admissions in public facilities and 40% of hospital deaths in Kenya (Onyango and Onyango, 2018). Although increased life expectancy is seen as a sign of development, people are ageing with more chronic disease and increased healthcare requirements (Bigna and Noubiap, 2019). The Global Burden of Disease Study 2017 (Gouda *et al.*, 2019, p. e1384) found that NCDs *"impose a formidable burden"* in SSA, in part resulting from the growing and ageing population. Naghavi and Forouzanfar (2013, p. 95) describe this burden of NCDs as *"a growing health iceberg hidden under epidemics of infectious disease"* that global health has not addressed until recently. Gouda *et al.* (2019) propose that NCDs need to be prioritised within health and development agendas.

Since 2010, health services management in Kenya has been devolved to county governments, except for referral hospitals – the public health system is organised into six levels *(Table 1)*. The government health system owns 47.6% of all health facilities and government spending accounts for 29.3% of healthcare funding (Ministry of Health, 2014a). Donor funds account for 31% and households contribute 35.9% to healthcare funding (Chuma *et al.*, 2012). The Kenyan health sector also includes private for-profit (37.8% ownership of health facilities), non-governmental (3.2% ownership) and faith-based facilities (11.4% ownership) (Chuma *et al.*, 2012; Ministry of Health, 2014a). For example, Christian Health Association of Kenya is a faith-based organisation with a goal to promote access to quality healthcare. The organisation collaborates with the government on disease programmes, for example, 'Action for Diabetes in Kenya' (CHAK, 2017). Furthermore, donors such as The Global Fund support the government in the fight against 'the three diseases': malaria, tuberculosis and HIV. For the period 2018-2021, Kenya received US$384 million in grants from The Global Fund (2018).

Level of public care	Facilities	No. of facilities
6	National referral hospitals (tertiary hospitals)	5
5	Provincial referral hospitals (secondary hospitals)	12
4	District referral hospitals (primary hospitals)	264
3	Health centres (managed by clinical officers)	1,012
2	Dispensaries/clinics (managed by nurses)	7,182
1	Community (village/households/community health workers)	Not available

Table 1. Outline of public care facilities in Kenya (Ministry of Health, 2014a)

The main national referral hospital in Nairobi holds Kenya's only public neurology clinic. It is the country's biggest hospital providing services to approximately 2,500 outpatients daily, although a report by The National Assembly (2019) identified that all areas of the hospital were largely understaffed, the availability of equipment was inadequate and NHIF did not cover many procedures. Due to understaffing and overwhelmed clinics and wards, registrars often run outpatient clinics with little supervision. Registrars also have limited specialist training, for example, in neurology. Similar issues exist in rural Kenya where clinical officers, not doctors, staff health centres. In Kenya, doctors undergo six years of medical training and seven to ten years of specialisation. Clinical officers, in contrast, undergo a three-year diploma in clinical medicine. The role of clinical officers was intended to bridge the gap between nurses and the low number of doctors, although their training is less than that of nurses.

In contrast to Kenya's largely overloaded and underfunded public healthcare system, its private health sector is one of the most developed in sub-Saharan Africa (Barnes *et al.*, 2010). However, Prince (2018) suggests that 90% of Kenyans cannot afford private care. Private facilities offer faster testing and results than public facilities (Prince, 2018) and have a more reliable supply of medicines, although often for a higher cost. Many healthcare professionals often begin their practice in public facilities, eventually moving to work in private hospitals, where conditions and pay are superior, or combining the two.

1.5.1 Specialist services for Parkinson's disease in Kenya

PD is best managed by movement disorders specialists who have speciality training in the diagnosis and management of chronic conditions of the nervous system (WHO, 2004). However, Bower *et al.* (2014) note a significant shortage of neurologists in Africa. World Health Organization (WHO) recommends a ratio of one neurologist per 100,000 people (WHO, 2004) yet the average number of neurologists in SSA is thought to be 0.03 per 100,000 people (Howlett, 2014); although this varies greatly between countries. Bower *et al.* (2014) suggest that 26 million people live in SSA nations where there are no neurologists, while 270 million people live in countries with less than five neurologists. Kenya has 20 neurologists located in major cities: 16 in the capital city, Nairobi (population 4.4 million), two in Mombasa (population 1.2 million) and two in Kisumu (population 1.16 million)[1]. This number is high compared to neighbouring Tanzania and Uganda, for example, which each have four neurologists. The number of geriatricians in SSA is also low. Dotchin *et al.* (2013) carried out a survey to identify the number of geriatricians in Africa – at the time of publication, Kenya had none, while only seven countries (four in SSA, including South Africa, Zimbabwe, Senegal and Ivory Coast) had postgraduate geriatric training schemes. However, the situation may have changed since the survey was conducted, for example, a hospital in Benin, Nigeria now has a geriatric training programme (Akoria, 2016). WHO (2004) also showed that at the time of publication of the Neurology Atlas, there were no neurology nurses in SSA, compared with 2.43 per 100,000 population in Europe.

Levodopa + carbidopa is the most commonly prescribed PD medication globally yet is largely unavailable and unaffordable in Kenya (Mokaya *et al.*, 2016). One of the main reasons for the high costs of levodopa in Kenya, and other countries on the continent, is that the drug (brand name or generic) is not legally registered, despite being included in Kenya's Essential Medicines List since 2016 (Ministry of Health, 2019). This is partly due to the 'low demand' for these drugs and expensive and lengthy process of registration for pharmaceutical companies. However, the result is unreliable supplies of branded levodopa entering the country through parallel importation, which allows medication to be imported from markets where it is available. A distributor can act as a parallel channel to import the product to

[1] Note: these are populations of the major cities in which neurologists are located, not including the populations of surrounding rural counties.

Kenya, in some cases through an intermediate country (McKeith, 2014; Pharmacy and Poisons Board, 2018). The Pharmacy and Poisons Board, under the Ministry of Health, should register all parallel imports, although levodopa is not registered (Pharmacy and Poisons Board, 2020), resulting in inconsistent supply and price fluctuations.

1.5.2 Poverty, pensions, and insurance coverage in Kenya

Kenya was classified as a low-income country until 2014 when its classification changed to lower-middle-income country. However, as of 2018, 34.4% of the population were living in extreme poverty (World Bank, 2019c). Although poverty rates are higher in rural Kenya (40% living in poverty compared to 29% in urban areas (Diwakar and Shepherd, 2018)), approximately 70% of Nairobi's residents live in slums and informal settlements (APHRC, 2014). Ezeh *et al.* (2006) found that older people living in slums were increasingly vulnerable because of weakening support networks, increased ill health, poor access to health facilities and lack of pension support. Furthermore, urban populations continue to grow despite an assumption by many researchers that older people would return to their rural homes on retirement because of better opportunities for care (Ezeh *et al.,* 2006). Unemployment is also thought to be higher in urban areas, with female unemployment (outside of the home) double that of men (SID, 2004).

During the years 2017-2019, only 11.3% of the working-age Kenyan population (aged 15-64) were actively contributing to a pension scheme (ILO, 2018). Pension schemes are often inaccessible to those working in the informal sector. UNDP (2006) suggested that at the time of publication, only 3% of the Kenyan population aged over 60 were receiving a pension. The National Social Security Fund established in 1965 is mandatory for all formal sector employees (67% of pension coverage), while the public service pension scheme is for public service employees (20% of pension coverage) (Raichura, 2008; IOPS, 2012). Privately managed occupational retirement schemes cover 1.65% of the workforce and individual retirement schemes have negligible cover (UNDP, 2006). The Older Persons Cash Transfer Programme was a means-tested pension scheme introduced in 2006 to support poor and vulnerable people aged over 65 (Chepngeno-Langat *et al.*, 2019) – it covered 343,751 people by 2017. A study conducted by the University of Southampton and APHRC (2019) found that 90% of eligible poor households did not receive benefits, potentially due to slow

bureaucratic enrolment processes. Beneficiaries received 2,000KSh (£15) per month and HelpAge International found that recipients were 10% more likely to have bought medicines, felt more appreciated and supported by their families, and more able to help others in their household (Knox-Vydmanov *et al.*, 2012). The programme ceased recruitment in 2017 and has been replaced with the universal *Inua Jamii 70+* which launched in June 2018 – the scheme currently has 523,129 people enrolled (KIPPRA, 2020) who are entitled to 2,000Ksh (£15) per month. As of the 2019 census (KNBS, 2019a) the population of Kenya aged 70+ was 1.2 million, meaning 43% of those eligible are enrolled. Although, the new scheme also excludes poor older adults aged 65-69.

Health insurance coverage is also scarce in Kenya; only 19% of the population have health insurance (Barasa *et al.*, 2018). The National Health Insurance Fund covered just 16% of the population in the 2016/17 financial year, with 32 private health insurance providers covering the additional 3% (Barasa *et al.,* 2018). Individuals employed in the informal sector account for 83% of all employed persons yet only 24% of National Health Insurance Fund enrolments (NHIF, 2017). Barriers to voluntary membership for those in the informal sector include the flat-rate contribution (not income rated) and default penalties (Barasa *et al.*, 2017). Furthermore, in 2017, contribution rates increased by 213% from 160Ksh (£1.20) to 500Ksh (£3.70) (Barasa *et al.*, 2017) making membership unaffordable for many informal workers. Mbau *et al.* (2020) identified that lower-income groups (informal sector) were contributing more of their income towards premiums than higher-income groups (formal sector). For example, someone earning 1,000Ksh (£7.50) per month would be spending 50% of their salary on premiums compared to 4% for someone earning 15,00KSh (£110), creating further health inequalities. In 2018, lack of financial protection for healthcare costs resulted in 1.1 million individuals in Kenya pushed into poverty because of out-of-pocket healthcare payments, with a higher probability among older people, those affected by chronic disease and people regularly accessing outpatient services (Salari *et al.*, 2019). Furthermore, poor coverage of pension schemes means older people continue to rely on family incomes for care in later life.

Many older people with PD in Kenya will be navigating their condition, care and treatment in the context of poor availability of affordable healthcare (including specialist neurological

services), limited coverage of both pension schemes and health insurance, and general lack of means in later life.

Chapter 2. Literature Review

Chapter overview

This chapter presents a review and critical analysis of literature relevant to the experiences of people with Parkinson's disease living in Kenya, sub-Saharan Africa and globally. First, I provide some further background information about PD, including incidence and prevalence rates. Second, I review literature around the experiences of PD in SSA, including diagnosis and management in the context of scarce resources and services. Third, I review wider scholarship on the experiences of PWPD globally. Fourth, I look at theoretical approaches to chronic disease management in SSA, drawing on the experiences of people living with conditions such as HIV/AIDS, cancer, and diabetes – areas which have undergone more exploration. Lastly, I review literature on old age in SSA to understand how older people negotiate growing old with a chronic, progressive condition.

Within this chapter, I bring together literature from several fields of research from a comprehensive and critical narrative review. A systematic review was not appropriate for the broad scope of the literature relevant to the thesis. I conducted an initial review prior to fieldwork, reading ethnographic literature (including books and monographs) around global health and medical anthropology to familiarise myself with the field, existing ethnographic research in Africa and relevant theories on the experience of NCD management. I searched numerous databases (Ovid, Medline, Embase, PubMed, Elsevier) for studies relevant to the thesis, including broad search terms, such as global health; non-communicable diseases; ageing in Africa; anthropology; Parkinson's disease; low- and middle-income countries; alternative therapies. More specific terms were used to narrow the focus of results around PD and ageing in Africa and other low-income countries, including terms such as prevalence; diagnosis; management; financial burden; caregiving; intergenerational relationships; improvisation; tinkering; reciprocity. Articles were selected on their relevance to the broad topic and if they helped situate this research. I reviewed and analysed the studies and used a snowballing technique to identify further publications from the bibliographies. I also used Google Scholar for more broad search terms and concepts, or to identify particular books. I used websites, for example the World Health Organization, United Nations and Kenyan

National Bureau of Statistics, for statistics and relevant information through reports. Through data collection and analysis, further concepts and ideas emerged, and I carried out another literature search after fieldwork; this also identified more recent publications. I continued reviewing literature throughout the writing of the thesis to keep the review as up-to-date as possible.

2.1 Parkinson's disease: an overview

Parkinson's disease is a neurodegenerative movement disorder that increases in prevalence with age. James Parkinson first identified "The Shaking Palsy" in an essay in the 19th Century which described the clinical features of this newly-recognised, progressive, disabling condition (Parkinson, 1817). The aetiology of PD remains unknown, although an interplay of genetic factors and environmental triggers (for example, toxins) may result in dopaminergic cell loss in the brain characteristic of PD (de Lau and Breteler, 2006). Mutations in the parkin or LRKK2 genes are commonly found in familial PD, although are not seen in sporadic (idiopathic) PD, which accounts for the majority of cases (Chen and Tsai, 2010). PD involves a host of motor and non-motor complications (described in Chapter One) and requires a clinical diagnosis – a DaTscan[2] (where available) can be used to distinguish PD from essential tremor or drug-induced Parkinsonism (Seifert and Wiener, 2013).

The Hoehn and Yahr disease severity scale can be used to monitor disease progression, which is unpredictable and different for everyone. The scale ranges from Stage 1, with mild symptoms on one side of the body, to Stage 5, where PWPD are bedridden and require constant care (Hoehn and Yahr, 1967). Treatment with levodopa is to address symptoms (Birkmayer and Hornykiewicz, 1961) as there is currently no cure. Physical exercise is also thought to play an important role in improving gait and fitness, while also perhaps putting PWPD at the centre of their care (Rosenthal and Dorsey, 2013; Bhalsing *et al.*, 2018). Furthermore, certain foods, including vegetables, fruits and caffeine, are thought to have a neuroprotective role (Seidl *et al.*, 2014) while mitigating gut inflammation is thought to be a novel avenue for gut microbiome directed PD treatment (Gorecki *et al.*, 2020). Healthy diets and exercise can also provide constipation relief – a common non-motor symptom that affects quality of life (Pedrosa Carrasco *et al.*, 2018). Use of physiotherapy, speech therapy

[2] Dopamine Transporter scan.

and occupational therapy are also effective in symptom control (NICE, 2017). However, management becomes more difficult as the condition progresses.

PWPD can live long lives if their condition is well controlled. A 20-year follow-up study in Germany by Diem-Zangerl *et al.* (2009) found that a PD diagnosis was not associated with excess mortality (compared with age-matched controls) during the first ten years of disease and associated with moderate increase in mortality after 20 years. However, functional status may decline significantly during these years. Factors including age at onset, disease duration and Hoehn and Yahr stage can be associated with increased mortality. In the UK, Pennington *et al.* (2010) identified the underlying causes of death among PWPD, which included: idiopathic PD (29%), malignancies (12%), ischaemic heart disease (12%), pneumonia (11%) and cerebrovascular disease (9%). These data suggest that PWPD often die from comorbid complications. UK National Institute for Health and Care Excellence (NICE) clinical guidelines suggest the use of palliative care at advanced disease stages to improve quality of life for PWPD and families (NICE, 2017).

2.1.1 Incidence and prevalence of Parkinson's disease globally

The Global Burden of Disease Study 2015 identified a 117% increase in PD prevalence globally from 1990 to 2015 (which may also be a function of improved diagnosis), 111% increase in disability-adjusted life-years caused by PD and 115% increase in deaths (Feigin *et al.*, 2017). As populations globally, and particularly in SSA, continue to age, this burden is expected to grow. The double burden from infectious diseases and NCDs poses a challenge to unprepared, under-funded health services, such as those in SSA (Gouda *et al.*, 2019).

PD prevalence and incidence estimates from high-income countries (HICs) range because of genetic and environmental factors. Hirsch *et al.* (2016) conducted a systematic review and meta-analysis of the incidence of PD globally, including: 16 studies from Europe, five from Asia, four from North America, one from Australia and one from South America. They identified increasing incidence rates with age, peaking between 70-79 years (104.99 per 100,000 female population and 132.72 per 100,000 male population). In Europe, von Campenhausen *et al.* (2005) identified 39 high quality prevalence and incidence studies from 14 countries in their systematic literature search. Prevalence rates ranged from 108 to 257 per 100,000 population. Studies in Asia have identified generally lower age-standardised

rates than in Europe (Pringsheim *et al.*, 2014). Chen and Tsai (2010) identified prevalence rates ranging from 15 to 328 per 100,000 population in several studies across Asia, while in South Korea, Park *et al.* (2019) reported an incidence between 22.4 and 27.8 cases per 100,000 population. In the USA, Wright Willis *et al.* (2010) identified higher age-standardised prevalence rates among 'Whites' and men, and lower rates among 'Blacks' and 'Asians' (50% lower prevalence than 'Whites') and women. Also in North America, Marras *et al.* (2018) found a prevalence among those over 45-years-old of 572 (488 for females and 667 for males) per 100,000 population (standardised by age and sex to the 2010 US population). A study in Egypt (North Africa) identified a much lower prevalence (age and sex adjusted) of 213.15 per 100,000 population aged over 40 (El-Tallawy *et al.*, 2013). Tysnes and Storstein (2017) propose that use of different methodologies in epidemiological studies makes determining global incidence and prevalence rates difficult, alongside potential under-diagnosing. It is worth noting that many PD prevalence and incidence studies across the globe were conducted prior to the year 2010.

2.1.2 Prevalence of Parkinson's disease in sub-Saharan Africa

Compared to the rest of the world, there have been few epidemiological studies (and no incidence studies) conducted on PD in sub-Saharan Africa, making the true prevalence even more difficult to estimate (Okubadejo *et al.*, 2006); available estimates also vary dramatically. In their systematic review of epidemiologic and genetic studies on PD in Africa, Okubadejo *et al.* (2006) identified 28 studies from 13 countries (SSA and North Africa), including seven prevalence studies all conducted prior to 1995. Estimates from SSA ranged from seven per 100,000 population in Ethiopia (Tekle-Haimanot, 1985) to 20 per 100,000 population in Togo (Balogou *et al.*, 2001). More recently, Blanckenberg *et al.* (2013) and Williams *et al.* (2018) also reported these findings in their reviews of PD prevalence and genetics in SSA. However, these reviews included a more recent large-scale (population of 161,071 people) community-based door-to-door prevalence study conducted by Dotchin *et al.* (2008) in the Hai region of Tanzania. Using an adapted PD screening tool (Racette *et al.*, 2006) the authors identified an age-standardised prevalence rate (compared with the UK) of 40 per 100,000 population – this is higher than previously estimated in SSA yet lower than estimates from HICs (as high as 257 per 100,000 population). There are no PD prevalence estimates from Kenya, although the Hai region of Tanzania lies close to the Kenyan border.

Findings by Dotchin *et al.* (2008) suggest that PD is relatively common in the region and the incidence will likely rise as life expectancies continue to increase. However, further epidemiological studies are required to gather a more accurate, up-to-date picture of PD prevalence across SSA.

2.2 Living with and managing Parkinson's disease in sub-Saharan Africa

2.2.1 Experiences of Parkinson's disease

There are relatively few studies exploring people's experiences of chronic illness in sub-Saharan Africa, with the exception of HIV/AIDS which the success of Antiretroviral Therapy (ART) has made into a chronic condition (Nguyen *et al.*, 2010; Whyte, 2014). Larsen (2014) suggests that illness perceptions, influenced by social interactions and past experiences, can influence peoples' beliefs about chronic disease, treatment, and coping mechanisms. Understanding PWPDs' experiences may outline any barriers to PD diagnosis, treatment and services and determine ways to improve knowledge and awareness.

Soundy *et al.* (2014) carried out a systematic review and meta-ethnography on the experiences of people living with Parkinson's disease globally, identifying 37 qualitative studies. Their review identified one study from SSA, an exploration of the experiences of PD in Tanzania by Mshana *et al.* (2011) – social science research on PD in the region is lacking. However, two additional quantitative cross-sectional studies on the beliefs and attitudes towards PD in Uganda (Kaddumukasa *et al.*, 2015) and South Africa (Mokaya *et al.*, 2017), and a mixed methods study on the experience of PD caregivers in Ethiopia (Walga, 2019) provide useful insights.

Mshana *et al.* (2011) conducted interviews with 28 PWPD, 28 caregivers, four community health workers and two traditional healers, and held six focus group discussions. The authors identified low awareness, resulting in misconceptions, stigma, and the perception that PD was *"normal"* old age, delaying diagnosis. PWPD experienced emotional, psychological, physical, and financial difficulties, which contributed to a deteriorated quality of life for them and their caregivers. Most PWPD had not obtained any biomedical treatment due to misdiagnoses and financial barriers. However, help from faith and traditional healers had been sought. Although this study was conducted in just one rural area of Tanzania and

experiences may vary between other SSA populations, and particularly within urban settings, Mshana *et al.* (2011) provide useful, albeit limited, insights into the experiences of PWPD in a low-resource context in SSA.

Kaddumukasa *et al.* (2015) conducted a cross-sectional community-based study exploring knowledge and attitudes towards PD in a rural and urban region of central Uganda, which involved a questionnaire survey with 377 randomly selected adult participants (from the general population and identified from an ongoing neurological study) ranging from 18-85 years. The authors found that urban dwellers had significantly more knowledge about PD than their rural counterparts did. However, stigmatising perceptions were common in both groups, including beliefs that PD was contagious or a form of insanity. In Cape Town, South Africa, Mokaya *et al.* (2017) carried out a cross-sectional study to explore the beliefs, knowledge, and attitudes towards PD among a Xhosa-speaking black population. The study involved questionnaire surveys with 25 PWPD, 98 members of the public and 31 traditional healers. Similar to findings in Tanzania and Uganda, the authors identified stigmatising perceptions and low awareness, although knowledge about PD was higher among PWPD and traditional healers than the public. They also found that greater worry and anxiety among PWPD was associated with lower levels of disease knowledge. Finally, Walga (2019) conducted a mixed-methods study in Ethiopia to explore caregivers' experiences of PD. The author recruited 20 caregivers from a PD patient support group and administered a questionnaire including open and close-ended questions during a group meeting. The study identified that delayed diagnosis was common, medication was largely unavailable and unaffordable while awareness in the community was low. Caregivers expressed difficulties caring for PWPD and identified the limited support available to them.

These studies provide an insight into the limited awareness about PD in some African settings including stigmatising perceptions, issues with delayed diagnoses, limited access to medication and the significant caregiver burden resulting from prolonged care. All authors recommend further longitudinal qualitative studies exploring the lived experiences of PD in SSA.

2.2.2 Diagnosis and management of Parkinson's disease in sub-Saharan Africa

In the UK, National Institute for Health and Care Excellence (NICE, 2017) provide recommended guidelines for the treatment and management of PD. Symptomatic therapeutic drugs include: levodopa + carbidopa, dopamine agonists (e.g. Pramipexole), MAO-B inhibitors (e.g. Rasagiline), COMT inhibitors (e.g. Entacapone) and glutamate antagonists (e.g. Amantadine). Non-pharmacological recommendations include nurse specialist interventions, physiotherapy, physical activity, occupational therapy, speech and language therapy, nutrition advice, occasionally deep brain stimulation (in advanced cases) and palliative care at the end of life. This range of treatment and allied health professional services reflects the complex and progressive nature of PD. However, in the context of Kenya and much of SSA, disease management is foregrounded by limited resources, particularly specialist services and medication, as highlighted in Chapter One.

In 2004, the WHO Neurology Atlas (WHO, 2004) reported that PD medication was available to 79.1% of PWPD in Europe yet only 12.5% of PWPD in SSA; although this value may be lower if undiagnosed cases are taken into account. Mokaya *et al.* (2016) in their pharmacy survey across Kenya also identified that PD medication was only available in 50% of outlets while the mean cost of 100 tablets (approximately one month's supply) of levodopa was £35. The authors estimated that after deducting basic living expenses, including rent (25.2% of wage), transportation (15.7%), food (33.7%), utilities (9.8%) and sport/leisure (8.6%), a minimum wage earner would have £6 (7% of net salary) left to spend on healthcare costs every month (including medication), making levodopa unaffordable. Dotchin and Walker (2012) suggest in their report on the management of PD in SSA that medication costs, coupled with consultation fees and transport to clinics, could cost more than a family's combined monthly household income.

The WHO model list of essential medicines for anti-parkinsonism medication includes biperiden, an anticholinergic medication (sold as Benzhexol in Kenya) that is very rarely used in the UK due to significant adverse side effects, as well as levodopa + carbidopa, in both 4:1 and 10:1 ratios (WHO, 2019b). The 4:1 ratio is ideal while the 10:1 ratio does not contain sufficient dopa-decarboxylase inhibitor (DDCI) (carbidopa). Dotchin and Walker (2012) suggest anticholinergics and 10:1 ratios of levodopa + carbidopa are often the only PD

medication stocked in hospitals in SSA, yet are relatively 'outdated', resulting in nausea and hallucinations, which can lead to 'non-compliance'. Other drugs and non-pharmacological recommendations by NICE are either very expensive or unavailable. Consequently, even if PWPD are diagnosed (which is often delayed), it is not certain they will find or maintain a constant supply of treatment, or have regular long-term follow-up (Dotchin *et al.*, 2007). Dotchin *et al.* (2011) argue that encouraging pharmaceutical companies to make cheaper generic PD medication available and providing access to movement disorder specialists and PD nurses, are crucial for management in SSA. However, a trial is currently underway in Ghana to assess whether *Mucuna pruriens*, a leguminous plant with naturally high levodopa concentrations, could be used as a cheaper, alternative symptomatic treatment for PD (Fothergill-Misbah *et al.*, 2020a). In addition, cueing therapy, involving the use of an external stimulus to facilitate initiation and continuation of gait (Nieuwboer *et al.*, 2007), resulted in significant improvements in gait among drug-naïve PWPD in Tanzania (Rochester *et al.*, 2010). However, the authors propose cueing as an adjunct to PD management and use of cueing alone is unlikely to be sufficiently sustainable.

Non-drug therapies that are widely used in SSA, including traditional medicine, herbal and faith healing, have been reported in relation to PD treatment. Mokaya *et al.* (2017) found that 53% of the 154 participants (25 PWPD, 98 members of public, 31 traditional healers) in South Africa believed traditional healing methods could be used to treat PD. The authors suggest that when neurological services are so inaccessible, PWPD will seek out alternative treatment and information, especially, as they found, if traditional healers stated they could treat PD using plants, steaming (purification) or special prayers. The use of alternative therapies in SSA is discussed further in Section 2.4.5.

As late-stage PD is associated with significant pain and suffering (Lennaerts *et al.*, 2017), palliative care is recommended at the end of life in HICs. Consequently, end-of-life care often takes place in institutional settings, especially considering the prevalence of comorbidities in advanced PWPD. However, few healthcare professionals in Kenya receive any palliative care training while services are lacking (Ali, 2016); there is limited research exploring end-of-life care for PWPD in Kenya or SSA. Downing *et al.* (2014) explored people's preferences for end-of-life care in various settings in Nairobi using a street survey and found that 51.1% of people identified home as their preferred place of death – hospital was the

second most preferred place of death. However, 24.7% identified home as the least preferred place of death with people not wanting to be a burden on their families. Participants also identified pain at the end of life as a significant concern; something that advanced PWPD would likely experience.

2.3 Experiences of people with Parkinson's disease globally

It is possible to see how ideas from the available research on Parkinson's disease in sub-Saharan Africa fit within wider scholarship. This section explores literature on the lived experiences of PWPD globally, particularly in high-income countries where most research has been conducted. Whilst the constraints experienced in Kenya concerning accessibility and affordability of services will differ, it is useful to examine what might be learned from research in HICs. Bramley and Eatough (2005, p. 224) suggest that PWPD can live long lives and the challenge is to *"uncover the wider reaching demands of PD and establish how patients can successfully adjust to them in order to enhance their quality of life".*

2.3.1 The financial burden of Parkinson's disease

The financial burden of PD is an issue that has been acknowledged globally. This section illustrates the economic consequences of the disease using examples of research conducted in three different country income categories: UK (high-income), China (upper-middle-income), and India (lower-middle-income).

In the UK, which has a National Health Service (NHS), free at the point of delivery, Gumber *et al.* (2017) assessed the economic, social and financial cost of PD on PWPD, caregivers and families. In 2017, the annual economic burden on a household affected by PD was £16,582 because of living, caring and out-of-pocket healthcare expenses and reduced household income. Added costs came from health services including podiatrists, chiropractors and often physiotherapists (outside of the NHS). Social care costs included alterations to accommodation and payments for daily living assistance, while societal costs included productivity loss. Despite free treatment in the UK, many PWPD and their families experience financial strain.

In China, Yang and Chen (2017) identified the annual costs incurred by PWPD as £2,338, which the authors acknowledge is far less than other 'Western' countries. However, the lower average household income in China results in PD contributing to a heavy economic burden. Furthermore, in LMICs, such as India, Ragothaman *et al.* (2006) propose that PD can cause significant financial strain. As health insurance only covers 3% of the Indian population, medication remains too expensive for the majority. Also in India, Sanyal *et al.* (2015) identified that 91% of the 150 caregivers included in their study reported financial worries associated with caring for PWPD. Mshana *et al*. (2011) identified the 'dire' economic consequences of PD in Tanzania where PWPD and family members were unable to work, resulting in a total loss of income as there is no welfare state. As highlighted in Chapter One, pension and insurance coverage is very low in Kenya and much of SSA; only 19% of the Kenyan population have health insurance (Barasa *et al.*, 2018) and healthcare and medication costs in both private and public facilities are out-of-pocket. With 413 million people in SSA (population one billion) living in extreme poverty as of 2015 (less than £1.50 per day) and the continent not being on track to reach the Sustainable Development Goal of eradicating poverty by 2030 (Beegle and Christiaensen, 2019), PD has the potential to have devastating financial implications (Dotchin and Walker, 2012).

2.3.2 Social identity, spiritual strategies and social support

This section explores the impact of PD on people's social identity in countries with different income categories (as defined by the World Bank) and health and social support systems. Tajfel and Turner (1979) proposed that social identity is a person's sense of who they are based on the social groups they belong to, for example, one's family. Soundy *et al.* (2014) conducted a systematic review on the experiences of PWPD globally (29 of 37 articles included were from the UK, USA, and Sweden). They identified the difficulties people had adjusting to life with PD, the importance of maintaining individual identities rather than becoming a 'patient', the impact of social support on wellbeing and the use of physical and spiritual strategies. PWPD also identified a loss of social identity concerning who they used to be (for example, a mother), or in terms of activities they used to do. In Tanzania, Mshana *et al.* (2011) identified similar findings among PWPD who expressed a sense of "loss of self" (Charmaz, 1983).

In their interpretative phenomenological analysis case study in the UK, Bramley and Eatough (2005) identified that PD can disrupt people's sense of self and agency through a loss of independence, resulting in feelings of frustration and sadness, creating tensions between a previous and new self. In the USA, Stanley-Hermanns and Engebretson (2010) also found that PWPD reflected on their former self in an attempt to revise their perception of their new self. Charmaz (1995) suggests that a constant adapting and re-negotiating is required in the face of chronic illness, although it poses many challenges – adapting to impairment and a different identity can be made easier through kinship networks. Roger and Medved (2010, p. 7) in their study in Canada on managing identity found that PWPD and caregivers *"constructed their daily lives through and with each other"* – family members play a crucial role in enabling PWPD to maintain social identity, remain independent, self-sufficient and ensure a sense of "personhood". In South Africa, Comaroff and Comaroff (2001) suggest that "personhood" is an intrinsically social construction where people exist in relation to others. In the USA, Solimeo (2009) carried out ethnographic research with PWPD and their caregivers. She identified how PWPD withdrew from social situations, hindered by their physical abilities, or embarrassed by their symptoms. Bramely and Eatough (2005) identified similar findings in the UK where freezing of gait in public and other physical symptoms resulted in social pressures, negative perceptions, and feelings of embarrassment.

Soundy *et al.* (2014) found that PWPD in 14 of the 37 studies included in their review acknowledged the importance of being able to relate to others with PD through support groups and generate a form of sociality. Solimeo (2009) also identified the use of support groups in preventing social isolation and normalising the PD experience in the USA. She notes how support groups provided a space where PWPD felt accepted and experienced camaraderie. However, these groups did not appeal to all and were 'depressing' for some. Numerous PD support groups and organisations exist across HICs. For example, the charity 'Parkinson's UK' estimates there are 365 local groups across the UK while online support groups and forums are gaining popularity (Parkinson's UK, 2019a). In Ethiopia (LIC) Walga (2019) refers to the existence of a PD support group and the "rare support" provided to participants. However, the potential benefits of PD support groups in SSA has not been explored.

Spiritual strategies have also been identified as an important way for PWPD globally to cope with their condition and for healing, as well as ensuring hope (Soundy *et al.,* 2014). In Tanzania, Mshana *et al.* (2011) found that several PWPD used faith healing and prayers. This form of spiritual support offered by faith healers is lacking in biomedical care (de-Graft Aikins *et al.*, 2010). In the USA, Stanley-Hermanns and Engebretson (2010) described how PWPD 'surrendered' to a 'Higher Power' when describing their spirituality and hope for the future. Prizer *et al.* (2020) also explored spiritual wellbeing among PWPD in the USA and found that spirituality can reduce several non-motor symptoms, such as anxiety and depression, resulting in an increased quality of life. Asare and Danquah (2017) suggest that for many Africans, healthcare involves spiritual beliefs as well as biomedicine – the use of alternative therapeutic landscapes, including spiritual strategies, is explored further in Section 2.4.5.

2.3.3 Caregiving and caregivers

Literature surrounding the impact of PD on caregivers globally is extensive. Mosley *et al.* (2017, p. 235) in their review of caregiver burden from PD globally describe it as a *"multidimensional construct that reflects the unique experience of caregiving for individuals from different backgrounds, with differing levels of resilience and resources, facing distinctive illness-specific symptoms".* PWPD have increasing, but varying, care requirements at later disease stages, resulting in higher caregiver burden. In the USA, Solimeo (2009, p. 153) found that caregivers of PWPD felt "*overworked, fatigued, and overwhelmed"*, which contributed to a sense of rapid ageing. However, spouses also found satisfaction in the care they provided, by allowing their partners with PD to 'age well'. Bhimani (2014) conducted a scoping review of literature to understand the burden on caregivers of PWPD globally. She identified that caregivers tended to be older women (usually spouses), while the experience of male caregivers was largely absent from the literature.

Mosley *et al*. (2017) note how motor and non-motor, including neuropsychiatric, symptoms result in caregivers taking on additional responsibilities on behalf of PWPD, including: emotional support, coordination of care and medication, and assistance with communication and activities of daily living, particularly towards the end of life. Furthermore, PWPDs' non-motor symptoms have been widely reported to impact on

caregivers well-being (Martinez-Martin *et al.*, 2007; Martinez-Martin *et al.*, 2015; Mosley *et al.*, 2017). Mosley *et al.* (2017) identified that caregivers experience greater distress around diagnosis during a period of limited information and uncertainty regarding their role. Walga (2019) found similar worries in Ethiopia among caregivers. In the UK, McLaughlin *et al.* (2011) in their qualitative study with informal family caregivers of PWPD described the emotional impact of diagnosis but also relief that it was not "something worse", such as cancer. Likewise, Mosley *et al.* (2017) identified that a lack of information about disease progression or the need for palliative services could result in confusion and distress.

In their review of palliative care in advanced PD (in HICs), Lokk and Delbari (2012) found that institutional care at later disease stages, where available, could provide a relief from caregiver responsibilities in the home. However, as discussed, care homes, and palliative care services, are practically non-existent in Kenya and expensive where available – so care is essentially a family matter. Hasson *et al.* (2010) explored end-of-life experiences of informal family caregivers of PWPD in the UK, who were often unaware that palliative care was available, or death was imminent. Several also felt unsupported and struggled to cope after PWPDs' death, experiencing a sense of loss in their role and often loneliness, particularly because their previous social connections were eroded as care requirements increased.

In India, Sanyal *et al.* (2015) found that caring for PWPD was the responsibility of women who saw it as their "social obligation" to take on the role, while many offspring also took on caring roles – Dotchin *et al.* (2014) also saw this in Tanzania. A high prevalence of female caregivers of PWPD has also been identified in Malaysia (Razali *et al.*, 2011), Turkey (Ozdilek and Gunal, 2012) and Brazil (Carod-Artal *et al.*, 2013). Findings from India and Malaysia identified the key role of family members in care, particularly in reducing caregiver burden as responsibilities were shared, although advanced PD was associated with increased burden, as found in other HICs and in Turkey (Ozdilek and Gunal, 2012) and Brazil (Carod-Artal *et al.,* 2013). Razali *et al.* (2011) also identified that several Malay participants suggested it was "sinful" to express the burden of care. In Tanzania, Dotchin *et al.* (2014) note how formal support systems and palliative care services are non-existent, resulting in all care work being carried out in the home; although multigenerational living and increased care opportunities for older people are common in Tanzania and other regions of SSA (Aboderin, 2004b; Dotchin *et al.*, 2014). Dotchin *et al*. (2014) suggest that if PD is diagnosed

earlier and treated effectively, the burden of care on family members in SSA could be significantly lowered. Most research on the impact of PD on caregiving comes from HICs with developed healthcare systems, formal social support, caregiver allowances and palliative care services. Despite this, researchers continue to call for additional formal support and education for caregivers in HICs to reduce burden and strain (Tan *et al.*, 2012). The experiences of caregivers in a context such as Kenya, where caring responsibilities on the family are largely unknown, require further research.

2.3.4 People with Parkinson's disease and family members' experiences of stigma

Stigma associated with PD has been observed and reported across the world. Stigma is a complex phenomenon that can arise from cultural and community perceptions and beliefs about disease (Bos *et al.*, 2008). Major and O'Brien (2005, p. 394) describe stigma as *"a powerful phenomenon with far-ranging effects on its targets";* it can negatively affect psychological and physical well-being as well as social status. Goffman (1963) described how stigma can be linked to physical appearance, as with the visible symptoms of PD, and can discredit and devalue individuals, marking them as 'different' or 'tainted'. However, Parker and Aggleton (2003) suggest, with regards to stigma surrounding HIV/AIDS, that the view of stigma as a *"static attitude rather than a constantly changing social process"* has limited approaches, ignoring the "structural violence" that results in social inequalities in which stigma is embedded (Castro and Farmer, 2005).

The concept of "structural violence" is a way to describe the *"social arrangements that put individuals and populations in harm's way"* (Farmer *et al.* (2006, p. 1686). Castro and Farmer (2005, p. 55) propose "structural violence" as a conceptual framework to understand stigma surrounding HIV/AIDS, which they suggest *"predisposes the human body to pathogenic vulnerability"*, increasing risk of infection and determining who has access to therapy. Although poverty and social inequalities do not influence who develops PD, forms of "structural violence", such as availability and cost of medication, could determine access to services and treatment among PWPD in Kenya. In contrast to the stigma surrounding HIV/AIDS, for example, involving associations with victim blaming, promiscuity and drug use (often consequences of "structural violence"), in South Africa, Mokaya *et al.* (2017)

identified that stigmatising perceptions primarily resulted from the limited knowledge about what caused PD (including witchcraft or mental illness).

Maffoni and Giardini (2017) conducted a review of qualitative literature to understand the stigma experienced by PWPD globally; this included 13 qualitative studies from six HICs, one upper-middle-income country (Iran), one lower-middle-income country (Tanzania), and a metaethnography by Soundy *et al*. (2014). The review identified stigma arising from visible symptoms. For example, in Israel, Posen *et al.* (2001, p. 82) found that women described their bodies as *"traitors",* revealing their condition to the public, while in Iran, Soleimani *et al.* (2016) found that PWPDs' body image resulted in embarrassment and self-isolation. In the USA, Chiong-Rivero *et al.* (2011) describe how PWPD also experienced feelings of stigma from a changing self and loss of social roles, for example, no longer being able to provide for their family. This has also been identified by Nijhof (1995, p. 196) in the Netherlands where PWPD reported PD as a *"problem of shame"* due to their self-perceived physical dependency.

Stigma was also linked to relational and communicational challenges. In the UK, Hermanns (2013) identified that PWPD were frequently labelled as drunk and facial masking resulted in unintentional alienation, while shaking and drooling led to feelings of embarrassment. Scambler (2004) refers to the distinction between "enacted" stigma (discrimination by others towards someone because of their condition), and "felt" stigma associated with 'shame', similar to the experiences noted by Hermanns (2013). Feelings of enacted and felt stigma have also been described among people living with dementia in Nigeria who felt ashamed about their condition (Adebiyi *et al.*, 2016). Stigma also resulted from changes in perceptions towards PWPD and by PWPD towards others. In Tanzania, Mshana *et al.* (2011) found that because PD was associated with 'old age', two younger PWPD (aged 41 and 57) included in their study experienced greater stigmatising perceptions, with people believing they had been bewitched or cursed. Schrag *et al.* (2003) identified similar findings among younger PWPD (onset before 50-years-old) in the UK who experienced greater depression and disruption. This may be because younger-onset PD is usually associated with longer disease duration having a more profound social and psychosocial effect (Schrag *et al.,* 2003). Mshana *et al.* (2011) also reported that perceptions about PD being associated with "witchcraft" in Tanzania resulted in shame on the whole family. Kaddumukasa *et al.* (2015)

in Uganda also identified stigma towards PWPD resulting from perceptions about cause of disease.

Perceptions about disease resulting in stigma have been well documented in SSA among people with HIV/AIDS (Yuh *et al.*, 2014; McHenry *et al.*, 2017), epilepsy (Baskind and Birbeck, 2005; Hunter *et al.*, 2012), mental health problems (Monteiro, 2015) and diabetes (Hall *et al.*, 2016). Stigma can result in people being discriminated against or not seeking treatment (or instead seeking treatment to remove spirits, for example) and can have significant consequences on well-being. HIV/AIDS has been associated with discrimination and 'blame' because of the nature of transmission and issues around morality. Although PD may not be associated with morality issues, PWPD still experience stigma because of associations with 'blame', as Mshana *et al*. (2011) identified, because PWPD forcefully took something belonging to other people, or because of social conflict. Mokaya *et al.* (2017) described how half of the 98 members of the general public included in their study in South Africa felt that PWPD should not be living in the community. However, literature on stigma relating to PD globally has not reported any association with witchcraft or perceptions about cause of disease.

2.4 Theoretical approaches to chronic disease management

Research on PD in sub-Saharan Africa has highlighted the scarce and unaffordable treatment and services and poor awareness in the region. However, no studies have used an in-depth ethnographic approach to understand how PWPD negotiate services and manage their condition. Therefore, this section explores, and reviews, concepts and theories derived from ethnographic studies exploring HIV/AIDS, cancer and diabetes in SSA (and other settings globally). As Whyte (2014) suggests, ethnography reveals the association between a disease and the specific context it is situated within, considering life's adversities and societal change. Diseases are deeply embedded in social reality and people's understandings of their illness provide an understanding of their relationship with society (Herzlich, 1985).

The requirements, manifestations, recommendations, and consequences of chronic disease management vary hugely; it would be unwise to 'umbrella' chronic conditions into one singular category. However, literature about other conditions may provide useful insights into how PWPD might navigate therapeutic landscapes and social support within a resource-

poor context. It is revealing to examine how peoples' experiences of other chronic diseases might differ from PD. In this section, I look at ideas around "improvising" medicine and healthcare, and the use of "tinkering", "strategies", "biotactics" and the self-management of chronic disease. I explore the sociality of treatment in the SSA context and finally, discuss how people may draw on alternative therapeutic landscapes, or what much of the literature refers to as traditional, complementary and alternative medicine.

2.4.1 Understanding the differences between chronic conditions

Human Immunodeficiency Virus (HIV) damages the immune system and results in Acquired Immune Deficiency Syndrome (AIDS) which has resulted in approximately 32 million deaths globally since the start of the epidemic in the early 1980s (UNAIDS, 2019). Although HIV/AIDS is a communicable disease, it is now widely considered a chronic condition (Arts and Hazuda, 2012). Highly effective treatment, ART, when taken in a regimental manner can supress HIV and prevent disease progression. ART only began to become available and affordable in SSA in 2001, which was followed by the establishment of clinics. Mikkelsen *et al.* (2017) suggest that the scale up of ART over the past 15 years has been one of the most 'remarkable' achievements in public health but acknowledge that coverage is still sub-optimal. Whyte (2014) explored the rollout of ART in Botswana in her ethnography where a generation of HIV-infected people, "biogeneration" (who experienced both HIV diagnosis and treatment), had to learn to live with a chronic condition. Whyte (2012) suggests that this success could mean that African healthcare systems could be oriented towards treating long-term conditions.

The focus of ethnographic research on HIV/AIDS could be attributed to global publicity and the large amount of international support and donor funding targeted at reducing AIDS-related illnesses and deaths. The high politicisation has been said to stem from the prejudice and stigma surrounding transmission and the social and economic injustices exacerbated by the epidemic (Piot *et al.*, 2007). By contrast, many other chronic conditions have been 'neglected' by researchers, donor support and local policy (de Graft Aikins, 2010). Nguyen *et al.* (2010) explored the local response to the HIV epidemic in West Africa and propose that little was left for those suffering from 'other' diseases, which they suggest is a form of triage. Triage refers to the distribution of scarce healthcare resources where demand outstrips

availability (Iserson and Moskop, 2007). Nguyen *et al.* (2010) argue that this new form of triage produces exclusion, inequality and creates a world where people can only survive if they have a life-threatening illness such as AIDS. Similarly, Men *et al.* (2012, p. 11) describe the access to healthcare services for HIV/AIDS patients and diabetic patients in Cambodia, where some said they *"wished they had AIDS"* because of access to free treatment and social assistance. Similarly, Livingston (2012) has suggested that cancer, despite being on track to be the next global epidemic, is also not yet "visible" in Africa. Furthermore, Whyte (2016) has described the emergence of diabetes as a social phenomenon in Uganda. How people living with diabetes make their lives more habitable has also been explored in HICs (Guell, 2009; Mol, 2009). PD has not received the same political activism or publicity as HIV/AIDS, it affects far fewer people and primarily people who are regarded as 'old'; these are important distinctions to make when thinking about comparisons.

One similar characteristic of all chronic diseases is the need to manage one's condition while managing other aspects of life (van Olmen *et al.*, 2011); although exactly how much and what kind of self-management varies between conditions. Bury (1982) exploring rheumatoid arthritis in the UK describes chronic illness as a disruptive event, using the term "biographical disruption" to understand the impact, or rupture, disease can have on everyday life's activities and routines, affecting people's narratives about their futures and life trajectories. Many chronic conditions also require complex life-long treatment regimens, without which significant deterioration, suffering, and severe complications can occur. van Olmen *et al.* (2011) suggest that conditions like HIV/AIDS and diabetes share characteristics in terms of the possibilities of management, the role of family support, involvement of healthcare professionals, people's experience of disease and the adjustments and challenges required in life. The authors propose a push towards "full self-management" of chronic conditions in LMICs.

PD is primarily a disease of older people, and progressive and degenerative in nature; a significant difference from some other chronic conditions. PWPD are often managing frailty, comorbidities and cognitive impairment associated with later life combined with the challenging deterioration associated with PD. Although the life expectancy of PWPD is relatively unchanged compared with control populations (Diem-Zangerl *et al.*, 2009), PD symptoms generally result in significant and progressing disability for many years.

2.4.2 "Improvising" medicine and healthcare

Livingston (2012) suggests that one of the most defining features of healthcare and biomedicine in SSA is "improvisation". Livingston's hospital-based ethnography, situated within an under-resourced oncology ward in Botswana, explores how biomedicine is contextualised while examining how patients maintain their humanity in the face of illness. She acknowledges how clinical recommendations developed through clinical trials in HICs are culturally ill suited for practicing oncology in Botswana, resulting in improvised management and varied illness experiences. Whyte (2012, p. 64) draws attention to the difficulties people face in managing a chronic condition when biomedical services are *"under-funded, poorly functioning, quite donor-dependent and poorly oriented to the control of chronic conditions".* Although biomedicine is in some sense global, it is also highly contextualised and cultural – a condition can have the same biological process or underlying gene, but the clinical or personal experience differs depending on the context. PD could be perceived, understood, treated and experienced in very different ways depending on sociocultural, political-economic, technical and biological circumstances (Livingston, 2012).

DelVecchio Good *et al.* (1999) investigated the clinical realities and moral dilemmas of practicing medicine in Kenya, Tanzania and the USA before ART was widely available and accessible. They noted the challenge of practicing "good" medicine within resource constrained health services, as defined by 'Western' biomedical standards, where the HIV epidemic threatened patient care. Livingston (2012) described a similar situation in Botswana where medical centres were under-resourced, bed space was limited, machines broken, and drugs out of stock. She adds, "*Those few doctors and nurses who remained were forced to make terrible choices as they improvised in impossible circumstances"* (Livingston, 2012, p. 177). In these situations, improvisation and innovation are daily imperatives. van Olmen *et al.* (2011) suggest that scarce resources and low-quality healthcare often result in poor health outcomes in LMICs.

Rieder (2017, p. 3), in the context of rural Ethiopian clinical and biomedical practice, suggests that *"the contested nature of biomedicine becomes evident in gaps between established guidelines and sociomaterial dimensions of clinical realities produced through necessarily improvised and ad hoc practices".* She argues that with poor support and technology availability, biomedicine is improvised and contextualised. However, Rieder also notes how

"structural constraints" can outweigh physicians' abilities to improvise. Farmer (2001) suggests these constraints are a form of "structural violence" which constrain individual agency. Wendland (2010, p. 24), describes how medical students in her ethnography in Malawi coped creatively when their lives were *"in every respect shaped by the same structural violence that produces patients' suffering".* She notes how extreme resource constraints meant doing what was required was not possible – similar constraints exist concerning the diagnosis, treatment, and care for PWPD in SSA (Section 2.2.2). Instead, Wendland (2010, p. 135) describes how medical students *"used various combinations of avoidance and improvisation to cope".*

2.4.3 "Tinkering", "strategies", "biotactics" and self-management

Several concepts have been developed in different contexts to make sense of the changes people with chronic conditions make in their lives, and to their disease management, to make life more habitable or manageable. In Botswana, Livingston (2012) has referred to ideas around the "tinkering" of "best practice" medicine which is required to achieve 'good' care in complex circumstances. In the Netherlands, Mol (2009) defines "tinkering" as the adaptation of technologies and situations in order to achieve desired health outcomes. Mol (2009) discusses how people with diabetes may have to "tinker" or "doctor" regimens to fit with their bodies and within their schedules, which could be seen as a deviation from recommendations. Tight regulation of chronic disease management may not always be possible, especially if medication is unavailable or unaffordable. Mol and Law (2004) suggest that medicine should realise that what it is offering is therapeutic interventions into 'lived bodies' and daily lives. The concept differs from "improvisation", which involves coping and making difficult choices to provide some form of care in the face of suffering. Rieder (2017) argues that the success of "tinkering" depends on the nature and degree of structural constraints. In Ethiopia, she identified physicians' frustrations and disappointment because of the need to constantly improvise and "tinker" their practice. In this setting, although innovation is necessary, "tinkering" has its limitations.

Guell (2009) echoes that "tactics" and "strategies" are required for people to achieve a more 'liveable life'. de Certeau (1984) introduced the terms "strategies" and "tactics" to describe the ordinary practices of everyday life. "Strategies" encompass all aspects of daily life at all

times – these are 'hegemonic' in that they are associated with power. Tactics depend on situations and time and are developed to interfere with "strategies" – also thought of as 'tools of the weak' (de Certeau, 1984; Yilmaz, 2013). Guell (2009) coined the term "biotactics" as an extension of de Certeau's "tactics" and Foucault's "biopower" (Foucault, 1977) to understand how Turkish migrants living with diabetes in Germany manoeuvred health advice and adapted self-management recommendations to fit their lives (contrasting the idea of "tinkering", which relates more to the adjustment of practices or medication). Foucault's term "biopower", literally translated as having power over other bodies, incorporates concepts of anatomo-politics and biopolitics to describe the monitoring of lives and controlling of populations. "Biopower" can be used to model the way governments and policy control populations. Kleinman (2010) suggests that the importance of "biopower" within countries grows as health programmes develop. Guell (2009) argues that if recommendations about how to control diabetes using biomedical frameworks can be understood using Foucault's biopower, then "biotactics" can explain people's self-management of their condition (Guell, 2009).

Self-management describes the active role patients have in their treatment and daily management of chronic conditions (Grady and Gough, 2014) – a concept based on the social cognitive theory of self-regulation (Bandura, 1991), which proposes that people develop strategies by observing themselves within situations and responding with problem solving behaviours. van Olmen *et al.* (2011) suggest that people play a significant role in managing their own day-to-day lives and can become experts in living with their disease. Townsend *et al.* (2006) explored the self-management of people living with multiple chronic illnesses in Scotland. They found that people strive to manage their condition 'well' and see it as a 'moral obligation', but they often prioritise maintaining a 'normal life', creating a tension between symptom control and upholding social roles. Corbin and Strauss (1988) suggest that as people endeavour to manage symptoms, they are also attempting to manage daily life, linking 'illness work' and 'everyday life work'. Grady & Gough (2014) add that self-management exists within the context of healthcare providers, families, and communities. Whyte (2014) proposes that the supportive role of the family is crucial in the incorporation of chronic conditions into one's life, particularly where health services are scarce. However, in coastal Kenya, Abdulrehman *et al.* (2016) identified barriers to the self-management of

diabetes, including limited disease understanding and misconceptions, high poverty and high costs of biomedical treatment. These challenges may also affect PWPDs' ability to self-manage.

2.4.4 The sociality of treatment

Whyte (2014) refers to the "sociality of treatment" in the context of ART in Uganda where treatment and everyday life were both profoundly reliant on kinship. Whyte also identified the sociality that emerged from treatment programmes, using the term "clientship" to capture the personal relations that developed from this relationship. Among PWPD, Soundy *et al.* (2014) also propose the importance of social support in maintaining social identity.

The concept of "biosociality" was coined by Rabinow (1996) who believed that the existence of new biotechnologies could lead to revised perceptions of biologies, and in doing so create new socialities and identities based on biological conditions. Guell (2011) suggests that "biosociality" has been used to understand the social relations that emerge from biotechnological advances and high-tech therapy, as intended by Rabinow. However, she argues that "biosociality" can still exist around less 'high-tech' technologies. In Tanzania, Marsland (2012) suggests that a nuanced understanding of "biosociality" is required where "sociality" is taken as seriously as "bio", taking into account pre-existing social relations and networks. Although PD does not involve any 'high-tech' technologies (in the Kenyan setting, at least), Marsland's understanding of "biosociality" could provide a useful way to understand if PWPD form social groups around their condition. Whyte (2012) suggests that "biosociality" and "citizenship" have become central to anthropological research around chronic conditions.

The concept of "biological citizenship" invites us to look at how people transform their biomedical definition to make certain claims (Rose and Novas, 2007). Petryna (2003) used the term to refer to the demand for social welfare based on medical, scientific and legal criteria after the Chernobyl disaster. She describes "biological citizenship" as a 'complex bureaucratic process' that allows groups and populations to gain compensation and ultimately medical support, albeit selective and limited. Nguyen *et al.* (2010) introduced the term "therapeutic citizenship" to describe the sense of rights, responsibility and possibility of participation that people living with HIV had during the rollout of ART in West Africa.

Citizenship involves a political element and has been used to describe the lobbying for access to rights and technologies by certain groups (Guell, 2009). Whyte (2012) suggests that citizenship may be more relevant in societies where technology is available and accessible but acknowledges it may still prove useful for examining lived experiences of chronic disease in SSA.

Complementing the ideas of "biosociality" and "citizenship", Whyte (2014) introduced the term "therapeutic clientship" to understand the "biosociality" in patron-client relationships among people with HIV and healthcare providers in Uganda. She describes the sense of belonging people felt as a member of a clinic, where having their own file and clinic ID meant they belonged and were recognised, perhaps more so than by their own governments. Nguyen *et al.* (2010) also described this in Burkina Faso where clinic cards provided access to healthcare and essentially, life. Whyte *et al.* (2013) suggest that "therapeutic clientship" is more appropriate than citizenship for the context of Uganda because it entails a 'thinner' more 'restricted' set of rights and claims. Health services in SSA are often highly fragmented and no single organisation can provide people with citizen-like rights (Whyte *et al.,* 2013). The authors also propose that "therapeutic clientship" is heuristic and could be useful in exploring the relationships through which people with chronic conditions manage their lives.

In the context of SSA, Whyte (2014) suggests that "sociality" and "kinship" may act as a substitute for 'Western' notions of citizenship as the latter does not exist in the form of entitlements. How and if people access technology is largely dependent on "connections" and "clientship" – social relations between people with chronic conditions, their families, neighbours, healthcare providers and fellow sufferers can be viewed as resources for care (Whyte, 2012).

2.4.5 Alternative therapeutic landscapes

Alternative therapeutic landscapes involve the use of 'traditional medicine' which describes the indigenous health traditions of communities and cultures across the world and 'complementary and alternative medicine', approaches to healthcare outside of mainstream biomedical practices (Bodeker and Burford, 2008). Just as within biomedicine, diversity in traditional, complementary and alternative medicine exists in different contexts, sub-cultures and for different health conditions. Furthermore, 'herbalists' in Africa provide

advice on common health concerns or specialise in particular fields – these forms of treatment are seen as "complementary" but also often "competitive" (Olsen and Sargent, 2017).

Interactions with different healing landscapes for treatment have been observed widely in SSA. Kleinman (2017) has described "medical pluralism" as the 'reality' of African healthcare, a concept used to understand the diversity of practices within a health system (Gale, 2014). Olsen and Sargent (2017) propose that people draw on a "therapeutic continuum" incorporating different aspects of care, which are often used at the same time. Sargent and Kennell (2017, p. 227) with reference to healing in Benin, suggest that "therapeutic modalities" overlap and *"patients, often with the advice of kin and friends, consult diverse practitioners as diagnoses evolve over time, as efficacy of treatments waxes and wanes, as symptoms are interpreted and reinterpreted, and as new counsel is offered by respected others".* Mokgobi (2014) suggests that societies develop their own ways of dealing with illness by drawing on "cultural relativism" – cultural context is *"critical to an understanding of people's values, beliefs and practices"* (Howson, 2009, p. 1).

Mshana *et al.* (2008) explored the local understandings and treatment seeking behaviours of stroke patients in urban and rural Tanzania where beliefs about cause of disease and explanatory models outweighed other factors, including cost and distance, for treatment seeking. However, use of multiple treatment options, "medical pluralism", was common and incorporated hospital care, traditional medicine and faith healing. Mshana *et al.* (2008) argue that in SSA medical pluralism based on 'natural explanations' (illness theory) and 'supernatural explanations' (religious ideology) is common. The authors suggest a role for multiple healing systems in the treatment of stroke. In Uganda, Whyte (2014) acknowledged that people with HIV also tried herbal and traditional medicine and believed that God made ART work and so, faith and prayer were crucial to recovery.

Omonzejele (2008) in Nigeria and Mokgobi (2014) in South Africa have recognised the importance of spirituality and faith in chronic disease management. Asare and Danquah (2017) propose that for many Africans, wellbeing comprises spiritual involvement, healthcare and lifestyle. Janzen (2017) adds that in Western Equatorial Africa, "divination" is involved when dealing with misfortune or illness. Selman *et al.* (2010) believe that spiritual care is an intrinsic component of care globally which can improve quality of life, particularly

at the end of life – the authors have provided spiritual care recommendations for people receiving palliative care in SSA. Selman *et al.* (2013) also identified 'peace' as a measure of spiritual well-being at the end of life, while being at peace with others was fundamental, as identified by Seale and van der Geest (2004) in Ghana. Spirituality and faith may also be important components of PD management in Kenya.

The use of traditional Chinese medicine in treating the similar manifestations of PD dates back 2,200 years and is still commonly used in China (Wang *et al.*, 2011), and much of Africa more recently. Ayurveda, an ancient traditional medical science dating to 1500-1000 BC, is still practiced in India (Ovallath and Deepa, 2013). The use of herbal medicine among PWPD has been identified in Tanzania (Mshana *et al*., 2011) and Uganda (Kaddumukasa *et al.,* 2016). Kigen *et al.* (2013) suggest that the use of traditional medicine practices in Kenya is on the rise as biomedicine faces barriers to successful treatment of chronic conditions. However, they acknowledge the difficulties in identifying 'fake doctors' where desperate patients are often conned into treatment. This can be problematic for people with long-term conditions who may receive ineffective, and possibly expensive, treatment (Dotchin *et al.*, 2007). Marsland (2007) found that traditional healers in Tanzania were adopting modern practices, for example, using technologies to manufacture and bottle 'medicines' or learning biomedical techniques, in order to compete with biomedicine and convince clients of their legitimacy. Hampshire *et al.* (2017) also identified various "signals", for example, using biomedical diagrams, displaying religious symbols or being a widely-recognised brand, that healers in Ghana employed to convince people of their trustworthiness.

Barry (2006) proposes Csorda's theory of embodiment (Csordas, 1997) to understand how bodily experiences and changed bodily states can be therapeutic – whether an alternative therapy works is based on the difference it makes to bodies, beliefs, social and cultural experiences rather than according to scientific criteria. Consequently, traditional, complementary and alternative medicine offers a way for people to make sense of their condition, something biomedicine often cannot do. Furthermore, when biomedical services are inaccessible, people may seek out alternative services instead. However, factors including cost, distance, availability, past experiences, social networks, interactions with services and household dynamics all play a part in treatment seeking patterns (Mshana *et al.*, 2008).

2.5 Ageing in sub-Saharan Africa

As Parkinson's disease is largely associated with later life, it is necessary to understand how people make sense of ageing with the added complexities of progressing symptoms. Singer (1974), in a pioneering study on the social consequences of PD in the USA, acknowledged how symptoms accelerate and intensify the ageing process. Brod *et al.* (1998) suggest that PD as a disease of ageing, associated with physical and social decline, has implications beyond chronology. In her ethnography on PD in the USA, Solimeo (2009, p. 17) writes, *"Viewing PD as a condition, as a state of embodiment between disease and illness, emphasises the complexities inherent in its treatment and demonstrates the importance of social context in understanding the ageing experience".* Research on the experience of ageing in SSA is therefore an important backdrop for this study.

It is crucial to acknowledge that old age is socially determined and definitions of what it means to be old vary across SSA and beyond (Hoffman and Pype, 2016). Although the United Nations use age 60 as a cut-off point in defining older people, use of chronological age has been widely criticised (United Nations, 1991; HelpAge International, 2002). Use of socially constructed meanings that identify ageing as a process and stage can generate more accurate representations of local perceptions of old age (Ezeh *et al.*, 2006). In a qualitative study conducted in Nairobi exploring the meanings of being old, Ezeh *et al.* (2006) found that people's physical and reproductive attributes, marital status, lifestyle, life experiences and the person's role in the community were used to identify older people. However, for the purpose of describing population demographics, chronological age of over 60 is used.

The number of persons aged over 60 in SSA is set to dramatically increase in the next few decades, playing a significant role in shaping the size and distribution of the global population (United Nations, 2015a). In the 2009 Kenyan population census, there were 1.93 million people aged over 60; in the 2019 census, this number increased to 2.74 million (KNBS, 2009; KNBS, 2019a). However, the percentage of the older population is going to remain relatively low (Pillay, 2012) due to high 'Potential Support Ratios' – defined by the number of people aged 20-64 per the number of people aged 65 and over (United Nations, 2015b). Kenya has 19.73 'younger persons' for every older person, although fertility rates are falling and could contribute to population ageing.

2.5.1 Research on ageing in sub-Saharan Africa

There have been few studies, qualitative and quantitative, conducted on the experiences and needs of older SSA populations (Apt, 2001; Zimmer and Dayton, 2005; Hoffman and Pype, 2016). However, in line with recent developments, including the African Research on Ageing Network established in 2005 and the WHO study on global AGEing and adult health in 2002, ageing is gradually being recognised as an area requiring research. Aboderin and Hoffman (2015) note a growth in evidence available on the experiences of older people in the region, which argues towards great vulnerability and lack of care opportunities, but also notes the valuable role of older populations as carers and producers. The body of literature on ageing in SSA is increasing, but much of the research remains focussed on the impact of HIV/AIDS on older generations and family structures (Chepngeno-Langat *et al.*, 2010; Njororai and Njororai, 2013). Furthermore, no research in Kenya has explored the impact of chronic illness on the experience of ageing.

The majority of ethnographic research conducted in SSA has focussed on the living arrangements, family structures and intergenerational bonds (Apt, 2001) of rural communities, including older populations in rural Ghana (van der Geest, 1997; van der Geest, 2002a; van der Geest, 2004a) and rural western Kenya (Cattell, 2008). Darkwa (2002) suggests that as most older people live in rural SSA, welfare policy and research has largely focussed on their needs. For example, of Kenya's 2.74 million people aged over 60, 2.3 million (83.6%) live in rural areas (KNBS, 2019a). However, there are 450,380 people aged over 60 living in urban Kenya and this number is predicted to continue rising; their needs require further research (Aboderin, 2016).

2.5.2 Shifting intergenerational relationships

Family support has generally been seen as the main source of care for older persons in SSA for generations (Aboderin and Hoffman, 2015), while formal social support and healthcare systems tend to be lacking. "Traditional" care structures are typically embedded in complex cultural and historical systems, whereby older people care for younger generations as well (Apt, 2001). Older people have long been vital members of communities, with a wealth of knowledge and wisdom. However, with increasing life expectancies, as described in Chapter One, added life years are often not disability free. Increasing numbers of older people are

becoming more dependent on families for care. Whyte (2014) proposes the fluid nature of kinship networks where reconfiguration is driven by increased needs for support. In Zimbabwe, Kimuna (2005) suggests that older adults choose living arrangements based on requirements – this results in being able to live alone or needing to be amongst family. However, researchers are noticing a gradual shift in care structures and support (Hoffman and Pype, 2016), which could result in older people not having a say in where, or with whom, they live, or the support they receive.

With increasing economic challenges and the breakdown of extended family ties, families are becoming less able to care for older members (Apt, 2001). In rural western Kenya, Cattell (1989) found that older people felt they were no longer valued and received less respect than they did historically – the 416 older participants blamed "education" of younger generations as the main contributor to this change in values; van der Geest (2002a) identified similar findings in Ghana. However, both these studies were conducted in rural areas some time ago. In urban Ghana, Aboderin (2004b) conducted a qualitative study using a three-generational respondent sample to investigate the decline in material support for older people – including 51 respondents from three different income statuses and two ethnic groups. She found that adult offspring across all gender and ethnic groups were beginning to enforce a conditionality on reciprocity because of increasing resource constraints and changing values. A shift in focus of younger generations towards material goods and a re-focus of resource allocation on younger family members was also found (Aboderin, 2004b). Furthermore, Ezeh *et al.* (2006) in their study in Nairobi identified that several older people in informal settlements lived alone and lacked capital and care opportunities. Older people were also continuing to work in later life, although those with illness and disability may not be able to.

Urbanisation and material constraints are thought to be contributing to the reduced ability of families to reciprocate care for older people (Apt, 2001; Aboderin, 2004a), although with no alternative support available and no policies in place, people will continue to rely on their families for support in later life where possible. Modernisation theory, which suggests that modernisation contributes to a decline in the status of older people and reduced family support, has been used to understand the social and economic changes occurring in SSA (Cohen, 2006). However, Ferreira (1999) has argued that modernisation is an over-simplistic

theory – families are interacting with modernity not being acted upon. An alternative theory is that increased economic hardship, poverty and material deprivation are contributing to a decline in support (Aboderin, 2004a). However, discrepancies in wealth exist with varying access to services including health facilities, pension and insurance schemes. With insufficient means for care, material deprivation is likely to be a problem for older city-dwelling generations in particular (Apt, 1997). Despite this, there is a lack of substantial data to back up these claims and further research is required, particularly in urban areas (Hoffman and Pype, 2016). People living with PD are ageing with the added burden of a degenerative condition associated with increasing care requirements. With limited formal social support, as seen in Tanzania (Mshana *et al.,* 2011), care work is likely to fall on family members, while economic challenges, material constraints and shifting care networks are negotiated.

2.6 Chapter summary

This study aims to contribute to the scarce body of literature on PD in SSA using ethnographic methods to explore the lived experiences of PWPD living in Kenya and the social relations that emerge from treatment and management. Although there is substantial literature on the experiences of PWPD in high-income countries with developed healthcare systems, how people live with, and manage, PD in low-/middle-income countries with over-burdened healthcare systems is lacking. However, theories and concepts developed around other chronic conditions, such as “improvisation” and “biosociality”, and care resources for older people within the field of global health may provide useful insights into how PWPD might navigate therapeutic landscapes and social support in low-resource settings.

Chapter 3. Conducting ethnographic research with people with Parkinson's disease in Kenya

Chapter overview

In this chapter, I describe my ontological and epistemological standpoints and outline the methodological rationale for this ethnographic study. I then describe the process of "entering the field", providing an overview of recruitment and some research context. I provide a factual account of ethics processes, describe the methods used, how the data were analysed and a description of the PWPD sample. Finally, I provide some reflections on the challenges I encountered throughout fieldwork, including my positionality and the emotion of ethnography, particularly regarding a degenerative condition like PD in the context of scarce resources and high poverty.

3.1 Methodological rationale

This thesis draws on nine months of fieldwork conducted from March 2018 in spaces and places across Kenya and a second shorter period of data collection during May 2019. An ethnographic approach allowed me to gain a holistic and in-depth understanding of how PWPD and their families lived with, and managed, PD.

I approached this research from a relativist ontological and social constructionist epistemological perspective. From a social constructionist approach, meaning and experience are socially produced (Burr, 1995) as people engage with and interpret the world (Crotty, 2014). Guba and Lincoln (1994) propose that ontology seeks to understand what the nature of reality is and what can be known about it. Epistemology seeks to know how knowledge is created and communicated (Scotland, 2012). This research used an interpretivist paradigm (Kuhn, 1962) – paradigms are organising frameworks for theory and research that can be defined by their ontological, epistemological and methodological properties (Neuman, 2014).

As Berger and Luckmann (1966) propose, knowledge is socially constructed through interactions with the social world. Ethnography, as a methodology, can be used to acquire knowledge to study socio-cultural contexts, processes and meanings (Whitehead, 2004).

Winch (1958) proposed that researchers immerse themselves into a specific culture to fully understand people's beliefs and practices. The aim of ethnography is to generate a "thick description" of people's lives and meanings (Geertz, 1973). The goal of this study was to gain an empathetic understanding of participants' emotions, feelings, behaviours, experiences and social interactions within a culturally specific setting. As such, interpretivism, as a paradigm and theoretical approach to research, is concerned with the individuality of situations within particular social, cultural, political and economic contexts.

In order to address the broad research questions, I required a flexible yet rigorous methodological approach that was open to unanticipated findings (Wendland, 2010). Ethnography is both an approach to data collection and product of fieldwork – this study utilised: participant observation (and field notes), formal interviews, informal interviews, and questionnaires. Malinowski (1932, p. 25) proposed the use of participant observation as a tool to record the "imponderabilia" of everyday life in the form of a research diary, suggesting that *"the goal [of ethnography] is, briefly, to grasp the native's point of view, his relation to life, to realise his vision of his world".* Participant observation allows researchers to gain an understanding of what people do and how they experience and interpret this (Mack *et al.*, 2005). Formal in-depth semi-structured interviews with PWPD and family members took a biographical approach, reflected in the findings of this thesis. In-depth interviews allow researchers to learn about participants' experiences, emotions and opinions (Mack *et al.,* 2005), how they interpret the world and how they perceive relationships with others. Open-ended questions allowed conversations to shift naturally to avoid bias and my own preconceived ideas. Field notes taken during interviews, regarding emotion, were valuable during transcription and analysis. Finally, demographic data obtained from the questionnaire survey were able to describe the PWPD sample as a whole. Informal interviews occurred throughout the administration of questionnaires, and with healthcare professionals, and were recorded as field notes.

Weber used the word 'Verstehen' to represent how people interpret the meaning of actions and understand subjective realities (Bernstein, 1976), attempting to gain an empathetic understanding of participants and generate as close to an emic account as possible. In anthropology, this idea is similar to "cultural relativism". Interpretivism seeks to understand how individuals' subjective worldviews explain their behaviour (Winch, 1958). Winch (1964)

proposed that ideas about how the world works are culturally embedded – researchers cannot enter a "culture" with pre-conceived ideas about the world: although, as we are all to some extent products of our cultural backgrounds, we always do carry these ideas with us, which risks loss of objectivity, generating a more etic account (outsiders point of view). Ethnography must consider political-economic, sociocultural, historical and cultural contexts. Wittgenstein notes the risk of unintended social consequences (Merton, 1936) in bringing "baggage" into a culture (Whitaker, 1996) – as Scheper-Hughes (1992) adds, ethnographers must give voice to individuals and an opportunity to tell their life story and avoid reducing them to 'objects'.

3.2 Entering the field

This section describes the process of entering the field, including the recruitment of participants: PWPD, family members, healthcare professionals, herbal and religious healers. I also provide some context regarding the urban and rural locations in which fieldwork took place.

3.2.1 Recruitment

I chose Kenya as the location for this study partly because of pre-existing contacts with two neurologists in the country. These neurologists became in-country supervisors and facilitated access to two groups of PWPD with very different resources in Nairobi – those attending the only public neurology clinic in Kenya (located at the national referral hospital) and those attending a private neurology clinic in a private hospital. Although the Kenya Medical Research Institute (KEMRI) Scientific Ethics Review Unit approved this study in April 2018, I could not recruit from the hospitals for several months because of institution ethical delays – consequently, I found alternate ways to identify PWPD until July 2018 when I received these ethical approvals.

Before arriving in Kenya, I came across the website of a PD non-governmental organisation (NGO) based in Nairobi – Africa Parkinson's Disease Foundation (APDF), founded in 2013. I contacted the founder in April 2018, who informed me of a PD support group (PSG) that held meetings every month in Nairobi. I attended my first meeting in April and was given the opportunity to introduce my research to attendees. The group enabled access to PWPD with

different resources and experiences. However, attendees were largely of a higher socioeconomic status; meetings were conducted in English and outside the reach of many Kenyans. The meetings became a key site for recruitment of PWPD and family members, and a setting for ethnographic observations (Section 3.3.2).

I wanted to access PWPD from different places in Kenya to gain a more holistic understanding of PD management. One of my in-country supervisors connected me with a neurologist in Mombasa who ran a private neurology clinic (there is no public neurology clinic there). The neurologist granted me access to his patient files and a member of staff identified all the clinic's PD patients[3]. I began recruitment from the clinic in July 2018 and carried out an informal interview with the neurologist.

In August 2018, recruitment began from the public and private neurology clinics in Nairobi. At the private clinic, staff identified all PD patients. At the public clinic, my in-country supervisor connected me with staff at the information office of the neurology clinic who facilitated access to patient files, from which I identified PWPD. The files of patients attending the weekly Monday morning clinic were retrieved from the hospital file room every Friday – I went through on average 100 files per week to identify patients with a confirmed PD diagnosis. I noted down PWPDs' names and gave them to the office staff. On the Monday, the staff in the information office would shout out the names I had identified into the waiting room of patients, calling them over to speak with me. This process also allowed me to obtain data on the prevalence of neurological conditions being seen at the public neurology clinic (illustrated in Chapter Five). I also conducted two formal interviews and two informal interviews with neurologists (who also ran separate private clinics), five student registrars and carried out ethnographic observations during clinics hours (Section 3.3).

One of the founders of the Nairobi PD support group, William, moved to live in Kisumu in western Kenya during fieldwork. A man who ran a disability group in a village 65km south of Kisumu believed he had several PWPD attending meetings and contacted William, asking if

[3] Payment for a member of staff to identify PD patients from the clinic files was included in my fieldwork budget.

he would visit. I was invited to attend and observe the meeting with William and a private neurologist based in Kisumu in October 2018 – this meeting is described in Chapter Four.

Three PWPD recruited from the PD support group and private neurology clinic in Nairobi lived in rural Central Kenya. I spent seven days in the area over three separate visits, administering questionnaires and conducting interviews with PWPD, conducting informal interviews with medical staff in six different hospitals (four private and two public) and visiting local pharmacies to understand what services were available. The daughter of one PWPD introduced me to a community health volunteer whom I formally interviewed – he also invited me to attend a diabetes support group meeting, which he ran in several villages in the area (Section 3.3.2).

As eight PWPD sought treatment from herbal healers, I wanted to understand how they managed PD and informally interviewed three herbalists. Thirteen PWPD also identified using religious healing for the management of PD and so, with the guidance of the founder of APDF, I attended a religious healing event on the outskirts of Nairobi in August 2018. These encounters are described in Chapter Five.

3.2.2 Research context

This section describes the different locations in which fieldwork took place (*Map 1*). I spent most of the fieldwork period in Nairobi and Mombasa (and surrounding areas), and less time in rural central Kenya (seven days) and Kisumu and western Kenya (two days).

Nairobi city

Fieldwork began in the capital city of Kenya (province 1 on *Map 1*). Nairobi is a cosmopolitan city surrounded by wildlife, and home to 4.4 million people (KNBS, 2019b). Nairobi is one of the fastest growing cities in Africa, due to high immigration and birth rates, sprawled over an area of 435km^2. However, more than half of Nairobi's residents (2.5 million people) live in one of the city's 200 informal settlements (APHRC, 2014). Kibera, the largest informal settlement in Africa, is situated in the middle of Nairobi, lined by golf courses and large housing estates. This slum is home to 250,000 people who occupy 6% of Nairobi's land. Mathare, a collection of slums in Nairobi, has a population density of 68,941 people per km^2 (KNBS, 2019b). A highway separates Mathare from one of the richest areas in Nairobi,

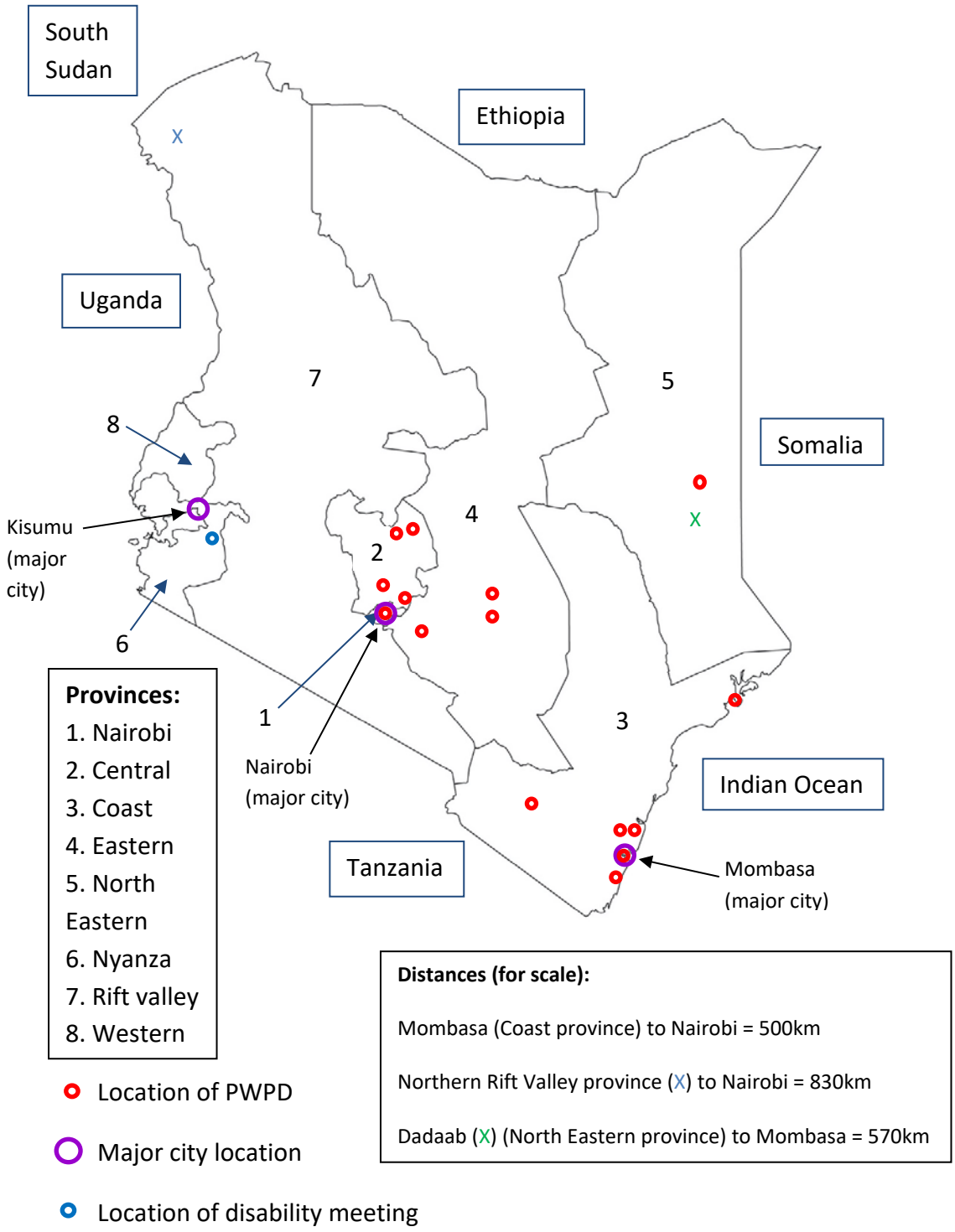
Muthaiga (in the sub-county of Westlands), home to embassies, hospitals, shopping malls, large residences and country clubs. Westlands has a population density of 3,167 people per km^2 (KNBS, 2019b). There are huge disparities in wealth, resources and living conditions in Nairobi – the presence of the United Nations Africa Headquarters adds to the high living costs in the city. Nairobi is home to most of Kenya's private hospitals and only public neurology clinic.

Kenya is 'urbanising' by 4.3% every year (World Bank, 2016) – rural dwellers seek out 'city life' in search of employment, although many end up living in slums (APHRC, 2014). There is also an increasing population of older people living and retiring in Nairobi. This population often end up staying in the city because of access to healthcare and services not available in villages, as well as dwindling ties with rural life (Ezeh *et al.*, 2006). It is also common for younger people to leave their older parents in rural Kenya (McIntosh, 2017). However, this creates a link to health services in Nairobi.

The *matatu* (minibus or bus) is the main form of public transport in Nairobi (and other major cities), which are often very cramped and difficult to board. *Matatu* services also connect Nairobi to other provinces. *The boda boda* (motorcycle taxi) is an alternative method of public transport, though difficult for older people to use. More developed areas of the city have footpaths but most of the city does not, making it difficult to travel by foot for older people or navigate wheelchairs.

Rural Central Kenya

Central province (province 2 on *Map 1*) is home to Mount Kenya. The area lies in the fertile foothills of the mountain at an altitude of 6,000 feet (*Image 1*). Tea and coffee farms are the main features of this region, interspersed with small towns and villages. The province is located 150 to 250km from Nairobi, so is considered relatively well connected to the capital. The province has a population of 5.45 million people across an area of 13,150km^2 and a low population density of 441 people per km^2 (KNBS, 2019b).



Map 1. Locations of provinces, major cities, PWPDs' residences and distances for scale

Image 1. View of Mount Kenya, Central province, from Nanyuki

Central province has several private hospitals and government hospitals in most large towns. There are no neurology services and no neurologists practicing in the area. Nyeri city is the province's headquarters, 25km from a smaller town, Karatina. Nanyuki is a town split between Central and Rift Valley province. It is home to a British military base and consequently, home to many wealthy expatriate families. These three towns were key fieldwork sites in the area (see *Map 1*).

Matatu services connect main towns in Central province to Nairobi but access to villages is difficult. *Boda bodas* are the most common method of transport used, making travelling difficult for older people – most households do not own cars and would have to hire a taxi to transport older parents to the nearest town or Nairobi.

Mombasa and coastal Kenya

Coast province of Kenya (province 3 on *Map 1*) is a coastal strip along the Indian Ocean but also covers inland rural regions – an area of 50,000Km^2 home to 4.3 million people. Mombasa city is the oldest and second largest city in Kenya, home to 1.2 million people (KNBS, 2019b). The island of Mombasa has a population density of 10,543 people per km^2 (KNBS, 2019b). Mombasa's historic rulers included the Omani, giving origins to its largely Muslim population, and Portuguese empires. I explored this region as a secondary urban context (described in the narrative below), as well as the rural areas surrounding Mombasa city within a 50km circumference.

7th August 2018

Several people with Parkinson's disease who attended the private neurology clinic in Mombasa resided in the Old Town, an area near Fort Jesus, one of the main touristic sites on the island. I was visiting one PWPD with Joel, who worked at the clinic and assisted with interpreting. The streets on the island were narrow and lined with old Lamu style doors[4]. I found an open area to park my car before the streets became too narrow to negotiate. A street vendor selling maize said he would keep an eye on the car for 100Ksh (75p) on our return. We wandered down the narrow streets asking passers-by if they could direct us to a certain building, the home of the PWPD we were visiting. Eventually, we found a sign directing us to the building. As we turned the corner, we saw the glistening sea of Mombasa creek at the end of the alley (*Image 2*). To our left was a condemned building in danger of slipping into the creek.

The main method of transport around Mombasa is the *matatu*, *tuk-tuk* or *boda boda.* Mombasa is one of the only places in Kenya where *tuk-tuks* can operate – they are enclosed, three-wheeled auto-rickshaws and are cheap and more accessible for older people than motorcycles. However, transport from Mombasa city to rural areas is more difficult. *Matatu* services run to main towns but not remote villages. Older people who cannot use *boda bodas* or *matatus* hire costly taxis to travel to the city. Mombasa is located 500km southeast of Nairobi, where the only public neurology clinic is, although two private clinics are available in the city. Buses, *matatus*, flights and a railway link the two cities.

Image 2. View of Mombasa creek from the Old Town

[4] Lamu is an island off the coast of Kenya in the coast province. The area produces wooden doors and furniture decorated with brass bolts, plates and studs – a Swahili influence.

Kisumu and western Kenya

Kisumu (see *Map 1)* is an inland port city on Lake Victoria (also known as Lake Nyanza or *Nam Lolwe* in *Luo* dialect), Africa's largest lake, and capital of Nyanza province. Kisumu is the third largest city and capital of 'western' Kenya. Lake Victoria covers an area twice the size of Wales and forms a natural boundary between Kenya, Tanzania and Uganda – the lake is bordered by Western and Nyanza province (provinces 8 and 6 on *Map 1*). Kisumu city is known for its fishing and agriculture and has a population of 26,000 people, while the county has a population of 1 million in an area of 1,300km^2 (KNBS, 2019b). Nyanza and Western provinces have a population of 13 million people with a population density of 568 people per km^2 (KNBS, 2019b). Two private neurologists practise in Kisumu city, serving the entire Western and Nyanza provinces. Buses and flights connect the region to Nairobi, 350km away.

3.3 Research methods

3.3.1 Ethics

Ethical approvals

Newcastle University Faculty of Medical Sciences Ethics Committee approved this research study in August 2017. The study was approved by Kenya Medical Research Institute in April 2018. Institutional ethical approvals to recruit from the public neurology clinic and private neurology clinic in Nairobi were obtained in July 2018. Ethics extensions for fieldwork conducted in May 2019 were obtained from Newcastle University in February 2019 and KEMRI in April 2019.

Informed consent

All PWPD involved in the questionnaire survey (including informal interviews) and all PWPD, family members and healthcare professionals involved in formal interviews were given an information sheet to read (or I read the information to them as requested) and signed a consent form prior to their participation. These were available in both English (Appendix A, C, F, I) and Kiswahili (Appendix B, D, G). All participants were made aware that they did not have to answer questions if they did not wish and could withdraw from the study at any point. All participants gave explicit consent for formal interviews to be audio-recorded. For

informal interviews with healthcare professionals and healers, verbal consent was obtained, and these were not audio-recorded; instead detailed notes were taken and typed up later in the day. These encounters were kept as informal as possible to allow conversations to flow naturally.

Participants were aware that the information they shared would contribute towards the study's objectives and would be published in order to improve the situation of life with PD in Kenya; including the use of quotes from recorded interviews or specific details about events they had experienced. They were also made aware that their names would not be included with any identifiable information or used in any publications. As such, quotes and information about them could be identified by themselves, but likely no one else. Issues surrounding confidentiality and anonymity are discussed further in the following section.

For ethnographic observations in clinics, support groups, the church healing event, diabetes support group and disability group meeting, participants were made aware, as far as possible, of my position. Consent in ethnographic research is an on-going process, not a one-off event, and requires renegotiation over time. In private neurology clinics, neurologists approved observations and the receptionists informed patients of my position. In the public neurology clinic, I sought approval from the chief nurse, information office staff, nurses and neurologists in the ward. However, informing everyone at the clinic waiting room (typically over 200 people) of my presence was impossible and impractical (Murphy and Dingwall, 2001). As Bourgois (1990) noted from his research in Central America, participant observation and fieldwork by its very definition dangerously stretches the anthropological ethic of "informed consent". Observations were focussed on general practices, rather than individual behaviours and characteristics, and there was no risk or harm to any individuals. Similar challenges with informed consent occurred regarding the church healing event, although in both the church and clinical settings, the presence of strangers is a normal expectation and therefore unlikely to be ethically problematic (Murphy and Dingwall, 2001). At the two rural group meetings (disability and diabetes), I informed the group leaders about my position and this was relayed to attendees. I obtained verbal consent from PWPD and family members while in their homes and herbal healers when in their clinics – participants were made aware of the research I was conducting, which would involve capturing data on spaces and their interactions with others.

Confidentiality, anonymity, and data protection

Names were removed from all questionnaires and interviews, and I informed participants that data would be confidential. However, as I discuss within this section, the personal information they disclosed could be identified by themselves, and possibly others who know them, and in this sense, data cannot be fully anonymised. Study numbers were used, which were kept separate to signed consent forms; field notes also used study numbers. Hard copies of data were locked away during fieldwork and post-fieldwork. Participants were not identifiable from recordings and interviews were stored on a secure, password-locked drive on my computer initially and transferred to my password-protected University drive on return to the UK.

Interpreters were required for several participants who attended the public neurology clinic and many who lived in Mombasa who did not speak English. Although I speak conversational Kiswahili, I did not want to miss any details or risk losing meaning. Adult offspring sometimes acted as interpreters. This raised certain challenges; for example, PWPD may not have been as open or commented on any issues with the care they received, and this could have influenced the data. However, some PWPD felt more comfortable in having a family member present and may not have participated if this was not possible. Often, someone outside the family acted as interpreter: in Mombasa this was Joel (introduced in Section 3.2.2), in Nairobi this was the founder of APDF or at the public neurology clinic, the information officer. Interpreters did not know the participants beforehand. They also signed the consent form to ensure confidentiality. In all cases, I requested that questions and responses were translated verbatim.

Pseudonyms are used for all participants throughout this thesis and identifiable details have been removed as much as possible, including sites of observations. However, I have taken the decision that I could not anonymise participants fully, although all doctors are un-identifiable. As Murphy and Dingwall (2001, p. 341) discuss, *"Field notes and interview transcripts inevitably record sufficient detail to make participants identifiable"*. Removing all identifiable details within narratives would risk losing context and meaning. Therefore, participants are likely to be able to recognise details about themselves or others within support groups (if they have shared stories about themselves during meetings). Any personal data that I thought participants had disclosed in confidence and would not want shared, or

may have been incriminating or caused private shame, have not been included, for example critical viewpoints about healthcare professionals. However, as Davis (1993) has suggested, what may or may not cause offence to participants is not a straightforward decision. It is also possible that ethnographic accounts can create alternate versions of relationships that people may not have been aware of. Some participants may also be disappointed by what has been left out of a report; Ellis (1995) has written about how publications can often cause hurt and offence to research participants.

During fieldwork, I used member-checking, returning analysed data to participants (Birt *et al.*, 2016), during support group meetings to improve the accuracy, validity and trustworthiness of certain findings that were common among participants. Overall, people described wanting their stories to be heard and told, which they hoped would help improve the situation for PWPD in Kenya as a collective. Perhaps the use of co-producing, or "collaborative ethnography" as Hampshire and Owusu (2013) have described, could avoid these challenges with identifiability, ensuring participants are involved in discussions about field notes. However, this could prove difficult with a large sample.

The data obtained from this study followed the guidelines of the UK Data Protection Act 1998 and the Statement of Ethical Practice for the British Sociological Association. The British Sociological Association gratefully acknowledges the use made of the ethical codes and statements of the Social Research Association, the American Sociology Association and the Association of Social Anthropologists of the UK and the Commonwealth. When conducting ethnographic observations, the Ethical Guidelines of the Association of Social Anthropologists of the UK and Commonwealth, the professional body overseeing anthropological research, were followed. Guidelines set out a series of commitments to which anthropologists must adhere.

3.3.2 Data collection: ethnographic observations

Ethnographic observations took place in: support group meetings in Nairobi and Mombasa (once established); the public neurology clinic in Nairobi; private neurology clinics (Nairobi and Mombasa); participants homes; a church healing event; a diabetes support group meeting in Central province; a disability group meeting in Nyanza province; and the clinics of two herbal healers – a total of 164.5 hours (*Table 2*). Reeves (2008) propose observational

dimensions that should be documented during participant observation: the space, actors, activities, objects, people's actions, events and sequences of events, goals and accomplishments, and emotions. The details recorded during observations in different sites (e.g. support group meetings or neurology clinic) varied depending on context – these are described in the sub-sections below. Mack *et al.* (2005) suggest that the goal of observation is to understand life as an 'insider' while remaining an 'outsider', being as unobtrusive as possible. Reflexivity throughout the process of fieldwork allows researchers to reflect on ideas and experiences to ensure integrity (Arber, 2006).

Location	**Hours of observations**
Nairobi PSG	30
Mombasa PSG	12
Public neurology clinic	36
Private neurology clinics	12
Participant homes	66
Church healing event	2
Diabetes support group meeting	1
Disability group meeting	2
Healer clinics	3.5
TOTAL	**164.5**

Table 2. Hours of ethnographic observations from different locations

Oral consent for observations was obtained throughout fieldwork. In most cases, field notes were handwritten and provided detailed and nuanced descriptions of the dimensions stated above. However, in some circumstances (mainly whilst carrying out observations in the public neurology clinic and church healing event) I opted to make notes on my password-protected smartphone, saving these notes to my University account. During these situations, I stood out as the only 'white' person and found it obvious or intrusive to handwrite notes in my research diary. Note-taking on my smartphone made my presence less obvious. Gorman (2016, p. 224) notes how ethnographers are increasingly using smartphones as note-taking mediums, where the *"everyday-ness of the smartphone"* creates opportunities for participants to feel more comfortable than a "scientific notebook" or recording device.

However, this could affect relationships and interactions. I was aware of this and limited the use of my smartphone during one-on-one conversations. The Communications Authority of Kenya (2019) estimates that 42.2 million Kenyan's are internet users and 20.7 million Kenyans own mobile phones (KNBS, 2019c) – seeing someone in a social space using a phone is perceived as normal.

PD support group meetings

I was able to attend ten support group meetings in Nairobi over the course of fieldwork, capturing 30 hours of rich observational data. Meetings were held in a small classroom located in a church compound in the middle of Nairobi. The group could use the room through donations to the church, which more affluent members contributed to. The room had an abundance of chairs – some had small desks attached, which PWPD found difficult to manoeuvre. Before attendees arrived, committee members or PWPDs' caregivers organised the chairs into rows. Some PWPD attended meetings with their spouse, adult offspring or employed caregivers, others were alone. Often family members came alone if PWPD could not attend. Sometimes healthcare professionals were invited to meetings to observe or give talks. On occasion, a dance group or art therapist would lead sessions. Usually, a group of 20-45 people attended meetings – this depended on the time of year and weather. If it was raining or cold, PWPD felt that their symptoms worsened, whilst several visited their rural homes or travelled over the holidays. Several 'core' members attended meetings most months; others were occasional. Furthermore, I informed PWPD I recruited from the public neurology clinic about the group meetings. Those who lived nearby were able to attend, although for others who could not understand English well, meetings were challenging. At times, attendees translated what was being said.

Through my awareness of the value of the support group in Nairobi, the absence of one in Mombasa and participants taking to the idea, I established a group in Mombasa in October 2018. Ethnographic action research can be used to bring about new activities through understandings of situations (Tacchi *et al.*, 2003). Informed reflection allows observations of actions to generate knowledge – a continuous cycle of planning, doing, observing and reflecting, involving people at all stages. Meetings were held in the waiting room of a private neurology clinic in Mombasa. The founder of APDF attended the first meeting. Although I

initiated the group meetings, involving PWPD, their family members and staff at the neurology clinic and providing them with ideas I had observed in Nairobi meant the group became self-sufficient once I left the field. I attended four meetings in Mombasa during fieldwork, totalling 12 hours of observations.

Observations in support group meetings aimed to understand the benefits and downfalls of the group, how participants interacted and engaged during meetings, and the role the groups played in the wider therapeutic landscape. I usually sat at the back of the classroom during meetings where I could observe and remain as unobtrusive as possible. I handwrote copious field notes in my research diary detailing information about the space, discussion topics and how people received them, discussions between members, interactions, people's actions and emotions, who participants attended meetings with and any changes that occurred over the months. These notes were written up in further detail later in the day. Furthermore, Gorman (2006) notes how advancing technology has created different mediums for participant observation, including social media and online 'text messages' or 'conversations' as ways of gaining insights. The PD support groups, through their respective WhatsApp groups, allowed me to observe the interactions between members through this platform of social media.

Public neurology clinic (national referral hospital)

Observations within the public neurology clinic in Nairobi offered insights into a group of PWPD with fewer resources who accessed biomedical care. The national referral hospital, the largest in Kenya, was located a short *matatu* ride, or 1.5km walk, from Kibera slum. People came from across the country, travelling long distances to attend their clinics and appointments. Some travelled overnight, arriving early to make sure they were seen or risk returning home without a prescription. Neurology outpatient clinics were held every Monday morning – by 8am people were already sprawled across the grounds, lying on benches, in corridors, in the gardens if it was not raining *(Image 3)*.

Image 3. People lying on the grass outside the main national referral hospital, waiting

I attended 12 neurology clinics, totalling 36 hours of observations; although questionnaires and informal interviews were also carried out with PWPD during clinic hours (Section 3.3.3). Observations provided an understanding of how public biomedical services in Kenya were contextualised (Livingston, 2012) and how PWPD manoeuvred health services. My base was the information office located in the centre of the large waiting room of the clinic. From here, I would spend time in different sections of the large waiting room: I observed how patients and their families manoeuvred the clinic and negotiated any challenges, people's actions and emotions throughout their visit, the 'system' of the clinic, routine of events, and interactions between patients, family members, friends and hospital staff. I spent time in the 'public' consultation corridor where I noted details about the consultations, and people's interactions with neurologists and registrars, their emotions and actions. Some neurologists used 'private' rooms, which I could not observe. I also spent some time outside of the clinic, observing the wider space, how the payment system worked, people's actions and emotions around the hospital. All field notes made at the hospital were done on my password-protected smartphone, this was much faster than handwriting notes, less obtrusive and obvious, and more practical, allowing me to make notes while standing or walking.

The public neurology clinic ran a first-come-first-served method and saw 100-150 patients during the three-hour clinic window. Patients had to provide proof of payment before being seen. People crowded around payment booths with their arms outstretched, separated from the cashier by metal bars and a grill, to pay their 650Ksh fee (£5.00) via M-Pesa. M-Pesa is Kenya's mobile phone money transfer service run by the mobile network Safaricom – the

hospital did not accept cash or card payments to reduce bribing and corruption. Patients then took their payment receipt to the information office. Five neurologists worked in the clinic, although on average only two or three were present – sometimes there were none. Consultation rooms were long corridors with benches and chairs spaced out (illustrated in Chapter Five). If patients were given a prescription, they could visit the hospital pharmacy next door, although the pharmacy did not stock any anti-Parkinsonian medication.

Private neurology clinics

Observations (totalling 12 hours) took place in two private neurology clinics (one in Nairobi and one in Mombasa), providing an understanding of how private Kenyan biomedicine was contextualised and how this experience differed from the public clinic. PWPD attending private clinics had more resources than those relying on public services. Private neurologists charged a significantly higher fee than the public clinic – ranging from £38 to £225. Approximately 16 neurologists practised across seven private clinics in Nairobi (in large private hospitals or smaller private facilities), two private neurologists practised in two different clinics in Mombasa and two private neurologists practised in one private hospital in Kisumu. Similar aspects were recorded as detailed within the public neurology clinic section; in particular, observations about the people attending the clinics and their interactions with neurologists. Field notes were typed on my password-protected smartphone for reasons discussed in the previous section.

Participant homes

Almost all questionnaires and interviews with PWPD recruited from the Parkinson's support group in Nairobi and private clinics in Mombasa and Nairobi were conducted in their homes. Although the time spent in each participant's home was limited, field notes included observation data about the spaces, including living situations and details about the surrounding areas, their relationships with family members and house help (if present), their ability to manoeuvre their homes, their emotions, actions and any events that took place while I was there. Detailed observations in participant homes were all written in my research diary throughout the duration of my visits. All PWPD and their families welcomed me into their homes (reflection in Section 3.5) – on some occasions, I stayed for several hours, which enabled me to witness PWPDs' changing state through the day as their medication began to

take effect or wore off, and the effect this had on their ability to carry out activities. In total, 66 hours of observations in participants' homes were carried out. I also spent many hours travelling to PWPDs' homes across Nairobi, Mombasa and Central Kenya and was able to explore the areas in which they lived. This provided me with an understanding of the long and expensive journeys many would have to make to access any services and details about these journeys were included in field notes.

Church healing event

I attended a church healing event on the outskirts of Nairobi (described in Chapter Five) with the founder of APDF. I spent two hours at the event, observing. I opted to make copious, detailed notes on my password-protected smartphone, a less obvious and intrusive option than making notes in a diary during a church service, drawing less attention to myself – this was also a more practical and quicker way of note-taking (as was done in the neurology clinics). Field notes detailed the order of events, the kinds of healing practices, types of healing requested, details about the space (including the hall, church and people), the pastor's interactions with attendees and objects, including the medical diagnoses they brought. The pastor spoke in Kiswahili and very quickly – I can speak and understand conversational Kiswahili but required much of what was said to be translated.

Diabetes support group meeting

While in central Kenya, I was able to interview a community health volunteer to understand his role in his community. The volunteer was trained in diabetes management – he visited family homes, testing people's blood sugar and blood pressure, and referring those who needed further care to clinics. He invited me to attend and observe a diabetes support group meeting (lasting one hour) in a village near Karatina – he ran meetings in several villages. The group allowed me to understand the importance of disease education in rural communities and the benefits of support groups for chronic conditions. They discussed their interactions with health services in neighbouring towns, as well as the role of the community health volunteer in rural Kenya. Observations included details about the space in which they met, the actors and people attending, their emotions about the services they accessed, and their goals for the future. All notes were handwritten in my research diary.

Disability group meeting

Observations during the two-hour disability group meeting I attended near Kisumu provided an understanding of the challenges of disease knowledge and differentiating disease symptoms. The neurologist drove us to the meeting and the 120km return journey (two hours each way) to this village (which would have taken far longer using public transport) also illustrated the challenges accessing a neurologist in Kisumu, creating difficulties with people seeking out services to obtain a diagnosis, or if diagnosed, following up treatment. Observations at the group meeting detailed the space (the hall where the meeting took place and surrounding area), the people who attended the meeting, the series of events and activities that took place, people's interactions with the neurologist and their emotions about the event. I handwrote these observations in my research diary.

Healer clinics

I visited the clinics of three healers in Kenya: one herbal clinic in Nairobi, one Chinese herbal clinic in Nairobi and one herbal clinic in a town in Central province – totalling 3.5 hours of observations. Informal interviews were conducted with all healers (Section 3.3.6) but handwritten field notes also included details about the clinics (i.e. the spaces), such as the 'medicines', supplements, books and posters they had on display, and the 'doctors' or healers' appearances, as well as their emotions, goals and actions.

3.3.3 Data collection: questionnaires and informal interviews with PWPD

A questionnaire survey was administered to 55 PWPD over the course of fieldwork (*Table 3*). Questions included demographic information and information about the disease itself, including: disease duration, medication, non-motor symptoms (using a non-motor symptoms questionnaire (NMSQ)[5]), caregiver status, household living situations, employment and pension status, use of alternative treatment and finally Hoehn and Yahr stage (determined using the motor examination in the Unified Parkinson's Disease Rating Scale (UPDRS)[6], which I received training in prior to fieldwork). I had planned to conduct fieldwork in stages, with

[5] The NMSQ was developed in 2006 and involves 30 yes/no questions (self-reported) about the non-motor symptoms PWPD had experienced in the past month (Chaudhuri *et al.*, 2006).
[6] The UPDRS has four parts: (i) non-motor experiences of daily living; (ii) motor experiences of daily living; (iii) motor examination); (iv) motor complications.

the questionnaire stage informing the interview stage. However, this did not work practically – I continued using the questionnaire survey with PWPD throughout fieldwork. Although often not utilised in ethnographic research, the questionnaire provided important structure to informal interviews, allowing for further exploration into areas PWPD wanted to discuss. Each question brought the opportunity for in-depth informal discussions with PWPD (and family members when present), which were recorded as detailed handwritten field notes. Three PWPD did not complete the NMSQ; one did not want to and two did not have time. Informal interviews or conversations were usually in-depth and did not require follow-up interviews. Several informal interviews with PWPD were brief (30 minutes), while others lasted up to three hours. In total, 72.5 hours of informal interviews with PWPD took place. Field notes were written and included my own observations.

	Number of PWPD recruited		
Recruitment site	Urban residence	Rural residence	Total
PD support group, Nairobi	15	3	18
Private neurology clinic, Mombasa	12	4	16
Public neurology clinic, Nairobi	8	4	12
Private neurology clinic, Nairobi	4	5	9
TOTAL PWPD recruited	39	16	**55**

Table 3. Number of PWPD recruited from each site and location of residence

3.3.4 Data collection: formal interviews with PWPD

I conducted nine formal audio-recorded follow-up interviews with PWPD, totalling 9.5 hours of recorded material. However, as discussed, most interviews with PWPD were informal (not audio-recorded). Four PWPD who participated in follow-up interviews attended private clinics and three were recruited from PSGs. It was more difficult to carry out formal follow-up interviews with PWPD from the public clinic as several lived outside of Nairobi or in more 'dangerous' areas.

Formal, in-depth, semi-structured interviews allowed the conversation to be guided by PWPD. A biographical approach assisted recollection of their journeys from symptom onset to the present day (interview schedule included in Appendix E). In eight interviews, PWPD

were alone; in one, the PWPD's son was also present. All formal interviews took place in English, lasting 30-90 minutes. Eight took place in PWPDs' own homes and one took place in a café (we sat outside at a distance from other people). I took notes during interviews about participants' emotions or actions, which were written up as field notes later in the day.

3.3.5 Data collection: formal interviews with family members

Formal interviews were conducted with 23 family members of 17 different PWPD during fieldwork (*Table 4*) – 12 daughters, six sons, four wives and one nephew, totalling 21.5 hours of interview material. Eleven family members lived with their relative with PD and seven either lived nearby and visited PWPD often or provided financial care from a distance. Five family members of PWPD who had died prior to the study were also interviewed. Interview durations varied from 30-135 minutes and lasted approximately one hour on average. Fourteen of the family members interviewed were recruited from the PD support group in Nairobi – PWPD either attended meetings too, their relative attended on their behalf or PWPD had died and their family members were still involved in the group.

	Number of family members recruited		
Recruitment site	Urban residence	Rural residence	Total
PD support group, Nairobi	14	0	14
Private neurology clinic, Mombasa	0	3	3
Private neurology clinic, Nairobi	2	-	2
Relation of family member	3	1	4
TOTAL recruited	19	4	**23**

Table 4. Number of family members formally interviewed and location of residence

In-depth semi-structured interviews with family members also took a biographical approach (interview schedule included in Appendix H). In all cases, PWPD were not present, which allowed family members to discuss their experiences freely. All but one of the interviews took place in English – one required an interpreter who also signed the consent form. Eleven interviews took place in a café (in quiet locations at a distance from other customers), ten took place at the interviewee's home, one took place in a private neurology clinic and one

was conducted in my car (the interviewee sold plants on the roadside and could not leave his shop).

3.3.6 Data collection: interviews with healthcare professionals and healers

I conducted three formal, audio-recorded interviews with healthcare professionals (two neurologists and a community health volunteer), a total of three hours of interview material. I also carried out informal interviews (not audio-recorded) with twenty-three additional healthcare professionals and healers: three private neurologists, two neurologists who worked in both private and public clinics, one palliative care specialist, two nurses, a group of five registrars at the government hospital in Nairobi, seven healthcare professionals from six different health facilities in Central province, two herbal healers and one Chinese herbalist (*Table 5*) – totalling 14.5 hours. Verbal consent was obtained from participants and informal interviews all lasted less than one hour. Healthcare professionals were generally busy during practicing hours. Instead, copious and detailed field notes were handwritten and written up in more detail electronically the same evening.

	Number recruited		
Type of practice	Urban	Rural	Total
Private			
Neurologist	3	-	
Palliative care specialist	1	-	
Doctor	-	5	9
Private and public		-	
Neurologist	4	-	4
Public			
Nurse	2	-	
Registrar	5	-	
Doctor	-	2	9
Community			
Community health volunteer	-	1	1
Alternative			
Herbalist	2	1	3
TOTAL recruited	17	9	**26**

Table 5. Number of healthcare professionals and herbalists recruited from urban and rural locations

3.3.7 Data collection: pharmacy survey

I visited 30 pharmacies across Nairobi, Mombasa, Kisumu and Central province using a convenience sample to determine the availability and cost of PD medication (specifically levodopa). This was done to understand the challenges of availability and affordability of levodopa, which was discussed by almost all participants. Levodopa was also reported as the most common medication PWPD were prescribed (more details discussed in Chapter Five). No structured sampling method was used (differing from the sampling method used by Mokaya *et al.* (2016) in their pharmacy survey). Pharmacies were located in areas I visited during fieldwork near participant homes, main hospitals where PWPD might visit, as well as central areas in towns and cities. I tried to capture a range of pharmacies, including independent or private facilities, private hospitals and government hospitals.

On entering facilities, I informed pharmacists of my research and explained that I was trying to gain a better understanding of the cost of levodopa in Kenya as part of the study. All pharmacists I approached consented to their participation. I asked whether they stocked any levodopa and if so, what preparation, and how much a single tablet of each preparation would cost. If levodopa was available, pharmacists identified costs from their computer systems. Pharmacy names and exact locations are not included in the thesis. Findings from this survey are described in Chapter Five.

3.3.8 Data analysis

Fieldwork data were analysed using inductive thematic analysis, a method that aligned with my epistemological position, allowing themes to be identified from the data but also maintaining the depth of individual stories and experiences (Braun and Clarke, 2006). Thematic analysis within an interpretivist paradigm seeks to *"theorise the socio-cultural contexts, and structural conditions, that enable the individual accounts that are provided"* (Braun and Clarke, 2006, p. 14). Inductive analysis allows themes to be identified that do not fit within a pre-existing coding frame – analysis is data-driven (Braun and Clarke, 2006). However, it is impossible for researchers to free themselves completely of their epistemological standpoints and therefore, researcher reflexivity is important throughout the analysis process. I followed Braun and Clarke's six-phase process of thematic analysis:

familiarisation with data, generation of initial codes, search for themes, review of themes, defining and naming of themes, and production of the report, which I outline below.

Phase I: Familiarisation with data

I listened to interview recordings to familiarise myself with the data and transcribed and verified all interview recordings – the transcription process enabled immersion in the data. Transcribed interviews and field notes were read and re-read during fieldwork in a reflexive manner to focus data collection. The analysis process was iterative, reflexive, and required constant reviewing of transcripts, field notes, questionnaire data and my own personal reflections. Notes were taken during this phase, including ideas for possible codes. More intensive analysis was carried out after fieldwork.

Phase II: Generation of initial codes

Initial notes and comments were made on printed transcripts and field notes, on which quotes, and themes, were highlighted, colour coded, and discussed with the supervisory team. I prefer to have physical copies of data and work better using colours and handwritten notes and codes which can be spread out, rather than the restricted view of a computer screen. Therefore, I made the decision not to use qualitative coding software (NVivo). Furthermore, I did not want the data to be decontextualised. As such, initial codes (both empirical and theoretical) were identified from printed material and recorded in an Excel document with supporting quotes and data from transcripts.

Phase III-V: Search, review, defining and naming of themes

Initial empirical and theoretical codes and supporting data were collated into themes (main and sub-themes). Thematic maps were used to review themes and collated extracts re-read to ensure patterns were clear. Themes were reviewed and refined using triangulation of observation, interview and questionnaire data and after discussions with the supervisory team. Triangulation is a way to use different sources to test the quality of information, accuracy of ethnographic material and put the situation into perspective (Fetterman, 2019). Narrative accounts were written from interview and field note material and refining was complete once the themes told a story of the data.

Phase VI: Production of the report

Throughout the writing of this thesis, extracts and material from all methods of data collection are used to support themes and ensure that participants' individual experiences and contexts emerge from the writing (Stanley-Hermanns and Engebretson, 2010). Data, narratives and theoretical concepts are intertwined throughout analysis and writing to assist with the interpretation of material, relating the analysis to the literature and study's research questions.

3.4 Description of PD sample

This section provides an outline of the data collected as part of the questionnaire survey with 55 PWPD (described in Section 3.3.3). It highlights the disparities in resources between participants and the more urban population included. The survey sample included 32 male and 23 female participants[7], with ages ranging from 33 to 81 years old (median age 66.5 years). Four had been diagnosed under the age of 50, which is classified as young onset. Time since diagnosis ranged from one month to 18 years, although onset of symptoms usually began years before. Eight PWPD in the sample had been diagnosed during the year of fieldwork and most had a relatively recent diagnosis; 51 were diagnosed less than ten years ago. Hoehn and Yahr scores[8] ranged from 1 (unilateral involvement only) to 5 (wheelchair bound or bedridden unless aided), with a median of 2. Non-motor symptoms were self-reported using the non-motor symptoms questionnaire (NMSQ) (maximum score of 30) – the lowest score was 2 and the highest 29, demonstrating the diverse sample. Average NMSQ score was 12.9 ± 5.8; roughly, the average number of non-motor symptoms PWPD experienced in the past month was 13 out of a possible 30.

Twenty-seven of the questionnaire respondents lived in Nairobi at the time of the study – many had migrated from rural areas. Eight lived in Nairobi's surrounding rural areas, 12 in Mombasa city, four in rural Coastal Kenya and four in rural Central Kenya. Most (n=32) were Protestant, eight were Catholic, 12 were Muslim (largely from Mombasa) and one was Hindu. Two PWPD identified with no religion.

[7] Studies from HICs have identified the incidence and prevalence of PD as 1.5-2 times higher in men (Haaxma *et al.*, 2006).
[8] I assessed these scores using the UPDRS as part of the questionnaire survey.

Thirty-five respondents were married at the time of the study, ten widowed, six divorced and four never married. The number of children respondents had ranged from zero to 14 – the most common number was two and the median was four. PWPD in the sample had between zero and 20 grandchildren. Five lived alone at the time of the study. It was most common for respondents to live with one other person (n=15), usually a spouse or a child, a reflection of the urban, nuclear families included. Two lived with over ten other people in one household. Thirty-one respondents reported having a main caregiver; 27 informal family caregivers (22 female) and four formal employed caregivers. All those with employed caregivers lived in Nairobi, attended a private neurology clinic, were diagnosed 6-10 years ago, had been in well-paid jobs, while three had pensions.

The PWPD in my sample had very different financial and social resources and living situations. Most were previously employed in the formal or public sector and 13 were self-employed – this ranged between owning a small fruit and vegetable stall to owning a large, successful company. Most respondents employed in the public sector were teachers. Eight, all women, had never been engaged in paid work, although often had crucial roles within the household. Nineteen were still employed in a range of occupations and sectors at the time of the study. Twenty respondents, who all attended a private neurology clinic, had a pension. Fourteen had a public service pension scheme. Six had an individual or occupational scheme; they all had high earning jobs and four were still employed at the time of study.

Overall, 34 respondents attended private neurology clinics in Nairobi (n=22) and Mombasa (n=12), 12 attended the public neurology clinic and nine did not attend any neurology clinic. In Mombasa, some PWPD travelled up to 165km one-way to attend the private clinic. Respondents attending the private clinic in Nairobi travelled up to 200km one-way and those attending the government clinic travelled up to 175km one-way. However, most lived within Nairobi or Mombasa, reflecting on the largely urban population included. Respondents utilised religious healing (n=13) and herbal healing (n=8). Eighteen attended the Nairobi PSG (either themselves or a family member). All PWPD in my sample attending the support group accessed either a private clinic or no clinic. No respondents attending the government clinic knew about the PSG in Nairobi.

3.5 Methodological reflections: positionality and the emotion of ethnography

The final section of this chapter explores some of the challenges I faced during fieldwork and reflections of my experience. I explore my positionality as a researcher and the need for reflexivity throughout the research process. I discuss the emotion of fieldwork and the constraints I experienced around sharing my knowledge with participants.

Throughout this study, I knew that I would observe suffering. I saw pain, depression and emotional trauma and learnt about the deeply upsetting stigma families experienced. However, I did not anticipate the emotional burden participants' stories would have on me. I cried with daughters and wives, held back tears for others and often found myself crying alone at home after a day of emotional interviews and revelations. The most difficult aspect of fieldwork was knowing there was little I could do to relieve participants' suffering at that moment in time; except perhaps listen to their experiences. During the study period, I witnessed the progressing disability of particular PWPD and since leaving the field, I continue to hear about the deaths of individuals – those who I became close with affect me the most. I also experienced many moments of laughter and joy throughout fieldwork. I joked with participants, ate in their homes with their families, met their grandchildren, learnt from them and laughed at fun and exciting stories of their lives. I received so much thanks and gratitude from families for the work I was doing – they were so grateful someone was interested in their *"forgotten"* condition. Establishing the support group in Mombasa was a small way to repay their kindness by giving families a safe space to learn and share.

For many, I became a crucial source of information, but I have constantly been aware of the tensions within anthropology and ethnography and my role to remain "objective", but also the fact that I am not clinically trained. In a context of such depravation and suffering, how can researchers not share knowledge when people have nowhere else to go? Scheper-Hughes (1995, p. 410) describes how the anthropologist's role is *"to observe, to document, to understand, and later to write about [their] lives and their pain as fully, as truthfully, and as sensitively"* as possible. However, she also acknowledges how anthropologists can be blinded to suffering, calling for a more committed, grounded, "barefoot" anthropology. Finding ways to deal with the emotional burden and "compassion stress" of taking on people's worries and struggles was difficult, but my supervisory team were kind,

compassionate and understanding, helping me through the tears and deaths. Reflexivity was crucial in ensuring I was neither too close nor too detached from the emotion of participants. As Josselson (1996, p. 70) wrote, we honour participants through our *"anxiety, dread, guilt, and shame"*.

Positionality and reflexivity

DeLuca and Maddox (2016) suggest that without identifying one's positionality, researchers cannot conduct honest ethnographic research. My 'self' as a young, female, white, middle-class, researcher of British and Kenyan nationality able to speak conversational Kiswahili became inevitably tangled in my interactions with participants. As Chiseri-Strater (1996, p. 115) wrote, *"All researchers are positioned"*. However, positionality is dynamic and is negotiated throughout interactions (Lønsmann, 2016). Furthermore, Sanford (2006, p. 6) proposes that *"it is the very unequal power relations produced by wealth that enable anthropologists to travel the world and carry out research".* Angel-Ajani (2006, p. 85) suggests that for as long as anthropologists have been in the field, *"the race, gender, age, and social position of the anthropologist has affected the ways in which they are received".* These factors determine what kind of information the researcher receives. Author reflexivity allows researchers to understand how participants' perceptions could influence interactions (Davies, 2008).

Negotiating my positionality

Including a diverse range of participants in this study resulted in the constant need to negotiate my different 'positions' and power dynamics. At times, I was the white, educated researcher with more resources and all the answers, offering to pay for PWPDs' bus fare or *chai* (tea). At other times, I was treated as a young student with fewer resources by wealthier family members who wanted to pay for my *kahawa* (coffee). On several occasions, I was a young, inexperienced researcher speaking to 'superior' neurologists who made the power dynamics clear.

On occasion at the public neurology clinic, I felt that my power and position had an effect on PWPDs' willingness to see me when I was perceived as the white *daktari* (doctor) who could provide them with something more than they were currently receiving – in a way, I could through my research, but perhaps not in the way they had imagined. Berger (2015) also

notes how position can affect access to 'the field'. Reflecting on this allows researchers to think about ways their position may affect knowledge production (Berger, 2015). The perception of me as an 'expert' at the public neurology clinic may also have resulted in PWPD withholding information, such as their use of alternative therapeutic landscapes.

I often had to negotiate and reflect on my position during Nairobi support group meetings where I was 'adopted' as an 'expert'. I wanted to remain as 'observer' but was regularly asked for input on topics – members knew I grew up in Kenya, spoke some Kiswahili and they felt I belonged in the group as a Kenyan. Consequently, they often forgot what my role was. On establishing the Mombasa group, it was inevitable that I would need to play an authoritative role initially until the group could run self-sufficiently. This affected my ability to observe as I was essentially running the groups, but I tried to ensure that meetings were patient-led and on leaving the field, they have succeeded in becoming independent.

In another situation, I was invited to the home of a woman whose mother had PD. Unbeknown to me, she had asked a nurse to attend to change her mother's catheter. Suddenly, the nurse had her gloves on and had begun the process, handing me gloves to wear. In shock, I did as she said, just assisting, but not doing anything that required medical experience. The PWPD was so stiff it took all my strength to hold her legs apart. The whole experience was quite an ordeal and extremely eye opening, but the daughter expected and needed my help, and as a human being, I could not deny her this. She was very open with me during the interview which took place after this; perhaps I had gained her trust.

Suffering, positionality and helplessness

One of the most difficult aspects of fieldwork was the suffering and desperation I witnessed and consequently, the feelings of helplessness I often experienced. As Bourgois (2006, p. xii) writes, *"Anthropologists cannot escape physically, ethically, and emotionally the suffering or the brutality of their research subjects and the historical epoch in which they live".* Several participants, particularly those attending the government neurology clinic, were alone, could not afford consultations, scans or medication, had no information and nowhere to learn about PD. I found myself in a quandary, not knowing whether I was ethically 'allowed' to help or if I was becoming too involved in participants' lives. Guillemin and Gillam (2004) refer

to the day-to-day ethical issues that arise in practice in the field that require complex and spontaneous negotiation.

My position as a white researcher put me in a situation where people often expected me to have money and knowledge and therefore, be able to help, particularly financially. For example, several PWPD asked me for money or to contribute to medication costs – usually, I did not help. However, on one occasion I did pay for a participant's scans after getting to know the family; it was also a relatively small amount and for a medical reason. Luttrell (2000, p. 499) proposes that *"the meaning of Whiteness and Blackness is complex, contingent and embodied in a web of everyday relationships and structures of power".* I constantly negotiated where to draw the line in terms of whom I helped and did not – it is impossible to help everyone. I often feel that I did not, or could not, do enough to help families for whom PD was financially devastating. Ultimately, I was able to help in most circumstances, but I had to remember that my role as a researcher was to remain objective, neutral and not risk any influence on participants.

Positionality, power and sharing knowledge

Literature suggests that researchers should direct participants to alternative resources for disease information – but I was in a fieldwork setting where some people had no access to resources. I have acquired substantial knowledge about PD, as is expected through the process of conducting a PhD, and struggled with the ethical recommendations of withholding the most basic information from participants. Scheper-Hughes (1995, p. 411) proposes the need for anthropologists to remain *"neutral, dispassionate, cool and rational"* observing the human condition, but questions, *"What makes anthropology and anthropologists exempt from human responsibility to take an ethical stand on the working out of historical events as we are privileged to witness them?"*. Although not relating to political events, I resonate with her dilemma. Scheper-Hughes suggests that anthropologists should "see", "listen", "touch" and "record", for not doing so or not intervening could be a "hostile act". She continues, *"If anthropologists deny themselves the power to identify an ill or a wrong…they collaborate with the relations of power and silence that allow the destruction to continue"* (Scheper-Hughes, 1995, p. 419).

One particular situation I found myself in, which I explore further in Chapter Four, was having to disclose nine PWPDs' diagnosis before involving them in research. I want to make clear that I was not making the diagnosis – it had already been made by a neurologist, often years before, and recorded in their patient files. PWPD knew they had a neurological condition; they had just not been told the name. I found this very difficult and struggled with the ethics behind the healthcare professionals' decisions not to disclose a diagnosis and the ethics around my decision to tell participants. My position influenced the way I perceived these experiences and initially, I was furious with the hospital. How could anyone manage their condition properly without even knowing what it was? Over time, through reflection, speaking with my supervisors and further analysis of data, I have realised the reasons for this withholding of information – the need to maintain hope, which I struggled to see with my biomedical background and view that patients should have autonomy. The medicine practised in the government hospital was very different to my experience in the UK, or in private facilities in Kenya as a child, and this guided my thinking and position regarding disclosure. However, what guided me to disclosing PWPDs' diagnosis was *their desire to know*. I also want to make clear that I was not eradicating hope; rather, knowing appeared to give them hope. Furthermore, directing 12 PWPD to support groups for more information meant I did not have to directly give advice. Although, when PWPD did have access to the internet, I directed them to the 'Parkinson's UK' website, and sent several participants a Kiswahili PD information sheet, called *"Ugonjwa wa Parkinson'* via email or WhatsApp.

Benefits to participants, privilege and giving back

Several participants queried at the start of the research whether I was finding a cure or if there would be any direct benefit to them. Solimeo (2009) discussed similar dilemmas in her ethnographic research with PWPD in the USA. I made clear during the consent process that the only direct benefit might be a better understanding of their condition – for many, this was enough. However, I also reimbursed participants for travel costs and paid for several teas, coffees and cakes on the occasions when interviews took place in cafés, so no one was out of pocket due to their participation.

An aspect of fieldwork where I was very aware of my privilege and position was the customary gestures of families to give *me* something (despite often struggling to feed their own families). Families insisted on making me *chai* or buying biscuits, bread and jam – I felt

guilty that they had spent money in anticipation of my arrival or cooked large amounts of delicious food for us to feast on, including expensive meat. On some occasions, I had met PWPD and their families at their *duka* (small shop) where they expressed their concerns about business and affording medication. When I could, I used these opportunities to purchase fruits and vegetables from them to thank them for their hospitality and time, although this was not always possible.

The consequences of sharing on positionality

Several participants asked me to tell them about my life, my link to Kenya, why I knew some Kiswahili and about my parents. It was important to be able to share with them, but I constantly assessed where to draw the line. Mackworth-Young *et al.* (2019) described a similar situation researching young women with HIV in Zambia where boundaries were blurred between researcher and researched. I felt that sharing information about myself and being so involved in the support groups made participants trust me, sometimes as a 'friend', but I was often unable to help them in the ways they thought I could. For example, several families asked me to get involved with their families' perceptions and understandings of PD, which I often felt was inappropriate. One participant I was about to interview saw that my surname was 'Arab' and asked if I was Muslim. I said no, to which he responded that he felt *"sad"*. I wondered whether he now had a preconceived perception of me. During the interview, he suggested I convert and asked me to 'prostrate' on the floor as they do in Mosque, which I did. Fieldwork constantly required on-the-spot negotiation of situations.

Empathy, emotion and power

Researchers must develop rapport with participants, a crucial aspect of qualitative research (Gaglio *et al.*, 2006), which develops through empathy (Watts, 2008). Watts proposes the difficulty remaining 'detached' when researching such an emotionally charged area, particularly with those living with chronic illness or dying. Despite growing up in Kenya, the same place where so many people experienced suffering, I experienced a privileged upbringing. I had always been aware of this vast gap in resources and privilege between myself and others, and the suffering going on around me, but have been unable to do anything about it. Through listening, empathising and telling participants' stories, I am

shedding light on challenges that many in policy, government, research and charity are not aware of.

At times I found it hard to empathise with families when I had not directly experienced PD in my own life, although as Watts (2008, p. 9) suggests, *"Empathy is the intuitive relational self"*. Although I had conducted similar qualitative research with PWPD in Tanzania, I was still relatively unfamiliar with the research area. Berger (2015) proposes this can be an empowering experience, particularly among disadvantaged populations, where new and innovative directions can be taken. However, this also means the researcher cannot fully understand participants' experiences. I was more 'powerful' in many interactions by virtue of not having PD. Being able to reflect on aspects around positionality allows researchers to self-scrutinise, ensuring the credibility and trustworthiness of data and interpretation (Berger, 2015). However, no research can be freed of the researcher's personality, biases and assumptions (Sword, 1999). Blackman (2007, p. 701) suggests that *"to reveal what is usually hidden is to cross emotional borders in fieldwork accounts"*, and in doing so, disclosure produces a more transparent and realistic account of fieldwork. I hope that through this research I have not misinterpreted people's voices but allowed participants to tell their stories.

Leaving the field

My departure from the field was difficult as I had become close to so many participants. I attended support group meetings in Nairobi and Mombasa days before I left Kenya, which provided an opportunity to thank the members and provide a brief summary of some of my preliminary findings. However, knowing that I will always return to Kenya (it is 'home') and being part of the WhatsApp group made my departure less finite.

On leaving the field, I recall crying for some hours after learning about the death of one PWPD who had taken part in this study. I felt responsible that I could not save him from his suffering and desperation. He had no support and I, his only contact, had left the field. I often blame myself for not being there for him. 'Could being there have prevented his death?' 'Had he tried to contact me?', I will never know, and I try to remember that his experience has not been lost with his death. I can tell his, and many others' stories within this thesis and beyond the academy. Watts (2008) suggests that close engagement with

participants in the field results in issues with “attachment” on leaving the field, while sensitive research that witnesses suffering can affect the researcher’s emotional stress. Furthermore, providing participants with a research number to contact creates dilemmas upon leaving the field, particularly when the researcher is their only source of support. Mackworth-Young *et al.* (2019) add that anthropological guidelines for ending research in an ethical way are often deficient; perhaps a more critical reflection and guidance on this stage of fieldwork would be useful. Bloor and Wood (2000) propose that care must be taken to do no harm to participants by departing from the field. I ensured I maintained, and continue to maintain, contact with participants through the support group WhatsApp conversations where possible.

3.6 Chapter summary

The use of ethnography, and the different practical methods of data collection and analysis, enabled a “thick description” of the lives of PWPD, considering the particular social, cultural, political and economic contexts of Kenya. The chapter has described the different fieldwork settings, and a detailed reflection of my positionality and the challenges I faced, which I think is important to fully understand the circumstances in which this research was conducted. The following chapters describe the narratives of participants’ lives, following the biographical approach I used during interviews, and how their experiences relate to existing literature outlined in Chapters One and Two.

Chapter 4. Diagnostic journeys

Chapter overview

This chapter presents an analysis of PWPDs' diagnostic journeys. I look at the range of initial symptoms PWPD in Kenya experience and how these sit within expectations around norms of ageing and associated comorbidities. I discuss how and when PWPD distinguish their "problematic" symptoms from those more generally associated with growing older, through a threat to "personhood" (Degnen, 2018). I explore the complex process of diagnosis, misdiagnosis and the importance of terms, labelling and meaning. Lastly, I look at information provision and understanding about PD at diagnosis and the uncertainty generated from not knowing the name 'Parkinson's disease'.

The experience of PWPDs' diagnostic journeys is prefaced with an account of Leah, a 78-year-old lady with PD, and her two daughters. Leah's diagnosis was particularly complex, thought provoking and in-depth and her journey encompasses many of the experiences of PWPD in this study and is a useful way to illustrate the themes I discuss in this chapter.

Narrative 1: Esther, Pauline and Leah

Leah lived in rural Kenya with her husband. One of her daughters, Esther, lived and worked in Nairobi, while her other daughter, Pauline, lived near Leah; she looked after her parents while also running her own business.

Esther told me that Leah began experiencing symptoms nine years ago: *"She'd been complaining about back ache and all those old things that we just assumed were old people problems"*. Esther added that Leah's voice began trailing soon after and the family thought Leah was pretending: *"We'd tell her, 'speak up'".* However, they did not think it was anything serious. Esther described how Leah had backache and hypertension and was being treated for both conditions in a local private hospital. Six years after the onset of symptoms, Esther took Leah to have her back pain assessed in Nairobi.

Esther recalled the day they visited a specialist orthopaedic doctor at his private clinic in Nairobi. He explained that after hearing Leah speak and seeing how she walked, he knew she needed to see a neurologist. Esther took Leah to see a neurologist but found it difficult to get an appointment: *"Every time you go to one of them [neurologists], first of all getting even there was such a hassle. Then when you got in, it's like the work of the receptionist is to turn people away".* Esther decided to see a

neurosurgeon instead, who was also a family friend, who confirmed that Leah probably had PD. Yet Esther added, *"She was very clear in her mind, her memory was very good. So, the issue is she doesn't shake…She has no tremors, so it's difficult to diagnose".* Leah had an MRI scan at a private hospital in Nairobi to rule out other conditions, was prescribed PD medication and returned home.

Leah was still hypertensive and visited a heart specialist who ran a clinic in a local hospital. Esther said that Leah told the heart specialist she was taking PD medication. Esther explained, *"So, she put all the medicines there on the table. He said, 'Why are you taking all this'. 'Uhh the doctor said I have Parkinson's'. 'You have no Parkinson's. You have no facial expression like Parkinson's. You're not shaking, you have no Parkinson's'. Cancelled all these medicines".* Pauline also discussed this visit: *"He said she does not have Parkinson's…He said, 'Because she is smiling, people with Parkinson's do not smile'".* Leah's symptoms were being controlled by her medication, which led the heart specialist to believe she did not have PD.

After Leah was "un-diagnosed", Esther took her to see a different private neurologist in Nairobi who requested another MRI scan on Leah's back and prescribed Leah painkillers. The neurologist told Leah she did not have PD. Leah took the painkillers and Esther added, *"By the third day…she actually almost died…it was quite a crisis".* Esther told me this looking concerned, but almost laughing at the situation now. Esther said they *"abandoned"* the painkillers and Leah continued taking hypertension medication.

Two years later, Esther recalled visiting Leah: *"First, now you could completely not hear what she's saying. The walking was terrible, and she was very slim…She had wasted".* Pauline recalled how Esther took Leah back to Nairobi once again to see another private neurologist. She explained: *"He just told her, 'Can you write your name'. So, she wrote her name. 'Can you write again'? I think like five or six times and then it had this slanting because it started big names then it went like that".* The neurologist diagnosed Leah with PD again and prescribed medication. Pauline sighed, *"But we had lost one and a half years"* and added that the neurologist was overwhelmed with patients. When I asked Esther whether the neurologist advised Leah about anything, she added: *"Five minutes in his office is too much…The doctor looks at her like, 'Oh, Leah, how are you'. Writes something and it's finished…You see, in six months, it's five minutes, after those six months, it's like your basically on your own".* Esther said she learnt more about PD on the internet, such as controlling protein before taking the medication, adding, *"No one tells you such things".*

Esther decided to take Leah to see the original neurosurgeon who diagnosed her: "*Of course, he was like, 'Where have you been for two years".* Esther, exasperated, went on: *"How do I know it is Parkinson's? She's not shaking, the doctor says, the top*

doctor in Kenya says it's not Parkinson's". The sisters reported that Leah greatly improved after she began taking PD medication again.

Leah continued to visit the local private hospital near her village for her hypertension. Esther described having learnt to tell all doctors Leah encountered about her PD. Esther laughed as she told me how she could see the medical staff 'Googling' Leah's medication, adding: *"So, what help are you getting from them?".* The sisters described educating the doctors about PD, after which the hospital began stocking the PD medication Leah required.

Esther added that there was nowhere to find out more about PD or anyone to relate to: *"Then it's not like these other diseases…Other than the day I came to the support group, I've never seen any other person with Parkinson's".* Esther said she thought Leah was the *"only Kenyan"* with PD and added that she did not think PD happened in Kenya. She went on, *"It's never been featured in the newspapers. No doctors talk about it the way they talk about anything else. There's no awareness about it at all".*

Leah's story, as told by her two daughters, demonstrates how people may interpret the symptoms of PD when there is little or no prior knowledge of the disease, or knowledge that it exists in Kenya. Knowledge of blood pressure is commonplace, easily tested for with a machine and in most diagnosed cases, manageable with access to affordable medication. Distinguishing backache and *"old people problems"* from PD is far more challenging, resulting in numerous misdiagnoses, even among 'specialists'. Throughout this chapter I refer to Leah's story as I introduce the different themes that emerged from fieldwork, as well as introducing other participants and narratives.

4.1 Symptoms of Parkinson's disease and expectations of ageing

4.1.1 Parkinson's disease symptoms hidden by trajectories of ageing and comorbidities

This first section explores participants' expectations of norms around ageing and how these expectations could disguise the symptoms of PD. Participants often recalled their experience before diagnosis with phrases like: *"I started feeling funny"* or had *"strange feelings"* or *"my body was not behaving well".* Ordinary aches, pains, fatigue, and slowness were usually the main cause for concern, although participants reported having a limited biomedical understanding of the cause of these rudimentary symptoms. Yet these changes appeared to be an important part of PWPDs' story, which enabled them to obtain a diagnosis.

Several PWPD described how their expectations of what people 'should' experience as they age, for example back pain, were disguising the symptoms of PD. Leah experienced *"old people problems"* and backache for six years before her family realised it may not be 'normal' ageing. Similarly, Gloria, aged 76, was treated unsuccessfully for back pain for 14 years: *"It was only pain, pain, pain, muscular pain, everywhere"*.

Being 'slow' appeared to be another important symptom acknowledged by several participants. Aliya described her perception of her mother's slowness:

> *"She [PWPD] thought it was something normal and didn't go to the doctor. She had slow movement, so thought she was just ageing" (Aliya, daughter of 67-year-old PWPD)*

Slowness, or bradykinesia, is a key motor feature and the most common clinical presentation of PD (DeMaagd and Philip, 2015). However, several older participants described not thinking 'being slow' was cause for concern, associating it with a general expectation of slowness in older people. Many family members described noticing how almost all the activities PWPD did took more time, including getting dressed, eating and walking. Danny recalled how he noticed his father becoming slower but doubted himself at first:

> *"We could tell something…wasn't too right…At the time I thought maybe it's just old age…Or I mean like my dad at the time had just retired…We thought maybe yeah, he's taking it easy" (Danny, son of 83-year-old PWPD)*

Several family members reported that once this slowness, deterioration and pain significantly impacted on PWPDs' daily lives and their ability to carry out tasks or work, often after some years, they realised something was 'wrong' and it was no longer 'normal' ageing or *"taking it easy",* but something that required attention:

> *"I was feeling very weak and I decided to stop doing what I was doing at home, now digging and cultivating and carrying the maize on the head…Going back in the shamba (land) to dig, plant vegetables, cook sukumawiki (spinach). I stopped. So, I decided now to look after myself, my back by then was too bad. I decided to go for medical attention" (Gloria, 76-year-old PWPD)*

As Gloria experienced, many PWPD described only seeking help when they could no longer do certain activities, or as one PWPD explained, *"With my hands I could not eat ugali (maize*

meal)". Degnen (2018) describes these changes as a threat to "personhood", an idea explored further in Chapter Six as PD symptoms continued to progress. PWPD commonly described visiting a range of medical specialists on many occasions. Several, like Leah, visited orthopaedic specialists because of their pain, accumulating various scans, MRIs and X-Rays used to determine aetiology or exclude other diseases. A private neurologist in Nairobi acknowledged that PWPD often attended his clinic with pain[9] after numerous referrals from different specialists, potentially delaying diagnosis.

As well as common aches, pains and slowness, comorbidities associated with growing older could further confuse and disguise the symptoms of PD. Almost all PWPD in this study had additional health conditions, such as hypertension, diabetes or arthritis. Participants often described attributing bouts of dizziness and weakness or falls to existing hypertension or low blood sugar. Although their understanding was still limited, several expressed the knowledge they had about conditions like diabetes (*'sukari'* in Kiswahili which translates as 'sugar') and having a better understanding of how these conditions made them feel when they were not controlled. Similarly, in Uganda, Whyte (2016) describes how people with diabetes and hypertension could tell if their pressure or sugar was high because of the effect it had on their bodies.

In addition, several participants described attributing the symptoms they were experiencing to other better-known conditions that they did not already have. For example, arthritis mirrored the similar symptoms PD was causing, pain in the arms, legs, and neck:

> *"They were thinking it is arthritis, most people from my village once they get a small, small disease, they just say it is arthritis…Most of them have actually been treated for arthritis which they did not have" (Pauline, daughter of 78-year-old PWPD)*

Other family members described similar experiences, although they acknowledged that the symptoms seemed more obvious since learning more about the condition. However, at the time, the slowness and pain were small pieces of a complex puzzle of which no one could make sense. Louise, the daughter of one 71-year-old PWPD, explained how her family were *"fighting an unknown",* while misdiagnoses *"kept them in the dark"* for several years.

[9] Chronic pain is experienced in up to 85% of PD cases. The gene *TRPM8* is thought to be a risk factor (Williams *et al.* 2020).

For many participants, the symptoms of PD mirrored those of better-known conditions, pre-existing comorbidities, or merely expected trajectories of ageing, which contributed to numerous incorrect diagnoses. As symptoms began to impact on daily life, participants acknowledged that they might be 'abnormal', similar to findings by Mshana *et al.* (2011) in Tanzania. Some participants in Kenya described making the decision to seek help themselves, often with the help of family. Others suggested it was friends or strangers who noticed their accelerated 'ageing'. Four PWPD in this study had been diagnosed before the age of 50 and described how their symptoms could not be attributed to 'old age'. These people reported seeking help for their symptoms earlier, attending numerous hospitals in their quest for a diagnosis. However, as PD is often thought of as a disease associated with old age, this made obtaining a diagnosis more difficult. These routes to diagnosis are discussed in Section 4.2.

4.1.2 Making sense of Parkinson's disease symptoms

Most PWPD in this study had no prior biomedical knowledge of PD and this section explores how participants made sense of, and explained, their symptoms with little understanding, or in some cases, a prior understanding of the disease. It describes the difficulties making sense of diseases that manifest in similar ways and challenges with the language used to describe symptoms and feelings. Several participants used analogies to describe the unexplainable sensations or *"strange"* symptoms they were experiencing, which led them to the realisation that something was not 'right'. Gloria described her interpretation of the feelings she experienced:

> *"In my foot down below…there appeared to be a ring of some ants…I could see a patch and inside that patch, there were some dudus (insects)…I could not see it but sensation. The ants were moving, a group of them, many, many, many, many they were coming up the leg, up to here [knee], and they go back down" (Gloria, 76-year-old PWPD)*

Gloria was experiencing restless legs syndrome (Piao *et al.*, 2017), which can result in strange sensations in the legs. PWPD recalled visiting doctors and pharmacists to try to understand what they were feeling. For instance, a pharmacist Gloria visited suggested her symptoms could be her *"nerves being attacked…like an askari (guard) attacking a thief".*

However, these descriptions and analogies may have made it more difficult for neurologists to make sense of, as discussed in Section 4.3.1.

In some cases, a prior understanding of PD and a belief of what symptoms might involve appeared to prevent PWPD seeking help. Participants recalled experiencing symptoms they felt were not 'typical' of PD and consequently, reported potentially dismissing or denying a diagnosis; just as Leah experienced with the cardiologist. Andrew (78-years) described a similar confusion around his PD diagnosis, because, as he explained, *"My Parkinson's does not shake"*. Not experiencing 'typical' symptoms associated with PD could further confuse participants' understanding of the disease and led some to seek out different opinions, ignore their symptoms altogether or believe they had been misdiagnosed. For others, the 'typical' symptoms ensured that PD was 'spotted' earlier; usually if they had a 'typical' tremor or a family member knew of PD. However, tremor only occurs in two thirds of PWPD at diagnosis (DeMaagd and Philip, 2015). In these cases, serendipity, position and what Whyte (2014) has described as "technical know-who", referring to the personal contacts and connections that enable access to treatment or care, played a role in diagnosis (Section 4.2).

As discussed, some participants described attributing their symptoms to other diseases altogether before a diagnosis. Several PWPD reported knowing people who had experienced a stroke and believed they were suffering from a stroke *"because of the hand trembling"*, as one PWPD described. The challenges of making sense of the symptoms of different diseases with no prior biomedical knowledge or experience was exemplified in a rural disability meeting I attended in western Kenya.

Narrative 2: Kisumu disability meeting

I travelled to a rural village outside of Kisumu city to attend a disability meeting with a neurologist and William, a PWPD. Kieran, the founder of the disability organisation believed he had 25 PWPD attending his meetings; a very large number for one village.

We followed Kieran down the long dirt tracks on his *'boda boda'* (motorbike taxi) and finally arrived at the huge hall built through county government funding Kieran had obtained. There were about 60 people waiting in the hall – a big shell of concrete bricks with a corrugated iron roof, no glass in the windows and plastic chairs scattered around the dusty floor (*Image 4*). Most attendees were older people, many with wooden walking sticks, but also some younger men and women and several

children. We introduced ourselves and the neurologist began asking about peoples' symptoms. He established that many of the older attendees had suffered from stroke; they had weakness down one side which had come on suddenly or had another disease altogether. The neurologist identified one man who he thought might have had PD. He used this man's symptoms and one of the stroke patients as examples of the difference between the two conditions.

Kieran produced a certificate he had printed from the UK Parkinson's disease society website in 2014. He had been researching PD for some time. Despite this, with limited disease knowledge and limited access to information, he had confused the symptoms of PD, stroke, and many other conditions (which were not all immediately identifiable) and 'diagnosed' all the group members with one blanket diagnosis of PD. As the neurologist disclosed that the members did not all have PD, there was some disappointment among the group. They now did not know what was wrong with them.

Image 4. Disability meeting in a village in Nyanza province, western Kenya

Similarities in the symptoms of PD and other conditions, such as stroke or arthritis, often created difficulties determining aetiology, as experienced at the disability meeting and as identified by several PWPD. In addition, the language used to make sense of feelings often confused symptoms further. For instance, *"weakness"* was used by PWPD to describe fatigue, frailty, dizziness or a general weak feeling in the body – similar to the symptoms of many other diseases. Furthermore, the disappointment exhibited by several attendees at the disability meeting illustrated a desire for people to obtain a diagnostic label that made sense of their bodily changes. However, despite suggesting that many may have suffered from a stroke, their access to any facilities or rehabilitation was limited. The importance of

labelling and the consequences of knowing the name of a diagnosis are explored in Section 4.3.

Limited disease knowledge, expected trajectories of ageing and difficulties in distinguishing the symptoms of different diseases delayed interactions with health services for many PWPD. The next section of this chapter explores how participants went about achieving a diagnosis.

4.2 The uncertainty of obtaining a Parkinson's disease diagnosis

This section explores the often uncertain and convoluted process of obtaining a PD diagnosis, experiences of misdiagnosis, perceptions of doctors' knowledge about PD and the role serendipity could play in PWPD interacting with health services. The section is prefaced with Annette's experience of diagnosis, illustrating how comorbidities could confuse the symptoms of PD and result in misdiagnoses. Annette was 78-years-old and her son, Jasper, could pay for the numerous consultations she required, something not all participants could do.

Narrative 3: Jasper and Annette

Annette was diagnosed with arthritis several years ago and had been taking medication for psychosis. Jasper explained that Annette had developed more symptoms over several months, including difficulty moving, pain and she had become mute. Initially, Jasper believed these symptoms were due to her arthritis but did not understand what the additional symptoms were. He began taking Annette for further tests, visiting numerous specialists in private hospitals, yet all the tests and further investigations identified nothing. Jasper described taking Annette to see a doctor two years ago. He explained, *"While we were seeing him, she had a tremor, and I asked him, 'What's that?' and he said, 'It's a signal from the brain' and dismissed it…I thought, 'OK it's not serious'".*

Jasper described how Annette had started drooling, so he took her to a private chest specialist: *"The doctor even before he saw her knew what the problem was, because she was shuffling and you know, she couldn't lift her feet. And so, when we got in…he said, 'This salivation you're seeing has nothing to do with the chest, this is actually Parkinson's'. And you know, finally, there was a sense of relief, I know that sounds crazy".* Jasper explained that the chest specialist was the 16th doctor Annette had seen, and the doctor who finally diagnosed her PD. Annette was prescribed medication and referred to a neurologist. Jasper described feeling *"disappointed"*

about the many misdiagnoses Annette had experienced. He added, *"It's not just because of mum, you know, the thousands who miss out on medication early into their condition because some doctor couldn't be bothered to carry out the tests".* Jasper joined the PD support group shortly after Annette's diagnosis.

Jasper and Annette's story highlights the possibilities of numerous misdiagnoses, limited knowledge about PD among various specialist doctors and the challenges with identifying the symptoms of PD. These experiences are discussed further in this section.

4.2.1 Tests, referrals, and misdiagnoses

Almost all PWPD described seeking help from biomedical services to try to resolve the uncertainty that surrounded their symptoms. However, this did not necessarily result in the straightforward solution for which participants hoped. Many reported spending months or years in search of a correct diagnosis while doctors could not identify the underlying cause of PWPDs' symptoms – Leah had experienced symptoms for six years before her PD diagnosis. PWPD described being treated for specific symptoms, such as pain, *"other diseases"* or a *"wrong disease"*; Walga (2019) described similar experiences of misdiagnosis among PWPD in Ethiopia. Most participants in Kenya had visited numerous doctors in different facilities and experienced frequent referrals in various levels of care with no conclusive diagnosis:

> *"My weakness started on my right side. So, I went to another district hospital, and they did an X-Ray which confirmed nothing. So, I proceeded on to [local private hospital], and there I was referred to [main national referral hospital]. That's where I started now the real follow up of the condition. I was told to do some MRIs" (Gideon, 33-year-old PWPD)*

Dr F, a neurologist in a private neurology clinic, explained that patients with other neurological conditions experienced similar problems with referrals, resulting in them being *"fed up"* of being *"passed around".* In addition to inconclusive referrals, many PWPD also described having undergone numerous costly tests, scans and exams. Dr A, a neurologist at the government neurology clinic in Nairobi, discussed the extensive scans patients had to pay for with no definitive results. He explained, *"It [scan] shows nothing. So, how it shows nothing, how can I be sick with nothing".* Many PWPD expressed their worry of not being able to afford further care as the costs of consultations and tests added up:

"If we didn't have money, we would not know the problem, because you go to a district hospital and get referred, ten years down the line and you're not seen" (Moses, son of 69-year-old PWPD)

For many PWPD, costly referrals were a substantial barrier to obtaining a diagnosis and deterred some from returning to a clinic until their symptoms worsened significantly. This is reminiscent of a description by Prince (2018), also in Kenya, of the 'back and forth' that children with undiagnosed cancer experienced between health centres, hospitals and healers often for months, only receiving a diagnosis after significant disease progression. Some participants reported almost giving up their quest for a diagnosis, thinking they might die not knowing what was killing them:

"I was almost giving up, because any time you go to the doctor, whatever you are getting is not helping you…The last time I went to that doctor, I told her "Daktari (doctor), now I'm going to die" (Christine, 55-year-old PWPD)

As Christine experienced, several participants also described doctors' limited knowledge about, or experience with, PD, which contributed to their misdiagnoses; or as one family member explained, *"They were not investigating fully".* When I asked Norah (71-years) if she knew of PD before her diagnosis, she responded, *"No, neither did the doctors".* Consequently, six participants described having travelled abroad (India or UK) for a consultation as they could afford to. Dr A also recognised the limited awareness amongst doctors who had not specialised in neurology, and the limited access to specialists:

"I think those components, education, education, education for the medical practitioners that there is a disease that's called this, and the management is this. But now it's prioritising, because what do you see in the clinic, mostly epilepsy or post-stroke, Parkinsonism is not there" (Dr A, neurologist)

Despite the need for PD education, Dr A rationally acknowledged the high prevalence of other pressing conditions, which doctors saw on a regular basis and with which they were more familiar. This issue is highlighted further in Chapter Five when exploring the management of PD. However, Jasper summed up his thoughts about his expectation of healthcare professionals to be able to identify PD:

"These are guys who go to school for what, seven years minimum, and when an old person comes before you, it's normally one or two things. It's Alzheimer's or

Parkinson's, or I don't know, maybe heart condition…There are things that automatically should come to your mind…It's just, you know, mind boggling that they just didn't spot it sooner." (Jasper, son of 78-year-old PWPD)

Delayed diagnoses contributed to significant worry, suffering and substantial out-of-pocket costs. Some participants described how several doctors continued to prescribe "unsuitable" treatment rather than referring PWPD to a different specialist, which resulted in worsening symptoms, and/or severe medical scares. In these cases, participants either continued with inappropriate treatment with no improvement or sought a different doctor. In Tanzania, Mshana *et al.* (2011) found that almost all PWPD in their study had not been diagnosed until being identified in a door-to-door PD prevalence study conducted by Dotchin *et al.* (2008). It is likely that many PWPD in Kenya remain undiagnosed.

The poor knowledge about PD among healthcare professionals and subsequent misdiagnoses appeared to result in further uncertainty. Subsequently, many PWPD who were eventually diagnosed described seeking out second, and third, opinions from different specialists, withholding their previous PD diagnosis for fear that it may be wrong, illustrating the potential lack of trust in medical professionals. This idea is explored further in Section 4.3.

4.2.2 Serendipitous diagnoses

Although many PWPD described eventually identifying that their symptoms were not because of 'normal' ageing, others described accepting their symptoms as those associated with growing older and therefore, did not seek help. Several PWPD therefore obtained a serendipitous diagnosis, where friends or strangers distinguished their symptoms from 'normal' ageing or where doctors 'spotted' PD symptoms in rural hospitals; although structural constraints could prevent this.

Several PWPD suggested that friends had spotted their symptoms. Frank, a recently diagnosed 77-year-old PWPD, described his serendipitous route to diagnosis:

Narrative 4: Frank

Frank lived in Mombasa town with his wife. Frank had a slight tremor and dragged his feet as he walked – I could hear him shuffling down the carpeted corridor towards his

> office before I saw him. Frank was in the early stages of his PD and his wife confirmed, *"For us, he is not sick".* He described how a good friend from his church had noticed his symptoms: *"I began shaking and did not know what it was. A good friend was concerned…'What's wrong with your hand', he told me. I told him, 'Nothing', because it didn't pain".* Frank had thought his symptoms were 'normal', explaining, *"I didn't know anything was wrong with me, I thought I'm just getting old".* He described ignoring his friend. Week after week, his friend pursued him at church. Eventually, Frank said he gave in and was referred to a neurologist at the beginning of 2018, where he was told his PD was in the early stages.
>
> Frank described accepting his disease; he also had diabetes and saw both conditions as challenges. Frank said he knew several people with diabetes but did not know anyone with PD. His wife acknowledged that many people probably did not know they had PD, adding, *"You think it is part of your old age, so you wouldn't know".*

Like Frank, serendipity played a key route to diagnosis for many PWPD who had accepted their symptoms as *"part of old age"* and requiring no further attention, or because they did not feel pain, they were not sick. Frank may not have achieved such an early diagnosis and began treatment so soon had his friend not thought his symptoms unusual.

For others, symptoms were 'spotted' by strangers. Matthew (62-years) attended the government neurology clinic. He described how he had noticed a tremor in his hand, his voice had lowered, speech had slowed, and it was painful to write but he had not thought these changes required attention. Matthew explained that someone at his church directed him to a neurologist after noticing these symptoms. Matthew obtained a diagnosis and attended a PSG meeting after we met; it was an art therapy session and PWPD were asked to paint how they felt. Matthew wrote out four words in different colours in large capital writing across his page, one of them was 'SERENDIPITY'.

In Central Kenya, the chief medical officer at a private hospital described sometimes being able to spot patients with undiagnosed PD during ward rounds when they had been admitted for other conditions, such as complications with diabetes or hypertension. He explained these patients had quite 'obvious' or 'severe' symptoms by the time they were admitted, which made this ad hoc PD diagnosis easier. In Uganda, Whyte (2016) described a similar situation where people were diagnosed with hypertension and diabetes by chance after being admitted for other conditions. The chief medical officer also described doing

grand rounds with staff to improve their PD knowledge. Another missionary (faith-based) hospital in the area had ten PWPD under regular follow up.

However, this serendipitous route to diagnosis did not occur in government hospitals in the area. From observations and speaking with consultants, it became clear that rural government hospitals were overwhelmed with more pressing, life threatening conditions, such as stroke, uncontrolled diabetes, and infectious diseases. Clinics appeared to be operating a form of triage where PD was not a priority and consultants indicated being too busy to notice any symptoms other than those the person presented with, nor did they have the time or resources to follow up patients – in this respect, structural constraints appeared to prevent serendipitous diagnoses. Furthermore, consultants from several government hospitals in the area, including the main county referral hospital, reported no PWPD ever having attended their hospital, adding that PD was not common, or people thought the symptoms were just *"old age".* Unless PWPD could afford to travel to a major city to see a neurologist, the time constraints in rural outpatient clinics coupled with healthcare professionals' limited knowledge about PD could mean that many cases went unrecognised and undiagnosed.

Misdiagnosing, or not diagnosing, PD was extremely common among participants who reported enduring complex and expensive diagnostic journeys, whether this was through serendipity or acknowledging their symptoms as 'abnormal'. The next section explores the significance of labelling for PWPD who were eventually diagnosed and for those who never received the name of their diagnosis.

4.3 Knowledge, information and understanding of PD at diagnosis

Participants described several barriers to gaining knowledge at diagnosis within different contexts and this often included not learning the name 'Parkinson's disease'. Many described their frustration that PD had been *"forgotten"* while 'other' diseases like stroke received more attention and publicity. I visited a diabetes support group meeting in rural Central Kenya where one of the elderly attendees explained, *"In Kenya we don't have it [PD]".* Paul was diagnosed with PD four years ago and described his perception of awareness:

"It's a nuisance, it's a constant problem…Go and talk of cancer or diabetes, everyone knows what it is. I feel this condition has not been given the time it deserves…People here don't understand. People here don't know this disease" (Paul, 70-year-old PWPD)

The limited knowledge among the general population and healthcare professionals, scarcity of information about PD and resulting potential for stigma appeared to contribute to great uncertainty, worry and stress for many participants.

4.3.1 Gaining knowledge at diagnosis: "No explanation was made to me"

Several participants recalled feeling alone, confused and receiving very little information from healthcare professionals (in both public and private facilities) during their quest for a diagnosis; as one family explained, *"We were totally clueless".* Some described not being told that PD was progressive or incurable and believed their medication would cure them. It appeared some participants had faith in doctors to 'cure' which may stem from the (mostly) treatable nature of many infectious diseases in recent decades. As Albert, the nephew of one PWPD*,* explained*: "When we are given medicine, we just assume it is for curing".* Dr A, a neurologist at the government neurology clinic, also acknowledged that neurologists often did not provide explanations about prognosis. He suggested that some PWPD attending the clinic were *"non-compliant"* with their medication and proposed a way to address this during initial consultations using simplistic explanations regarding the chronic, degenerative nature of PD:

"I think a lot of people's understanding is, is that the disease goes away. But…there are certain diseases which have been known here, like diabetes, so that it can be used as a comparison. 'OK, you know your disease is like diabetes where you need to take insulin everyday'… 'OK, this is what is happening, it's in your body, it's something has been going down. We don't know why, since we don't know why it's going down then it might continue going down, but we're going to replace it…It's going to be more difficult as we, as we move on"' (Dr A, neurologist)

Dr A's explanation did not provide much insight into PD, merely a description of the degenerative, chronic nature of the disease. Furthermore, few participants reported being provided with *any* verbal information at diagnosis, particularly at the government neurology clinic.

Participants also described the limited resources available to learn – as Amina, the daughter of one PWPD, described, *"There was practically no information in Kenya"* and no information in Kiswahili or regional languages. Some PWPD who attended private clinics were given information to read in English or websites of international organisations to visit, although this was rare. If they could afford to, some described visiting different private neurologists to try to obtain further information or 'double check' their diagnosis.

As a result of the limited information provided at diagnosis, few PWPD could provide an explanation of what PD involved. Some queried whether their condition was: their *"brain getting rotten";* caused by *"straining the brain more than someone selling cabbages"* [10]; caused by pesticides; or a punishment from God or Satan. Almost all participants reported how most of their knowledge about PD came 'later on' as they learnt from experience, through support group meetings (explored in Chapter Five), or carried out research online – usually the offspring of older PWPD 'Googled' PD on their mobile phones but not all participants, including those with fewer resources, had access to the internet. Meshack, a 40-year-old teacher with PD, described how he had 'Googled' his diagnosis on his phone, finding out that it was due to *"a deficit of dopamine in the brain".* Meshack clarified that he had learnt nothing from the government neurology clinic he attended.

Speaking to healthcare professionals in different settings across Kenya, including seven neurologists (private and public), seven medical consultants, five registrars and two nurses, provided a rounded picture of the reasons why PWPD were provided with limited information at diagnosis and potential explanations for why some were not given a name. These included: limited time during consultations and issues with continuity of care; challenges with English proficiency, communication, and pre-set attitudes towards 'less knowledgeable' patients; a reluctance to deliver bad news; and the limited opportunities for signposting. All neurologists working in the government clinic also had their own private clinics across Nairobi. Geissler (2015, p. 3) on exploring 'African Global Health' suggests that many doctors in Africa must work between government and private practice to earn *"liveable incomes"*.

[10] The PWPD implied that "selling cabbages" (i.e. working on a fruit and vegetable stall) was not as cognitively challenging or stimulating as working in an office, for example.

Time constraints and continuity of care

Almost all participants described how neurologists in both private and public clinics had limited time to spend with them; an issue highlighted by Esther regarding private clinics in the opening narrative of this chapter. Many PWPD described feeling rushed during appointments and not having the opportunity to ask questions. I also observed the extreme time constraints during the public neurology clinic, while public neurologists described how the main priority of the clinic was to get through queues, or as one neurologist explained, *"Churning out numbers"*.

Dr B described how extreme time constraints at the public neurology clinic also resulted in different interactions with patients between private and public clinics. Dr B acknowledged the possibility of not telling someone at the public clinic that they had PD. Saying the words 'Parkinson's disease' opened up the chance for patients, and family members, to ask questions, which there was no time to answer.

> *"I can picture myself…writing your prescription, saying, 'You need to take this, it'll help with your stiffness, it'll help with this, but it won't take away the shaking'. But I can picture myself not using the word [Parkinson's]" (Dr B, neurologist)*

This resulted in several PWPD who attended the public clinic not knowing they had PD. In contrast, neurologists suggested that they would disclose a PD diagnosis during private clinics, although any additional explanation may have still been limited. Furthermore, private neurologists described being PWPDs' *"personal doctor"*, whereas neurologists at the government clinic only saw new patients, while registrars, who had limited neurology training, saw returning patients.

> *"Then by the time you come back, I won't be the one who sees you. So, the next person who sees you, if they can read your handwriting, will prescribe something…or not" (Dr B, neurologist)*

Neurologists acknowledged that not all the information relating to PD could be disclosed during the first consultation and this would need to spill over to follow-up appointments. Several PWPD also described needing time to process their diagnosis before they asked questions, although, with registrars seeing follow-up patients, it was harder to provide the continuity of care required. Challenges with information provision at diagnosis have also

been identified in HICs; a study by Schrag *et al.* (2018) identified that only 38% of 1,775 PWPD surveyed from 11 European countries felt they had been given enough time to ask questions or discuss concerns with the doctor who diagnosed them. Dr A explained the issue with information provision in Kenya, but also acknowledged the challenges with overwhelmed clinics.

> *"In the clinic, sometimes I tend to see…newer diagnoses…The only thing is that follow up may not be…You look at somebody walking and say, 'OK, you're walking a little slower than before'. But if I'm seeing you for the first time, are you walking faster or walking slower…do I need to add you more medication or do I need to give you less medication…Although it's not possible that you see the same person, but it would make much more sense to follow up somebody" (Dr A, neurologist)*

The inability of neurologists to provide continuity of care in the public clinic and monitor patients over time resulted in many PWPD never receiving much information about their condition.

English proficiency, communication challenges and attitudes to patients

Several neurologists suggested that providing an explanation of PD was often difficult because the symptoms did not have a direct translation in Kiswahili, the most widely spoken language in Kenya. Therefore, explaining PD to people who did not speak English was more challenging, took more time and resulted in them receiving less information. As Dr B explained, "*I don't know how to say stiffness, slowness and shakes in Kiswahili".* There are no direct translations of these words and so, an explanation might require a more 'roundabout' approach; for example, '*nngumu'* might be used for stiffness, which translates as 'hard' or 'difficult', or *'kutetemeka'* (to tremble) for shakes.

Younger PWPD, or those attending clinics with offspring, tended to have a higher English proficiency and education level and so, received more information at diagnosis – three of 12 PWPD I encountered at the government neurology clinic had a basic understanding of their prognosis, or rather, knew that they had PD. Neurologists also suggested that patients who had a higher English proficiency and education level were better equipped to understand explanations. Neurologists categorised patients, just as Andersen (2004) identified in Ghanaian hospitals, determining what information they received. Similar challenges with language proficiency in the communication between doctors and patients have been

identified in Africa (Ferguson and Candib, 2002; Arnold *et al.*, 2014; Van den Berg, 2016). For example, Van den Berg (2016) explored the challenges in South African healthcare systems when doctors and patients did not speak the same language and suggested that effective communication and quality of information are crucial for successful outcomes for patients with chronic disease.

Neurologists also reported difficulties trying to make sense of PWPD or family members' explanations of symptoms because of communication challenges, which resulted in longer history taking:

> *"It spills over depending on your, well, one your complexity and how sick you are. So, if you're stretcher ridden…you're there with a relative who has no idea, that's going to drag out…Just trying to extract that information will take much longer" (Dr B, neurologist)*

Dr F, a neurologist in a private clinic, identified similar challenges. He suggested patients who were more 'educated' would present to the neurologist saying, *"Look, these are my symptoms. I think I might have Parkinson's. What do you think?"* However, he explained that neurologists often had to play *"detective"* so as not to miss any clues that could skew the diagnosis.

Finally, neurologists admitted being *"different doctors"* with patients who had fewer resources and often changed the way they interacted with these patients, becoming less patient and having a *"pre-set attitude",* as one neurologist described, before attending the government neurology clinic. This meant having an expectation that patients attending the government clinic were going to be old, uneducated, of a lower social class and lacking in English proficiency. These factors contributed to the limited information disclosed at diagnosis, a reluctance to answer PWPDs' questions due to a preconceived idea that they would not understand and neurologists' overall attitude that the clinic was a *"chore",* as one neurologist suggested.

Delivering bad news

Several neurologists described their reluctance to deliver bad news to people. A PD diagnosis was not a *"positive one"* and neurologists suggested it was not easy to disclose and much easier to prescribe for; especially if they were awaiting further tests for confirmation. PWPD

often reported seeing a great improvement after commencing treatment and this immediate, positive change was more optimistic than a long-term, degenerative prognosis. Neurologists also described not wanting to take away PWPDs' hopes of recovering by labelling them with a progressive disease with no cure. Dr A referred to Muhammad Ali as a well-known 'star' with PD, recalling his catchphrase:

> *"'Float like a butterfly, sting like a bee'. Now when you see him…he's doing nothing. He's there shaking, he cannot move, and therefore, it is very depressing. You say, 'Oh if this is what Parkinson's is then it's a terrible, terrible disease'. It is not a positive outlook" (Dr A, neurologist)*

With such a negative outlook, neurologists in the public clinic in particular were reluctant to share this diagnosis. Furthermore, several family members also described withholding the degenerative nature of PD from PWPD; Inaya (74-years) lived with her two adult offspring who chose not to disclose that her condition was incurable to maintain her hope of recovery. Mulemi (2008) exploring the experience of cancer inpatients in Kenya also found that doctors withheld diagnoses and prognoses from patients to maintain hope. However, Mulemi (2008, p. 123) found that patients expected to have their diagnosis disclosed, although adds that doctors in *"most local Kenyan cultures"* have doubts about disclosing bad news. Dr A described a similar perception of his and other doctors, adding, *"The same medical practitioners want also to be in denial like their patients"*.

> *"You know it is Parkinson's but don't want to put it clearly…It's not going to be a curable disease, you're going to get worse over time and you may get all these complications…and I think the patient also doesn't want to know" (Dr A, neurologist)*

Doctors are also cultural beings, and this reflected in their reluctance to deliver bad news to patients and admit their perceived 'failure' to cure – this idea is explored further in Chapters Five and Seven. Consequently, PWPD attending the public clinic often never learnt their diagnosis. Registrars whom they saw in follow-up consultations also had limited knowledge about PD and seemed to dismiss questions using simplistic terms such as *"nerve problem".*

Signposting and support

Several neurologists also discussed the barriers to additional information, resources and services for PD – mainly that services were simply inaccessible and unaffordable for the

majority, while PD nurse specialists, who in the context of a developed healthcare system would give ongoing advice and support to PWPD, were non-existent. Furthermore, the low number of neurologists in the country was limiting, as they were the only source of information and support; apart from support groups if accessible. Consequently, neurologists had to improvise and tailor biomedical knowledge to suit the resources available to them, particularly concerning prescribing pharmacological treatment. Dr C, a neurologist in the government clinic, explained that 'best practice' was *"practically not possible"*. How neurologists and PWPD negotiated limited resources and structural constraints is explored in Chapter Five.

4.3.2 Labelling and legitimacy

This section explores participants' experiences of being told the name of their diagnosis and receiving a disease label but also having it taken away. Many PWPD described wanting to understand what their symptoms meant and striving for a diagnosis that explained the strange things they had been experiencing. Stone (2018, p. 60) explored disease prestige and the hierarchy of suffering and suggests: *"Symptoms may herald illness, but it is the diagnosis that announces the presence of disease".* Several participants expressed the relief and hope that finally knowing their diagnosis brought. Mulemi (2008) identified similar findings among cancer patients in Kenya (attending the same government hospital as several PWPD in this study) who wanted to understand their symptoms.

In Section 4.2, I described Annette's long and arduous diagnostic journey. Jasper described how Annette's PD diagnosis legitimised her condition and entitled them to join a community of sufferers. Through the support group and his own research, Jasper explained how he had become a PD *"expert"* and found meaning in Annette's symptoms. Jutel (2010) on her exploration of disease diagnosis and labelling suggests that obtaining a medical diagnosis can explain, legitimise, and normalise a condition. Several participants reported finally being able to make sense of PWPDs' *"unexplainable"* symptoms; as Louise, the daughter of one 71-year-old PWPD, explained, *"Now we knew what we were fighting up agains*t". Consequently, PWPD reported being able to begin treatment, access information, join a PD support group and "fight" their PD, although access to these were contingent on social position, connections and affordability.

Despite this, several PWPD reported experiences of having a diagnosis removed after being told it was 'wrong' by family or healthcare professionals because they did not have 'typical' PD symptoms, they did not 'shake', they could smile, there was no PD in Kenya, or because PD was genetic and there was no one in their family who had it. Just as being diagnosed could legitimise a disease and had deep social implications, taking away that label also seemed to have significant social consequences. The following narrative describes how Chris (51-years), had his diagnosis "taken away":

Narrative 5: Chris

Chris explained that he had started feeling *'*funny*'* and sought help from a local private hospital in the outskirts of Nairobi. Chris underwent several tests, but the doctors could not diagnose his condition. "*My status continued worsening",* Chris sighed. He described losing concentration and said he felt uncoordinated. Chris went to several private hospitals, where blood and urine tests showed nothing. He said the doctors mentioned it might be *"about the nerves"* and put him on some (wrong) medication. The following year, Chris was referred to another private hospital to have a CT scan, MRI, and EEG, which all came back inconclusive. Chris added that the doctor who carried out the tests had told him, "*There is nothing like PD in Kenya"*. Chris was referred to a psychologist at the government hospital after being told he had severe depression and was prescribed medication. Chris recalled not thinking he was depressed. His condition worsened after he started medication and he went back twice to see the psychologist, but they changed nothing.

Whilst collecting a prescription in town, Chris described how a pharmacist mentioned that he looked like he had PD and referred him to a private clinic. By the end of the year, Chris had finally seen a private doctor (not a neurologist) who had prescribed him levodopa and told him he "*probably had PD"*. The doctor suggested that Chris attend the government neurology clinic for confirmation. Chris said he saw a neurologist at the clinic who doubted his diagnosis and instructed him to cease his medication. Chris explained his symptoms returned and his condition significantly worsened. He returned to the neurologist who saw he was not doing well and put him back on his PD medication. Chris, looking disappointed, said he now feared all neurologists. Chris continued to see the private doctor who had initially diagnosed his PD. He explained feeling confused about his journey: *"You know you have funny feelings and don't know what it's about".* He continued, *"I tell you we have spent so much time and money on MRI, EEG, psychologists".*

Chris' diagnostic journey contains elements of serendipity. However, after numerous referrals and tests, he was also made to feel responsible for his 'incorrect' diagnosis of a

disease that he was told did not exist in Kenya, similar to Leah's experience in *Narrative 1.* Both Chris and Leah (and their families) trusted the doctors who, as experts, told them they did not have PD.

In a unique situation, Annette's diagnosis was "taken away" when Jasper discovered she did not have PD, but drug induced Parkinsonism caused by her anti-psychotic medication. Annette's neurologist had not spotted this and after Jasper's initiative to change her psychosis medication, her symptoms ceased. Subsequently, Jasper reported feeling confused and lost, not knowing whether he still belonged to the PD support group, or what to do with the knowledge he had gained. Despite this being a unique case, it demonstrates the importance of labels in diagnosis, which can provide people with an 'identity'. Obtaining a diagnosis appeared to provide PWPD with meaning, legitimacy and allowed them and their family to "fight" PD. However, some PWPD I encountered had never had their diagnosis disclosed to them and subsequently, were never labelled.

4.3.3 Not knowing Parkinson's disease: "No one has ever mentioned such word"

Nine of 12 PWPD I encountered at the neurology clinic did not know they had PD, although they had been attending the clinic for up to 17 years. Never receiving a diagnostic label had important consequences for these participants, in terms of accessing services and 'knowing' PD. PWPD provided various alternate explanations for their condition, including: *"To do with the tremor and the shaking", "Something neurological", "The system is low", "The shaking problem", "The neuro problem" or "Disease ya nerves"* (nerve issue). These avoided the name PD, confirming what neurologists had suggested, but also may have provided a better understanding of the condition than 'Parkinson's', which did not provide much insight.

The following narrative of Magnus, a 66-year-old PWPD who attended the government neurology clinic, describes the social consequences of not having a diagnosis disclosed:

> *Narrative 6: Magnus*
>
> Magnus described how he began shaking in one arm in 2010. He was referred to the government neurology clinic via casualty and began taking PD medication in 2011. However, Magnus did not know what was wrong with him or what PD was, despite his diagnosis being confirmed in his file. He had been attending the neurology clinic

every three months for seven years and took his medication, which he believed was to stop the tremor, but never asked questions because he was *"nervous"*. Magnus said he had not minded not knowing his diagnosis because the medication was helping but he wanted to know now. However, doctors had noted in his file that he had issues with 'compliance'; one noted the need to stress how important his medication was, although Magnus denied missing doses. Magnus said he lived alone in Nairobi. His family lived in rural Kenya, but he rarely visited them. I invited Magnus to the support group where he could learn more about his condition. Magnus and I had met at the main government referral hospital and as I was leaving the neurology clinic, I noticed the hospital patient charter in the ward declaring that patients have the right to be told about their health and have their condition explained to them.

Magnus attended the next support group meeting with his son, who also lived in Nairobi. Magnus' son said he had tried to ask the doctors about his father's condition but said they had no time to explain; they just said his condition needed to be managed. They had spent seven years without any information about his illness. Magnus' son described how happy he was that his father had somewhere like the PSG where he could learn, socialise, and talk to other people about PD. He explained that Magnus refused to visit his family or move back to his village because people made assumptions about his condition, jumping to conclusions associated with witchcraft or superstitions. His son explained that Magnus was so happy he could finally return home because he could explain exactly what was wrong with him and people would no longer make assumptions about his appearance.

As discussed in Chapter Three, on several occasions I was put in a position where I felt I had to, and chose to, disclose PWPDs' diagnoses to them. Disclosing Magnus' diagnostic label allowed him to return home to his family, something he had been scared to do previously, and enabled him to join the PSG. His experience illustrates the social implications of not disclosing a diagnosis and how legitimising his condition and appearance allowed him to share his illness with family and gain further knowledge.

Martin (65-years) also attended the government neurology clinic. He also did not know he had PD, although he had been attending the clinic since 2015, and could not explain his condition to his family. He told me that his wife had abandoned him because of his condition and he now lived alone in Kibera slum. In England, Nettleton (2006) explored the experiences of neurology patients with medically unexplained symptoms and suggests that without an accepted diagnosis, society often does not give people permission to be ill. Although unconventional and difficult, all the PWPD whose diagnoses I disclosed described

how grateful and relieved they were to have a legitimate name for their condition[11]. Martin hoped he could reveal this 'new' diagnosis to his family, and they might accept his condition. Nzambi, a young-onset PWPD, also attended the government neurology clinic and was in a similar situation to Martin.

Narrative 7: Nzambi

You cannot help but stare at Nzambi and I am sure people in the clinic were doing just that. Because of his severe dyskinesia, Nzambi's whole body, especially his head, neck and jaw were writhing around and swaying. All this seemed more pronounced as he was missing a few of his bottom teeth and so his tongue protruded from his mouth with every involuntary movement of his head. Nzambi was 58-years-old but looked a lot older. He was wearing a well-used t-shirt, safari boots and a worn flat cap. Nzambi and I sat down to talk in one of the unused 'consultation rooms' in the clinic, a long corridor with a few chairs scattered along it.

Nzambi explained that he had a *"neuro problem"*. He said he bad pains in his neck as well as issues with a lot of shaking. He did not have a tremor, but the dyskinesia[12] is what he described as shaking. Nzambi said he was referred to the public neurology clinic when his problems began. He showed me his appointment cards dating back to 2001; they were tattered pieces of blue card stapled together which recorded his appointment dates for the last 17 years.

When I asked Nzambi what the doctors said was wrong with him, he responded, *"I don't know, but I have lots of X-Rays which show nothing".* Nzambi described asking the doctors several times about his condition but added, *"They only give me the same, same medicines"* which they said were *"for the sickness",* and no other information. Nzambi did not know what PD was, adding no one had ever mentioned that word. He had been attending the neurology clinic for 17 years, a neurologist confirmed his PD diagnosis recently, yet he had no idea he had it. Nzambi's phone rang and as he held it up to his ear his dyskinesia became worse, his hands and head jerking aggressively. Throughout our conversation, his head contorted constantly, twitching and writhing his face into strange expressions.

I suggested Nzambi attend the next support group meeting in Nairobi, which he did. He told me after the meeting that he had enjoyed it – he made friends with other PWPD and learnt more about how to manage his condition after speaking to a visiting occupational therapist,

[11] It would not have been possible to understand this group's experience had I not told them their diagnosis before their participation in the research.
[12] Involuntary, uncontrollable, erratic movements of the face, arms and legs.

things he had not previously been able to do. Several other PWPD from the public clinic also began to access the support group after learning about their diagnosis – this experience is explored further in Chapter Five. Disclosing Nzambi's diagnosis allowed him to make claims as someone with PD by accessing the support group, what Fassin (2009) and Marsland (2012) have referred to as "biolegitimacy".

Not knowing the name of their diagnosis did not prevent PWPD from receiving medication or being treated. However, it did prevent the opportunity to share a diagnosis with family and friends, learn how to manage PD, and took away the option of accessing additional services (where possible); although, these were largely scarce and expensive. Not being able to access support groups took away PWPDs' rights and responsibilities as someone with a disease. In addition, not knowing prevented PWPD from forming social groups based around their diagnosis, prevented them from 'belonging' to a diagnosis, negating the possibility of developing and maintaining "biosociality" (Rabinow, 1996; Marsland, 2012).

Although several PWPD were glad they finally knew the name of their diagnosis, David, whose mother, Maggie, had been attending the neurology clinic for seven years, explained: *"What I need is medication".* David was content accessing the medication his mother needed to survive – not knowing the name PD did not prevent this. For others, this was more of a concern and prevented them merely knowing about or accessing the holistic management required for PD.

4.4 Discussion

Expectations and old age

The first of three themes emerging from this chapter is where expectations about old age, ageing and the life course come from. Data presented illustrates beliefs about the changes in capabilities and bodily functions participants expected to experience as they aged and how disease fit within these expectations. Becoming stooped, slowing down, being in pain and developing a slight tremor appeared to be expected as people grew older and an inevitable part of the ageing process. Solimeo (2009), in her ethnography of PD in the USA, describes how the early symptoms of PD can resemble and overlap with those associated with "normal" old age. Similar findings were identified among people living with dementia in

Tanzania, where it was perceived, and accepted, as a normal disease of old people (Mushi *et al.*, 2014).

In contrast to findings regarding dementia in Tanzania which were thought "normal" even as the disease progressed, the bodily changes participants in Kenya experienced only seemed to require attention when they began to impact on their ability to carry out activities. These threats to "personhood" (Degnen, 2018) were defining moments and resulted in the realisation that things were no longer simply *"old people problems"*. Writing about polio survivors, Luborsky (1994, p. 240) suggests that the "person" category is *"earned by achieving and maintaining expected social roles and ideals*", where "person" refers to socially legitimated, full personhood. For some, symptoms resulted in PWPD no longer being able to maintain these expected "ideals".

Degnen (2018) discusses older age and cross-cultural perspectives on personhood and introduces ageing models that individualise the responsibility for how people age, rather than taking into account social, cultural, and economic inequalities people experience through the life course. Lamb *et al.* (2017) share concerns of this binary, simplistic view of individualised ageing. In Kenya, McIntosh (2017) suggests that 'success' in old age is associated with being amongst kin and being *partly* dependent on their assistance, whilst also being needed by family and community. Whyte (2017) echoes this view in Uganda, where she argues decline is an accepted and expected part of life that brings the opportunity of interdependent care. Both McIntosh and Whyte have described this as "desired interdependence". However, as participants' symptoms began to develop, they became increasingly dependent on others and unable to work or contribute to the family, although they were still amongst kin. This calls into question the limits of people's expectations to have some form of disability in later life and when this decline becomes problematic; perhaps when interdependence is no longer achievable. This idea is explored further in Chapter Six where we see how PWPDs' progressing symptoms impact on expectations of care.

However, what is interesting is where expectations of what ageing should look like come from, how these vary among different groups at different stages of life and when expectations become disease. Expectations, as Togonu-Bickersteth (1987) acknowledged in their study of old age in Nigeria, are complex and intertwined with political, social and

cultural factors. In their study, young adults identified “loss of rigor and strength” as the most “dreaded” eventuality of old age, while they anticipated the joy of being surrounded by children and grandchildren in later life, reinforcing the importance of interdependence. However, literature from SSA regarding perceptions about the physical aspects of the ageing process and why people expect to have some form of disability as they age is lacking, as echoed by Sagner (2002) in the book “Ageing in Africa: sociolinguistic and anthropological perspectives”.

Powell and Hendricks (2009) discuss the social construction of ageing, whereby historical, social, and cultural beliefs about the ageing process shape ideas about what it means to be old and assumptions which form individual perceptions about later life. For participants in the context of Kenya, this could include past experiences observing the physical states of older community dwellers and those with undiagnosed chronic disease, or traditional beliefs within families about the status, wisdom, and value of older people. Diseases associated with older age, like PD or dementia, largely ‘invisible’, unrecognised, and undiagnosed in Kenya until recent years, may have been contributing to a perception of later life associated with some form of declined physical capability. However, PD, as a progressive condition, has the potential to surpass accepted disability and dependence levels in later life, resulting in a possible threat to older people’s roles within the family and erosion of “desired interdependence”.

Uncertainty

This chapter raises important ideas about “uncertainty”, a theme that threads through the thesis and throughout PWPDs’ lives. Uncertainty was multifaceted and took on different forms and depths – it was evident from the insidious onset of symptoms, during initial consultations and even after diagnosis, often coupled with severe delays between the stages (Mulemi, 2017). In the USA, Solimeo (2009) has described how although a PD diagnosis can provide temporary relief and satisfaction, uncertainty and dismay about prognosis usually follows. Through the following chapters, we see how uncertainty unravels through disease management and the negotiation of healing landscapes, how it shapes knowing and is entangled within social relations.

Obtaining a diagnosis appeared to be an attempt to reduce and negotiate the uncertainty participants had experienced surrounding their previously unexplainable symptoms and make sense of their suffering. However, there are no clinical tests or numbers associated with PD, which makes the certainty of a diagnosis vaguer. This contrasts with the "digital certainty" Whyte (2014) talks of regarding HIV in Uganda, as well as the certainty of "numbers" associated with diabetes and hypertension (Whyte, 2016); although for HIV in the pre-ART era, the certainty of numbers was catastrophic and associated with death. Inconclusive diagnoses, which seemed to be a defining feature of the diagnostic journey in Kenya, and an important distinction from HIV or other diseases for which diagnostic tests exist, resulted in further ambiguity.

The underdeveloped, uncertain, unreliable and insecure biomedical health system also played a significant role in PWPDs' experiences of misdiagnoses, where the lack of specialists, or specialist knowledge, delayed accurate diagnoses. Furthermore, misdiagnoses made the certainty of a PD diagnosis more slippery, resulting in participants testing the care they received. In the context of insecure biomedical health landscapes where uncertainty dominates, people seek out some form of security and confidence in the form of a diagnosis. However, with no further advice regarding self-management, a crucial aspect of life with chronic disease, and no resources to gain more knowledge, uncertainty prevailed for many.

The differential treatment by doctors of PWPD determined the information they received at diagnosis. Andersen (2004, p. 2010), in the Ghanaian context, argues that this must be seen as a form of agency which has a rationale and is *"embedded in the bureaucratic organisation and biomedical discourse"* of hospital settings. Coupled with busy clinics, time constraints, poor communication and the inability to prescribe 'cures', this often resulted in further uncertainty. However, neurologists' *"pre-set attitudes"* to the government neurology clinics were partly responsible for their differential treatment. This had a negative influence on PWPDs' agency in their ability to make informed choices about their care.

Crucially, however, healthcare professionals' reluctance to disclose information was to avoid giving disheartening, *"depressing"* or bad news. Livingston (2012) suggests that the paternalistic doctor-patient relationship is at the heart of healthcare in low-resource settings (in this case, specifically in Botswana). On the one hand, the 'keeping quiet' of a diagnosis provided hope and possibilities for the future, as intended by healthcare professionals. On

the other hand, not knowing generated further uncertainty about how to live well, learn, gain legitimacy and form sociality around PD. Selman *et al.* (2009) explored the needs of patients with incurable progressive diseases and their families in Uganda and South Africa and found that withholding the truth increased fear and uncertainty, echoing findings from Kenya.

Despite this, participants had different reactions to a diagnosis and Livingston (2012, p. 166) suggests that that "*deeming autonomy as progress implies a uniformity of desire by patients within a particular national culture"*, which is not the case. People's individual differences and experiences require consideration when determining what to disclose. Improving communication, rapport and patient involvement in the diagnostic process could rid ambiguity about the information patients want to receive. Furthermore, the slippery certainty that came from obtaining a PD diagnosis appeared to disappear completely when participants were "un-diagnosed". In some way, the initial certainty surrounding disease appeared to be contingent on a name which could provide patients with a form of legitimacy, an issue discussed in the following section.

Position also played a role in the way participants sought to address uncertainty. Whyte (2016, p. 221), exploring the experience of people with diabetes and hypertension in Uganda, describes how *"position significantly affects chances of 'discovering the unknown"'.* Some participants spoke of their serendipitous diagnoses through connections, yet for others, no amount of serendipity could overcome the insurmountable structural obstacles to diagnosis, and indeed the continued management of PD. The important role kinship networks play in the management of PD is explored in subsequent chapters.

It is important to understand that uncertainty is multifaceted and nuanced – it can be seen as a negative state where a lack of understanding is foregrounding and limiting, but potentially, a source of hope. Whyte (2009, p. 213) in the book 'Dealing with uncertainty in contemporary African lives', suggests that uncertainty can be a *"basis of curiosity and exploration".* For participants in Kenya, their desire for a diagnosis and a way to make sense of their symptoms was an effort to seek some form of security and hope for the future. However, set within the context of insecure health systems, shifting kinship relations and lack of politicisation around PD, uncertainty became a defining feature of life; it can be reduced but it is almost impossible to eliminate, particularly concerning PD in Kenya. The

following chapters explore what uncertainty *does* to people living with a politically and societally 'invisible', unrecognised chronic disease and how PWPD and their families negotiate this within, and beyond, the home.

Labelling and legitimacy

Finally, this chapter raises issues about what a diagnosis *does* for PWPD. Knowing the name of a diagnosis had individual implications, by allowing PWPD to justify their sickness to themselves and their family, explain their pain and suffering and externalise their illness, and societal level implications, enabling PD to be recognised as a legitimate disease in society. However, there were also limits to the claims PWPD could make through their disease 'label' or services they could access.

As was clear from some PWPDs' diagnostic journeys, naming a condition helped to confirm its existence while providing a name to reference. The role of labelling and the language of disease diagnosis has been theorised in different ways. Frake (1961) found that a disease 'name' or 'label' were crucial aspects of illness for the Subanun in the Philippines. Similarly, Kleinman (1981) has argued that illness can be managed by labelling and explaining; although for participants in Kenya, labelling was not associated with any explanation. Naming symptoms as a diagnosis is crucial in the social construct of disease (Fleischman, 1999) and as Jutel (2011, p. 3) suggests, *"diagnosis provides a cultural expression of what a given society is prepared to accept as normal"*. Kleinman (1977) proposes that someone's illness experience must be validated by a doctor for them to legitimately be sick. However, without an explanation, the name of a diagnosis like PD may not mean anything when the disease is not known. As Fleischman (1999) describes about myelodysplasia[13], to non-specialists a name like PD in the context of Kenya is *"semantically opaque"* or indicates nothing. A more literal, simplistic explanation, such as *"nerve problem",* may be more relatable if additional information is unavailable, though this does not provide much insight into the condition.

"Biolegitimacy" could be used to understand the implications of labelling for PWPD. Fassin (2009, p. 52) coined the term "biolegitimacy", drawing on Foucault's "biopower", to

[13] A rare blood cancer.

understand the value attached to, and "worth" of, people's lives, focussing on *"meanings and values of life"* rather than power *over* life as Foucault proposes. Fassin discusses how, for example, medical legitimacy is overtaking political asylum in border security and public health, where the "worth" of life is attached to a diagnosis. He proposes that biolegitimacy gives foundation to what has been referred to as "biological citizenship" or "therapeutic citizenship" (Petryna, 2003; Rose and Novas, 2007; Nguyen *et al.*, 2010; Marsland, 2012; Whyte, 2014), which describes the political demand for treatment and 'citizenship-like' claims that can come with a diagnostic label, for example HIV/AIDS.

PD, being associated with old age, is one of the least visible conditions in the context of Kenya, which has resulted in near to no politicisation and almost no access to services and treatment. In other words, receiving a specific label and being put in a different therapeutic category determines what access people get to life-saving treatment. There are limits to the 'citizenship-like' claims someone with PD can make or the possibilities of legitimacy a 'label' can offer. In this sense, labelling, or 'knowing' a disease name, in a context of such structural constraint may not enable any tangible benefits. Whyte *et al.* (2013) has acknowledged that "citizenship" does not adequately convey the attenuated nature of claims people may have on services, nor recognise the existence of networks in accessing resources. The importance of labelling, without considering structural constraints (such as the accessibility and affordability of services and medication), connections, and the information patients receive at diagnosis, requires further consideration. As Whyte (2014) discusses regarding HIV in Uganda and Marsland (2012) in Tanzania, knowing the right people, establishing connections and reliance on kinship networks are also important for accessing services, as discussed in subsequent chapters.

However, knowing the name PD did have certain benefits. For example, knowing their disease 'label' allowed PWPD to research what access to services this enabled and for some, access support groups. Despite biologically experiencing PD, *not* being labelled prevented the ability to gain knowledge; importantly, PWPD stressed their want to know and have a name to refer to. Furthermore, *not* knowing prevented PWPD sharing their diagnosis and gaining recognition within their communities. As Jutel (2011) suggests, (contemporary) 'society' is prepared to accept things that are known, and acceptance comes through diagnosis. However, 'society' is comprised of different people and positionalities and so, the

use of society as a unified entity is questionable. Labelling provided a way to begin to enforce the existence of PD. Livingston (2012, p. 71), referring to cancer in Botswana, argues that linguistic translation is critical for the creation of disease. She writes, *"Knowledge production and disease creation (ontological emergence) need to be brought together"*, in order to bring "new" diseases into being.

Although obtaining a PD diagnosis did not lead to cure, or even access to services in many cases, it did provide hope in terms of treatment that could delay symptom progression, allowed participants to access information and support (albeit limited), make assumptions about their future and claims as someone with an accepted condition – legitimising their suffering. However, treatment was still largely unavailable, and many did not have the connections required to afford services; labelling may not be beneficial if access to life-changing medication is not possible, it may instead eliminate hope for the future. Chapter Five further discusses the importance of labels using the example of 'PD alert cards'.

4.5 Chapter summary

The diagnostic process was complex and convoluted for most participants; PWPD often did not distinguish their 'symptoms' from those associated with old age. This chapter has described the limits of biomedicine, where many PWPD in my sample experienced numerous misdiagnoses and were given very little information about their condition. The following chapter (Chapter Five) explores how PWPD continued to negotiate services across the wider healing landscape in Kenya, the constraints they experienced and the continued uncertainty of managing life with PD.

Chapter 5. Navigating therapeutic landscapes and social support

Chapter overview

This chapter describes how PWPD negotiate and manoeuvre different services and therapeutic landscapes across Kenya. First, I look at PWPDs' experience of navigating the private and public biomedical landscape, including the challenges of accessing pharmacological treatment, the financial and emotional toll this takes on families as well as ideas around "improvisation" (Livingston, 2012) and the use of "tinkering" (Mol, 2009) and "tactics" (Guell, 2009). I then explore PWPDs' interactions with alternative therapeutic approaches including herbal and religious healing and ideas around "medical pluralism" (Olsen and Sargent, 2017). Finally, I look at the role of support groups as a different kind of care for PWPD, operating within the wider therapeutic landscape, but also a source of support and "biosociality" (Marsland, 2012; Whyte, 2014). The chapter is situated in the context of a resource-poor biomedical healthcare system where neurology is not a priority and foregrounded by the need to improvise care, medication, and practices to suit this context.

This chapter is prefaced with the account of Nzambi, a 58-year-old man who had been living with PD for 17 years; his diagnostic journey was introduced in Chapter Four. This narrative explores the challenges of navigating services and support outside of the home for PWPD like Nzambi who were at an age where they "should" have still been economically active yet were living alone with very few resources and minimal support from family.

> *Narrative 8: Nzambi*
>
> Nzambi's home village is 70km south of Nairobi but he had been living and working in the city with his wife and two children for many years. However, Nzambi's wife left him this year. Nzambi was a driver but had been forced to stop working because his employers were concerned he could cause an accident. Nzambi was unemployed and had no support from his family. His sister and friends occasionally lent him money to buy medicines or for bus fares to attend appointments. Nzambi was a choir member at his church. The church sometimes helped him with money for food or medicines depending on the offerings. As we spoke, Nzambi struggled to remove his bulging wallet from his trouser pocket. He produced some receipts from the church – one for

200Ksh (£1.50), one for 100Ksh (80p) and another for 1000Ksh (£8). At home, Nzambi said he had electricity and a sofa, but no running water, sanitation, TV or radio.

Nzambi told me about his appointments over the last 17 years at the government neurology clinic, explaining, *"Every time I come to find a new doctor".* Each consultation cost him £5. Nzambi sighed and explained that the doctors usually read his previous appointment notes and kept his prescription the same, never asking how he was getting on. Nzambi said he was *"fed up"* with receiving the same medication, which he thought was not making him better. When we met again, he told me a registrar had prescribed him some new medication.

I told Nzambi about the support group for PWPD. Nzambi found it difficult to believe that there was anyone in Nairobi with the same condition. I wrote down the details of the group on a piece of paper. Nzambi folded the paper to put in his wallet and a few minutes later, forgot where he put it. From his wallet, he produced an old passport sized photo of himself dressed in sunglasses, a brown leather jacket and flat cap. His face was full and round, very different to the gaunt, toothless, frail man I saw in front of me.

Nzambi came to the support group meeting; it was a dance therapy session. He informed me he had lost his phone. Exactly one month after I first met Nzambi, we met again at the government neurology clinic. Nzambi looked better; his dyskinesia had reduced but he complained about his neck pain. He admitted he had enjoyed the support group: *"It's good, because I made a friend and we exchanged ideas".* Nzambi's new PD friend, whose name he had forgotten, had walked him to the bus stop after the meeting. Nzambi said his friend told him to think of happy things instead of his sickness. Nzambi told me he had continued dancing at home, practicing the moves he had learnt. He said he was excited for the next one, also adding, *"I have nothing else to do".* Nzambi was at the next meeting, which an occupational therapist led. He had a long conversation with the therapist over tea; explaining that he lived alone but wanted to learn about exercises to help manage his condition.

Nzambi's story highlights some of the challenges of living with PD in Kenya with no family or support system, and frustrating interactions with health systems and prescribing of medication; Nzambi's prescription had not changed in nine years. Symptoms are progressive and PWPD require more medication over time as their own dopamine reserves diminish. Nzambi was also able to access the support group after I disclosed the name of his condition and invited him to the group. His narrative encompasses the benefits of groups in terms of gaining information from specialists as well as social support; things Nzambi had not known about, and not received from the public neurology clinics, during his 17 years living with PD.

The management of PD in industrialised countries with advanced medical systems involves the use of a range of therapeutic drugs and allied health professional services as outlined in Chapter Two (NICE, 2017). In the context of Kenya, management was foregrounded by uncertainty and limited biomedical services and drugs. The complex journeys to diagnosis outlined in Chapter Four highlighted several issues with both public and private biomedical services and the lack of specialist knowledge among healthcare professionals. This complexity prevailed throughout PWPDs' journeys where a continuous manoeuvring through therapeutic landscapes was required. The range of available healing landscapes in Kenya was complex and included different aspects of treatment, healing and support: biomedical (Section 6.1), faith and herbal healing (Section 6.2) and support groups (Section 6.3).

5.1 Navigating public and private biomedical health services

This section explores the experiences of participants with different social, educational and financial resources navigating the Kenyan biomedical landscape. PWPD in this study accessed private (n=34) and public (n=12) neurology clinics, while nine were not accessing any outpatient clinic at the time of the study. Medication was difficult to obtain in both private and public sectors but those with more resources were better positioned to source and afford drugs, although this was often still difficult. For others with fewer resources, the continuous costs of care steered some towards destitution or resulted in periods with no medication. However, although participants paid more than ten times the price for private neurological services, PWPD often did not receive better care in terms of information, time spent with neurologists or choice of treatment, than those who accessed the public neurology clinic.

5.1.1 Resources and healthcare

The questionnaire survey of 55 PWPD showed that respondents used a range of biomedical services as well as religious healing and herbalism for the management of PD (*Table 6*). However, the number of practicing allied health professionals in Kenya was very low. For example, there are only 15 qualified speech and language therapists in major cities in Kenya (Yellow House Outreach, 2018) and no PD nurse specialists. Very few PWPD in this study had

accessed any additional services, shown in *Table 6*, and where available, stressed the high costs. This section therefore focusses on participants' interactions with private and public neurology outpatient clinics as the most utilised form of biomedical treatment.

Service	No. of PWPD who accessed services (n=55)
Outpatient neurology clinic	46
PD support group[14]	18
Religious healing	13
Physiotherapy	11
Herbalism	8
Speech and language therapy	2
Occupational therapy	0
Dietician	0

Table 6. Number of PWPD accessing services identified from the questionnaire survey

The monthly salary based on the national minimum wage in Kenya after tax, as determined by Mokaya *et al.* (2016), is 11,222Ksh (£84), which after basic living expenses leaves approximately 7% of the net salary, equating to 785Ksh (£6), for healthcare costs every month. However, many Kenyans may not receive minimum wage, particularly those working in the informal sector. Thirty-seven PWPD in this study were no longer engaged in income generating activities and pensions were rare, although 12 PWPD who were previously civil servants had access to the public service pension scheme and two were enrolled on the governments' National Social Security Fund, a contributory retirement scheme for formal sector employees. No PWPD were enrolled on the Older Persons Cash Transfer Programme, described in Chapter One, or the *Inua Jamii 70+* scheme that launched in June 2018 (Chepngeno-Langat *et al.*, 2019). Furthermore, the National Health Insurance Fund did not cover any outpatient services[15]. Almost all participants described the challenges of the low number of neurologists and high costs of consultations, particularly within private clinics. Private neurologists' fees ranged between 5,000Ksh (£38) and 30,000Ksh (£225) per

[14] This number only includes PWPD who accessed the group prior to the study, not those I directed to the group.

[15] At the time of the study, only civil servants were able to claim outpatient fees using the National Health Insurance Fund. The scheme is compulsory for people employed in the formal sector; those not in formal employment can make a voluntary contribution.

consultation depending on the type of private clinic. Nairobi has the only government neurology clinic in the country and outpatient consultations incurred a fee of 650Ksh (£5).

Private physiotherapists, usually only available in cities, cost 4,500Ksh (£35) per session, not far short of the average cost of private physiotherapist services in the UK (£40-£60). Private occupational therapy fees ranged from 1,500Ksh (£11) to 5,000Ksh (£38) per hour for home visits. Occupational therapy clinics ran every day at the main government referral hospital; although no PWPD attending the government neurology clinic reported being referred to the service. Using Mokaya *et al.*'s estimations, compared to minimum wage, the costs of various services demonstrate the relatively large amounts PWPD were paying for services in private and public clinics (in addition to buying medication). This also became evident during interviews and conversations with participants and is discussed further in Section 5.1.2. Paul (70-years) explained that he had used his entire public service pension on "*medicine and consultations".*

The accessibility of private services was also an issue that participants identified because of (a) the low numbers of healthcare professionals and (b) private services being concentrated in major cities (Nairobi, Mombasa or Kisumu). PWPD not in a major city described either having to travel to Nairobi to attend the government neurology clinic or see a private neurologist or allied health professional in a major city where available and dependent on resources. Travel contributed to added costs, particularly because several PWPD described being unable to use public transport due to their symptoms (as described in Chapter Three). Hiring a taxi to travel from rural villages to major cities could cost up to 15,000Ksh (£110) for up to 175km; a similar journey would cost 1,000Ksh (£8) using public transport. Meshack (40-years) was diagnosed with PD one year ago and travelled 160km from his home to attend the government neurology clinic, which he did less than once a year, re-using his old prescriptions to buy medicines over-the-counter instead. In addition to accessibility and affordability, neither private nor public clinics were described as satisfactory and the following sections describe participants' experiences of both.

Experience of private outpatient neurology clinics

Private neurologists in Kenya worked across seven private clinics in Nairobi, two in Mombasa and one in Kisumu. Almost all participants who accessed private neurology clinics (n=34) described them as being extremely expensive and reported the inadequate consultation times and subsequently, the limited information they received about their condition. Several described these consultations as *"prescription only"*.

Prince (2018) suggests that Kenya's private hospitals are among the best in Africa but unaffordable for most of the population. Several PWPD in my sample who accessed private clinics described being able to pay for their consultations through savings or pensions; nineteen PWPD who accessed private clinics had a pension while 14 were still employed at the time of the study. Others explained that their adult offspring paid for consultations, if they were financially able. Other families described going to great lengths to source the funds needed, selling assets, saving up family incomes or holding fundraisers. Dr A, a neurologist practicing in both a private and public clinic in Nairobi, referred to those who accessed private clinics as a *"selected group"* who had more resources or others who were *"sponsored".*

The private neurology landscape was a relatively small marketplace – several participants described having to wait months for an appointment due to the low number of practicing neurologists and overwhelmed clinics, despite their high fees. In Chapter Four (*Narrative 1*), Esther suggested it was the receptionist's job at one clinic to *"turn people away".* Furthermore, PWPDs' interactions with neurologists were brief. Eunice, the wife of one 79-year-old PWPD, had stopped taking her husband to clinics after 18 years of living with PD, despite being able to afford it, because she said they gained nothing yet paid high fees:

> *"They [neurologists] don't care, they don't. Because you know they are supposed to follow you up and see that they have seen you…They just prescribe some medicine, which seems to not be available in the counters" (Eunice, spouse of 79-year-old PWPD)*

Even though participants paid large amounts to see private neurologists, several reported feeling alone and receiving limited information about PD, which was often an over-simplistic,

over-optimistic picture of the condition, or just a prescription; for example, Soraya, aged 65, described being told *"just to use the medication forever".*

Several participants described how some private neurologists had not disclosed the untreatable, progressive nature of PD. This was apparently partly to avoid disclosing bad news, as discussed in Chapter Four, but also often to prevent PWPD from seeking treatment elsewhere, illustrating the competitive nature of the neurological marketplace. However, some PWPD explained that private neurologists *had* told them about the incurable, progressive nature of PD. This often resulted in PWPD seeking out advice from different private neurologists or as Dr B suggested: *"shopping around"*. PWPD described wanting to see if other private neurologists might have more time for them, could provide more information (that they wanted to hear), or prescribe different or 'better' medication. For others, it was the hope that a neurologist might be wrong (as discussed in Chapter Four) that resulted in "shopping" for a different neurologist; as long as there were other possibilities of treatment, some participants felt they had to keep trying.

The costs of private neurologists ranged quite substantially. Several adult offspring described feeling pressured into paying to see the most expensive neurologist or risk being accused by their community of not providing the best care for their parent. Sarah, the daughter of one 78-year-old PWPD, described this as *"emotional blackmail".* However, several participants (or their families) seemed to think that the greater the cost of services, the better the care. For example, Wanjiku, the daughter of one 71-year-old PWPD, explained why they sought care from a more expensive neurologist:

> *"Sometimes, you'd rather deal with somebody who knows what they are doing and pay higher than someone who is thinking or trying to figure it out…I'm happy to pay for the quality care…I have siblings, we pay for it together" (Wanjiku, daughter of 71-year-old PWPD)*

Wanjiku described being "*happy"* paying higher fees if the neurologists spent more time with her father. At a private clinic in Nairobi, I regularly observed how much time the neurologist spent with patients, fully investigating their condition and providing further information to read. PWPD had to pay a significant amount for this level of care, which was unaffordable for most. However, there were challenges associated with being honest about

the nature of PD. For example, Dr G described disclosing prognoses to patients, but Dr B described situations where patients had visited them because they did not 'like' what Dr G had told them. This highlights why other neurologists might have been reluctant to disclose bad news. Dr A described his perception of the care provided in his private clinic and the need to appear to care about patients:

> *"There is more time with the patients…The wife is there, you can ask personal questions…allow them to free talk because you have got more time…Of course, one thing you realise over time is in order to, not that you're marketing yourself, but one thing that you have to know over the years is that patients feel satisfied if you know them, if you are concerned about them…about his chicken rearing…about his coffee farm…about his children…So, that is a plus in terms of....I think winning people…winning people when they feel that you know them…They feel that you are caring about them…Therefore, the medicine would be in the context of that" (Dr A, neurologist)*

Dr A referred to the idea of *"winning people"* by allowing patients to talk about themselves, apparently justifying the extra consultation costs. The suggestion by Dr A about *"marketing yourself"* also illustrates the competitiveness of the healing landscape where neurologists needed to keep patients from seeking different specialists, as PWPD described, or alternative healing practices, which is discussed in Section 5.2. Several participants and neurologists also described how private neurosurgeons, who were not trained to manage PD, often took on patients. In the UK, neurosurgeons would only be involved in treatment if patients underwent deep brain stimulation surgery, although this is not available in Kenya. Moses described his experience after his mother, Judith, had seen a neurosurgeon for several years, adding: *"These Kenyan doctors, they'll never tell you there is another doctor who can do something better".*

Experience of public outpatient neurology clinics

This section refers to the only public neurology clinic in Kenya. Some PWPD with limited resources struggled to pay the £5 fee, particularly with the added costs of travel and medication – Nzambi was once unable to pay and was turned away from the clinic. All 12 participants who attended the public clinic described the quick consultations and limited information they received, which I was able to observe during clinic hours. Some described the *"pointless"* exercise of attending the clinic. Maggie (74-years) was diagnosed three years

ago and lived alone. Her eldest son, David, brought her to the clinic every six months, missing work to do so:

> *"They [doctors] don't say anything, they take the card and write the medicines…Always when I come every six months, only the same, same medicine…Wasting 650Ksh (£5) for nothing [attending the clinic], wasting fuel to get here and wasting time" (David, son of 74-year-old PWPD)*

David, like several other participants, described being able to use old prescriptions, avoiding the extra costs of the *"pointless"* clinics. Prescriptions were given for six months but PWPD sometimes used them for years. Philomena had travelled 90km to attend the neurology clinic with her 62-year-old mother with PD, Zia, who ran her own grocery shop and lived alone. Philomena described how the registrars would merely write her a new prescription every time she visited. In Uganda, Whyte (2016) experienced a similar practice of renewing prescriptions without testing among diabetic and hypertensive patients. Dr A, speaking about the government neurology clinic, echoed participants' concerns:

> *"I think [clinic] is basic prescription filling…You come, and you sit in a chair. It's a bit public, it's not very private…You [neurologist] say, 'How are you doing, you're OK? OK. Your medicines…OK, bye. Merry Christmas'. So, the personal things don't come in…It's not complete" (Dr A, neurologist)*

Consultations at the clinic were not carried out in private, as illustrated in *Narrative 9* and *Image 6* below. Dr A also described the lack of any *"package"* of care at the government clinic, including advice about symptoms or referral to additional services, whilst prescribed medicines were not available at the hospital pharmacy. Attending the government clinic, I observed the *"public", "prescription filling"* practice described by participants and Dr A. Matthew (62-years) was diagnosed one year ago and attended the clinic alone. Matthew was retired and used his savings to pay for his treatment; although he added that his six children wanted to help with these costs. Matthew's narrative demonstrates how patients physically manoeuvred this clinic, the brief encounters during consultations and highlights the challenges with access to medication.

> *Narrative 9: Matthew*
>
> Matthew was the only PWPD at the clinic today, although three others were due to attend. He paid for his consultation and was handed a torn piece of paper and piece

of blue card at the information office. The card was for his blood pressure measurement. Matthew's name was called out and he joined the queue of other patients seated on the benches that snaked around part of the clinic waiting room and led to the blood pressure station. Once someone had had their blood pressure measured and recorded on their piece of paper, everyone moved up a space on the benches. A security guard was monitoring the queue; the clinic was very busy and there had been reports of thefts. Patients began shouting at someone who tried to queue jump. Considering many patients had had strokes or had movement disorders, the system using the benches did not seem 'user-friendly'. Patients kept standing up and shuffling along the benches (*Image 5)*, negotiating their crutches around peoples' legs, family members rushing over to help. As soon as they managed to sit down, they had the whole ordeal again. An older man with a large wooden crutch under his right armpit struggled to move away from the blood pressure station. He took the tiniest of shuffling steps, holding up the rest of the queue and eventually managed to reach a bench, sitting down next to me.

Image 5. The waiting room where the government neurology clinic took place (on a non-clinic day) showing the benches patients negotiated

After Matthew's blood pressure was taken, he moved on to a different section of benches and waited to see a doctor. Matthew would see a registrar today, as he was not a new patient. There were only two neurologists and one registrar to see over 100 patients in three hours. If all patients were not seen, which happened quite often, they had to return home and were given another appointment date. Consultations occurred along a corridor of benches, where there was no privacy (*Image 6)*.

Matthew sat down with the registrar, who was surrounded by a group of medical students in their lab coats and backpacks. It looked quite daunting. I asked a nurse whether they needed permission from the patient to observe the consultation; she said they never asked the patient. A neurologist popped his head round the curtain

of one of the small “consultation rooms” and told the registrar to call the rest of their colleagues to the clinic to help. Matthew was sat down with the registrar for no longer than three minutes and received the same prescription he had been taking since his diagnosis one year ago. He said he could not get his prescription from the hospital pharmacy next to the clinic; they did not stock levodopa. Later, he said he would try and find it in town.

Image 6. Corridor of benches where 'public' consultations took place

Matthew’s experience in the clinic was a standard procedure as I witnessed through observations over several months. He was seen for a few minutes by a registrar and given a repeat prescription. Appointments ran on a ‘first-come-first-served’ basis. If patients turned up for the clinic too late, they would likely not be seen, and the clinic would not take their payment as there were not enough healthcare professionals to see everyone. Those who had travelled long distances had to return home without being seen. Often PWPD who were due to attend the clinic simply did not turn up and the hospital did not have the resources to follow them up. The clinic was usually overbooked; the majority were returning patients who saw registrars, although there were several ‘new’ patients who were yet to be diagnosed by neurologists. Dr C described the effect this had on his ability to practise and how the overwhelmed public clinics influenced care compared to his private clinic:

1st November 2018

Dr C said he only saw three patients per hour in his private neurology clinic and could be people’s *“personal doctor”*, whereas the government clinic was always overwhelmed. He added that patients were paying more to see him in his private clinic and so, he assumed they were of a higher status, would demand more answers and would have read more on the internet and so, would have more questions

> regarding treatment options. At the government clinic, he said he could not refer patients to specialists, and he was limited by medication options, both availability and affordability, and issues with people not taking their medicine as prescribed, but he did not have enough time to go through dosing timings and would not see them again.

Dr C also described not referring patients to additional specialists (occupational therapists, for example) at the government hospital because of affordability and lack of service capacity, reiterating what PWPD identified. There was also no continuity in care; doctors could not judge PWPDs' progression if they had never seen them before. In addition, registrars saw the majority of returning patients, yet often did not have the appropriate training and knowledge to manage advanced PD cases; Dr B described the consequences of this:

> *"You hardly get progressed to the drugs to deal with…the freezing, the gait problems, the incontinence…because we're just renewing your prescription. Then you'll get fed up because mum is getting fed up of getting worse. Then you'll come to me in private clinic and I'll realise 'Oh no, we need to move this, we need to change this, you're actually having dyskinesias'" (Dr B, neurologist)*

Dr B acknowledged that after receiving sub-optimal care at the government clinic, usually from registrars, the very few PWPD who could afford to would visit private clinics in search of 'better' care and more information. As Dr C described, no PWPD attending the public clinic had been referred to see any allied health professional services, while nine of 12 PWPD had not been told the name of their diagnosis, as discussed in Chapter Four. Dr A explained the challenges of this but also acknowledged the reality of the overwhelmed clinics:

> *"[Not referring patients to services] is really denying them that opportunity, uhh, of physio, of how to swallow…But the only thing is that sometimes…the support system is not so much to support a few shaking people" (Dr A, neurologist)*

Dr A described the limited procedures and services in place to support PWPD at the government clinic. *Table 7* outlines the average number of patients visiting the government neurology clinic with particular conditions (those with average attendance of one or more patients and not including patients who were undiagnosed before the clinic) over 12 weeks of clinics. The most common neurological conditions seen were epilepsy and stroke, while there were fewer than two PD cases on average per clinic, underscoring Dr A's point

regarding not being able to support *"a few shaking people".* Dr A also described the goal of clinic as getting PWPD into the system to start them on medication:

> *"If I spend my time seeing Parkinson's, I've taken one hour…Where you have limited resources, it's probably not the most cost-effective way of doing things. So, the most cost-effective way is to get a patient…get in, 'OK, I think this is Parkinson's'…and therefore, you put him through the process" (Dr A, neurologist)*

Neurologists described prioritising more common conditions, while the best care they felt they could give PWPD within the time constraints was a prescription to improve symptoms because there was no cure and additional services were largely unavailable.

Condition	**Average attendance over 12 clinics (number of patients)**
Seizure/epilepsy/convulsions	41.2
Stroke	20.5
Chronic headache	4.5
Peripheral neuropathy	4.0
Parkinson's disease	1.8
Migraine	1.8
Cerebral Palsy	1.2
Dementia	1.0
Myasthenia Gravis	1.0
Average number of returning patients per clinic	90

Table 7. Number of patients I identified from the government neurology clinic with specific conditions over 12-week period 01/10/18 – 17/12/18

Several participants also described feeling that neurology was not a priority for the government, while *"lifestyle diseases"* received more attention. Neurology was suggested to be a relatively under-resourced department and PD did not yet appear to fit into the government's health priorities; Kenya does not have a separate budget for neurological disorders (WHO, 2017). Consequently, there were challenges with access to medication because of the relatively low demand for drugs and low political visibility of PD.

5.1.2 Accessing and affording drug treatment for Parkinson's disease: "buying life"

Participants in this study came from diverse social, environmental, educational and financial backgrounds. This section explores how PWPD and families with more resources negotiated the challenges of availability and affordability of pharmaceutical drugs compared to those with fewer resources. However, most participants would only be able to access levodopa, the most basic form of PD treatment.

As discussed in Chapter One, levodopa + carbidopa enters Kenya through parallel importation, resulting in inconsistent supplies and fluctuations in prices, making it unaffordable for many. Of the 55 PWPD questionnaire survey respondents, 50 had been prescribed a levodopa + carbidopa formulation, although several were also taking other medications in combination. The most common and cheapest (on average) preparation prescribed was 100/10mg *(Table 8);* I was unable to identify costs for other medications. Average cost was based on roughly one month's supply (100 tablets) if taking three tablets per day as a typical early-stage dose.

Medication prescribed for PD	**No of PWPD (n=55)**	**Average cost of 100 tablets**	**Range of costs**
Levodopa/carbidopa *(mg/mg)* *(i.e. Sinemet)*			
100/10	28	£27	£16 - £52
100/25	17	£33	£24 - £39
200/50 (CR)	2	£54	£40 - £62
250/25	3	£49	£33 - £59
Dopamine agonist *(i.e. Pramipexole)*	12		
Anticholinergic *(i.e. Benzhexol)*	8	£3	£2 - £4
Glutamate antagonist *(i.e. Amantadine)*	3		

Table 8. PWPD prescribed specific medication and average cost and range of costs of 100 tablets worth of levodopa/carbidopa identified from 28 pharmacies across Kenya using a convenience sample

None of the four government referral hospitals included in this survey in four main cities and towns across Kenya stocked any levodopa at the time of visiting, highlighted in *Table 9*[16] (Fothergill-Misbah *et al.*, 2020b). As illustrated in *Narrative 9* in the previous section, Matthew was unable to obtain his prescription from the government hospital pharmacy. However, of all preparations, 100/10mg was the most available in independent and private hospital pharmacies.

PWPD had also been prescribed other medications *(Table 8)* which were often taken in combination or alone. Three PWPD were taking drugs that were not available in Kenya, including MAO-B inhibitors like Rasagiline or a levodopa/carbidopa/entacapone combination known as Stalevo. PWPD who had family members who travelled or lived abroad, and high levels of social, cultural and financial capital, were able to source these drugs from outside the continent. Amantadine was also largely unavailable in Kenya, although several pharmacists said they were able to source the drug using private parallel importation. Anticholinergics like Benzhexol (*Table 8*) were widely available at a low cost and were often prescribed if PWPD could not afford levodopa, although anticholinergics cannot act as a substitute for levodopa. Anticholinergics can help reduce tremor (something levodopa does not do so well), but can make other symptoms worse and cause confusion, hallucinations and memory loss, particularly in older people.

Almost all participants discussed the high cost of levodopa; the costs identified from a pharmacy survey are shown in *Table 8.* However, most PWPD were taking higher doses than estimated in the table – some with advanced disease required large and frequent doses to manage their symptoms. Jared (70-years) had been living with PD for 14 years; he scored 23 out of 30 on the non-motor symptom questionnaire (average score was 12.9 ± 5.8; range 2-29). His family explained that they needed 40,000Ksh (£300) worth of medication per month for Jared to live well. The high cost of medication was also a common topic of conversation at support group meetings. One pharmacist, a member of the group, had reduced the cost of levodopa at their pharmacy for members; although this only benefitted those who knew about the group who were usually of a higher socioeconomic status. For example, 100

[16] The data collected as part of this ethnographic study were recently published: Fothergill-Misbah, N., Maroo, H., Hooker, J., Kwasa, J., Walker, R. (2020) 'Parkinson's disease medication in Kenya – Situation analysis', *Pharmaceutical Journal of Kenya,* 24(2).

tablets of 100/10 would cost 2,200Ksh (£16) instead of 2,600Ksh (£19) saving members approximately £3 per month, and likely more. In addition, some more affluent members of PSGs would donate medication to other PWPD who were struggling. This would often take place through pharmacists who were members of the group to ensure fairness. Those who received donated medications described the huge but temporary relief this brought them and their families.

Location	Type of pharmacy (n=28)	Number of pharmacies stocking preparations of levodopa/carbidopa			
		100/10	100/25	200/50	250/25
Mombasa	Independent (n=8)	5	0	0	4
	Private hospital (n=4)	1	3	0	1
	Government hospital (n=1)	0	0	0	0
Nairobi	Independent (n=5)	3	2	2	3
	Private hospital (n=1)	1	1	1	1
	Government hospital (n=1)	0	0	0	0
Central Kenya	Independent (n=2)	2	0	1	1
	Private hospital (n=2)	2	1	0	0
	Mission hospital (n=1)	1	0	0	0
	Government hospital (n=2)	0	0	0	0
Kisumu	Private hospital (n=1)	1	0	0	0

Table 9. Location and type of pharmacy surveyed and availability of levodopa/carbidopa preparations

The majority of PWPD had to pay for medication costs out-of-pocket unless they had private insurance, although often medication was not covered. Five PWPD, all of a high socioeconomic status, had private health insurance schemes in Kenya or abroad. Shay (81-years) had been living with PD for 12 years, although was not diagnosed until six years ago. He described having *"very expensive"* private health insurance outside of Kenya, although this had a spending limit:

> *"In a year I can get medicine worth £1000. After I reach that limit, I have to buy my own medicines…These [Sinemet and Pramipexole] are expensive…Middle of the year, my limit is exhausted…The rest of the year I have to pay £1000" (Shay, 81-year-old PWPD)*

Shay had to pay for insurance and medication, demonstrating the significantly high costs. He added, *"I think the prices of medicines are prohibitive".* Furthermore, limited availability

(*Table 9*), coupled with frequent shortages contributed to further challenges, which are discussed in this section.

Martin (65-years) attended the government neurology clinic and was diagnosed with PD at the age of 62. He was unemployed and lived alone in a slum. This narrative describes the challenges many PWPD faced with accessing and affording medications, although Martin was navigating the therapeutic landscape in Kenya with no income or family resources.

> *Narrative 10: Martin*
>
> Martin attended the government neurology clinic for his *"shaking problem"* and said that friends and well-wishers usually paid for his consultation fees (£5). Martin also had hypertension and diabetes. He had been prescribed five medicines yet had no income: levodopa/carbidopa 250/25mg (the most expensive preparation available) and Benzhexol for PD, diabetes and hypertension medicines and an antidepressant. Just recently, in October 2018, he said he spent a whole week without any PD drugs and could not get out of bed. Martin said his biggest problem was his PD and he needed financial support.

Martin described how he often went days without taking any medication, although acknowledged that he had to source enough to be physically able to attend his clinic appointment. In this way, Martin selectively took his medication to be able to carry out necessary activities based on his resources. Several files of PWPD at the public clinic had *"poor compliance"* repeatedly written in them by doctors who had apparently interpreted their inability to take medicines as prescribed as deliberate choices. In contrast to Martin's experience, Richard (68-years) had been living with PD for ten years, attended a private clinic and had an individual pension scheme abroad. He explained, *"I've got used to [levodopa], they're not expensive",* although this perspective was rare and illustrated the large variation in resources among participants.

PWPD who had dependent children, or whose families had distanced themselves, stressed the overwhelming financial impact of PD. In contrast, several PWPD described not knowing how much their medication and consultations cost as their adult offspring paid for their care. Soraya (65-years) attended the government neurology clinic. She did not pay for her medication but her daughter, Evelyn, described the costs of Soraya's care:

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Soraya and Evelyn travelled 175km to attend the public clinic in Nairobi. The doctors at the clinic told them that Soraya had to take medicine forever and that they had to accept the sickness. Soraya had not been engaged in paid work through her life. Evelyn said she often told her mother to appreciate that she had eight children to take care of her. Evelyn explained that levodopa was costing her 6,000Ksh (£45) per month. I asked whether she shared this cost with her siblings, but she laughed and said only she paid for it. She added her siblings *"were not stable".* Evelyn explained, *"I have to buy it, I have to stand for it".*

Although medication was expensive, the adult offspring of several PWPD described feeling *"obliged"* to pay or *"responsible"* for buying medication for their parent or paying for consultations. Gloria (76-years) described initially being able to pay for her medication with her savings but after nine years of PD she added, *"I have consumed it all…my money is finished".* Gloria's adult daughter continued to pay for her treatment, but Gloria was uncertain how long her condition would go on for, or for how long she would live, and concerned about her complete dependence on others.

For some PWPD with larger families, the continuous costs of medication, consultation fees, occasional inpatient periods and herbal medication were described as financially devastating; as the spouse of one PWPD described, *"Nothing but drugs for the father [PWPD]"*. Jared (70-years), his wife, Constance and their daughter described how PD had affected them. Jared was diagnosed 14 years ago and had a very large family. However, they had been forced to sell assets to pay for his care, could no longer afford for him to attend the private neurology clinic and struggled to source his medication:

Daughter:	The condition is continuing. So, you drain, you drain, you drain, borrow, borrow, borrow, send, send, send.
Constance:	You have not paid; the drug is finished. You sell. We have cows; we have sold them.
Daughter:	Sell a plot.
Constance:	Like, we went to [neurologist], we sold a cow, a great cow. So, the problem has made us very poor. Poor.
Jared:	We have been drained.
Daughter:	It's draining our money.
Constance:	So, if month end you don't have 40,000Ksh, madam.
Daughter:	He won't survive.

Constance: And the disease, I call it a problematic disease. He has no peace and we have no peace. Unless you run away from him.

Natasha: Which you can't do.

Constance: Which you can't do.

(Constance, her daughter and husband, Jared)

Jared also experienced a period without treatment where Constance described thinking *"he was going".* Several other families described similar financial difficulties, where they reported having to sell their possessions and borrow money while others suggested *"resigning to fate"*. Tina's husband lived with PD for 16 years and the family described having to hold fundraisers towards the end of his life. She explained: *"When he [PWPD] died, he left us empty".*

The high costs of medication resulted in several PWPD taking it 'on and off' or stopping for periods of time as Martin described in *Narrative 10.* Others reported having to alter or reduce their doses because they could not afford to take it as prescribed. Gideon, a young-onset PWPD, described trying to provide for his young children; at one point, he was unable to *afford* his PD medication:

> *"They [doctors] gave me a prescription of [levodopa] 110…another one that was called Amantadine…I was able [to afford] at the beginning…then I was unable to buy. They dropped Amantadine for me; eventually I dropped the [levodopa] myself. I just couldn't buy any more. It was costing me about 25Ksh (20p) per tablet…So, if you are told to take five…that's too much for me, I couldn't make that in a day. So, I stopped. But after I stopped it got worse, I couldn't even get out of bed. I couldn't walk. I couldn't [afford], and my family wasn't able to support me" (Gideon, 33-year-old PWPD)*

Gideon's medication was initially reduced based on his means. However, Gideon was eventually forced to stop taking any medication. He explained, *"I can't manage to pay school fees for my son and also go to hospital".* Gideon used the money he had to provide for his family rather than pay for medication and clinics.

Several neurologists seemed unaware of, or did not discuss with PWPD, the high costs of medication when prescribing for those with fewer resources; Martin was prescribed medications he could not afford, as was Nzambi. However, both Dr A and Dr C acknowledged that they were unable to prescribe certain medications because of peoples' limited

resources and the high costs of drugs; Dr A described the consequences for PWPD attending private and public clinics:

> *"They decide maybe they don't increase the dose; they just take the little because that's what I can afford. Doctor increases the dose, I don't increase. He adds me another medication, I don't do it because it's going to cost me a lot of money. I'll use the same dose all along and I don't improve" (Dr A, neurologist)*

Although Dr A suggested that PWPD only altered or rationed their medication based on affordability, structural constraints, including availability, were also a significant issue. Julian described the consequences of not being able to *access* medication for his uncle Silvano, aged 67:

> *Narrative 11: Silvano*
>
> Julian explained that Silvano had worked with him at his flower shop on a busy road and after several years of experiencing symptoms had been spotted by Anya, a member of the PSG, who happened to be passing by. Through attending the PSG meetings, Silvano was sponsored by another member to see a neurologist and given subsidised medications. Silvano had been living with PD for 13 years and as he became less able to work, could no longer afford to live in Nairobi. In December 2017, Silvano's children decided that he should move back to his village to live with them. Julian explained: *"When we were moving him it was towards the end of the year and it was campaign time. There's no money, elections are here. Everybody is running around"*[17]*.* Around the same time, Julian said he had lost his mobile phone, along with all the contacts he had for the support group members. Consequently, Silvano could not source any medication; Julian explained, *"The drugs got finished".*
>
> Julian explained that the family were *"so helpless".* He added that they just prayed and hoped that God would sort the situation out*.* Julian added: *"There's nothing we could do and there's nothing I could say. I didn't have any money".* After five months without any symptomatic PD medication, Silvano's symptoms progressed and he died. Julian suggested: *"If there was medication he would still be here. But then again, you can't discuss what God decides".*

It was through their connection with Anya and the PSG that Silvano was able to receive medication. Whyte (2014) refers to this as "technical know-who" in Uganda among people

[17] Considering the history of election violence in Kenya, people often flee cities to the 'safety' of villages and many businesses do not operate during campaigns, which could result in lost income and challenges with access to pharmacies.

living with HIV whose connections led to “clientship”. However, due to an unfortunate loss of this connection (Julian losing his phone) coupled with their financial constraints, Silvano lost his access to medication. Julian also described the prolonged uncertainty Silvano’s family experienced where they felt helpless.

The poor accessibility of medication was a significant challenge for many participants. Constance, whose family lived in a village in Coast province, described the challenges they faced sourcing medication:

> *“Up to now, it’s very difficult to get [levodopa/carbidopa]. Very difficult. In fact, one month ago we missed it kabisa (completely) and the patient went down as far as drooling and couldn’t eat…The money you have is little, the drug cannot be found. We called Nairobi, they said there’s none. We went around Mombasa, there was no chemist that sells it. Then he was going…If when you get 2,000Ksh (£15) you can go to a shop and buy, still that would be better. But you get 10,000Ksh (£78), 15,000Ksh (£115), you want the drug, you call at Nairobi, none. You call at Mombasa, none. Then what do I do?” (Constance, spouse of 70-year-old PWPD)*

Constance described the difficulty accessing the medication she needed to keep her husband alive; explaining, *“In fact, you are buying life”.* Similarly, Esther described how she had spent a whole day searching for PD medication in Nairobi, *“In a day, I did nothing from morning to evening, I just looked for Parkinson’s [medication]”.*

For many PWPD, whether they were able to source medication when stocks ran out was contingent on their networks and social resources. Several participants described knowing wholesale pharmacists while others had asked pharmacists to import it specifically for them. Independent pharmacists explained they usually did not stock levodopa because it did not ‘move fast’. Urban government hospitals often ran out while rural government facilities reported never having any PD patients. In Ghana, Hamill *et al.* (2019) reported similarities in medicine shortages and poor availability, particularly within government health facilities. Several participants in Kenya who could afford to also described buying medication in bulk, keeping stock for months in advance. Others reported sourcing generics from India, although this was only those who had connections abroad (friends or family members), were of a higher socioeconomic status and were able to afford several months’ stock at a time. Participants explained that sourcing medication from abroad was significantly cheaper,

although those with no connections and limited financial resources were unable to do this. Louise described how she negotiated the poor availability and high costs of levodopa:

> *"Currently, when we don't have anybody to send [from India], it costs us 15,000Ksh (£115) a month to give her [PWPD] the full dosage. And when we send for the same [from India], a full dosage but for a whole year, it costs us about 20,000Ksh (£155). So, you can't even compare" (Louise, daughter of 71-year-old PWPD)*

For most PWPD, sourcing medication from abroad was not an option and they instead had to rely on pharmacies across Kenya, navigating stock-outs and high prices.

Some PWPD who could access and afford medication reported changing the dosing frequency of their medications based on how they felt or through experience, reducing doses to limit side effects or realising they needed higher doses; others took their medication to suit routines. Several PWPD, like Martin, described resourcefully taking their medication when they needed to attend appointments or carry out certain activities. Several family members described how PWPD would sometimes not take their medication or forget. For example, Amanda said she would find half-pills around the house. Aisha, a 67-year-old PWPD's daughter, explained, *"When she feels like taking, that's when she takes"* because the medication made her feel nauseous. Other PWPD experienced unpleasant side effects, which they may not have been warned about and which made them reluctant to take medication. This was often caused by inappropriate dosing preparations and schedules which many had not altered in years. It was, however, more common for PWPD to alter their medication because they could not afford or access it, due to external forces beyond their control.

A prescription was one of the only resources PWPD were able to receive from doctors, although medication was largely unavailable and unaffordable. Consequently, some PWPD described utilising different forms of healing in addition to biomedical treatment. How participants negotiated alternative therapeutic landscapes and made use of combinations of services for the management of PD is explored in the following section.

5.2 Navigating religious and herbal healing landscapes

This section draws on my interactions with, and observations of, religious and herbal healers and participants' own experiences of interactions with these practices, which were dependent on financial and social resources and influenced by the limits of biomedicine. Participants' hope, desperation, vulnerability, religious views, beliefs about cause of disease and suggestions from kinship networks regarding 'novel' or 'alternative' therapies also apparently contributed to the use of different practices. In contrast to the inaccessibility of biomedical services, herbalists and religious healers are widely available (but not necessarily affordable) and market their services aggressively; these practices have also had a long history within the Kenyan healing landscape. Similar pluralistic health seeking behaviours have also previously been identified among people living with dementia and their caregivers in neighbouring Tanzania (Mushi *et al.*, 2014). Olsen and Sargent (2017, p. 2) in their exploration of 'African medical pluralism' suggest that people draw on a *"therapeutic continuum"* of *"diverse healing modalities in search of working therapies"*.

The section is prefaced with Louise and Matilda's account of their interactions with different treatments. Their mother, Norah, was 71-years-old and had been diagnosed with PD ten years ago after a long diagnostic journey. She had recently moved to live with her daughters in Nairobi where they explained she would receive better care.

Narrative 12: Louise, Matilda and Norah

Louise and Matilda described the high costs of the pharmaceutical treatment that Norah had been prescribed, although they supported Norah financially. Initially, Louise said they had not tried any alternative medicines for Norah, adding, *"Maybe they [healers] would just lie to us".* Matilda reminded Louise that they had seen a healer in Nairobi from whom they had bought 15,000Ksh (£115) worth of herbs. She added, *"There was a lot of hype about him on a Christian programme"*. Louise explained that Norah tried the herbs, but they tasted so horrible she could not swallow them. Louise said they had also been to see a preacher who had prayed for Norah to be healed several times during a 'crusade on healing'. Apart from this, the sisters said they went to church every Sunday to pray for Norah. Matilda discussed their faith and explained, *"A disease is just a disease, but it helps you when you have faith in God. He can heal through doctors".* Louise agreed and said, *"Disease is part of what we go through in this life, part of the journey".* Louise also clarified, *"A lot of people believe in curses; our thoughts have never been this way".*

Louise and Matilda therefore drew on a "therapeutic continuum" through sourcing medication but also attending crusades on healing and accessing an expensive herbal healer who had been marketed on television; their religious faith was very important to them. However, they also acknowledged the potential for alternative healers to *"lie"* and dismissed the idea of *"curses"*, illustrating the role of religious beliefs as well as personal experience in seeking out treatment options.

5.2.1 Religious healing

All but two PWPD included in the questionnaire survey identified with a religion (*Figure 1)*. Thirteen PWPD had used religious healing and almost all participants described how prayers, especially praying for themselves at home, were a crucial part of treatment. If PWPD could not attend religious services, a pastor, priest, sheikh, or religious friendship group would visit their home to pray for them.

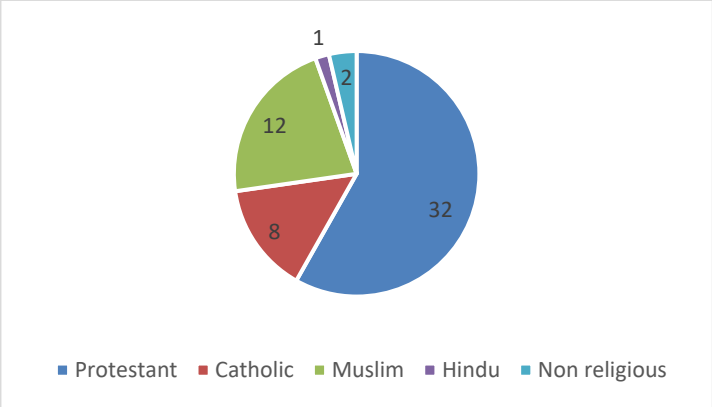


Figure 1. PWPDs' identified religions from the questionnaire survey

One of the reasons for the importance of prayers in managing PD was the belief by several participants that PWPD could have been cursed. Some believed either PWPD or someone in the family, for example, an ancestor or divorced partner, had done something wrong in the past or sinned, and PD was a curse from Satan. Yvonne described concerns about the cause of her mother's condition:

> *"Worry, uncertainty. You know, what happened, what did we do wrong? What did she do wrong...We always have that one [curses] in mind…Maybe relatives spoke because we believe in those altars of witchcraft…There's some people who can go out and curse you" (Yvonne, daughter of 77-year-old PWPD)*

In contrast, others described how someone outside the family could be responsible – as Gideon explained: *"Some say I'm bewitched, I'm cursed…Others say somebody became jealous of me, that I was rising up very fast and such. Many comments".* Consequently, if PD was a curse or given by God/Satan, prayers had the power to heal. Although drug treatment was important, prayer was equally crucial:

> *"We believe that the medicine from the doctor plus the spiritual things have to go together. Because even this medicine, God is the one who has helped the doctor to prescribe it or provide it. So, the two have to go together" (Julian, nephew of deceased PWPD)*

In Ghana, Asare and Danquah (2017) reviewed belief systems and suggest that for many people in Africa, 'wellbeing' includes spiritual involvement. For those who did not believe in curses, prayers were still an important way to make sense of suffering and gave participants hope for the future. As Constance explained, *"It is just the faith of God that has kept us surviving up to now; otherwise we could have lost hope".*

Several PWPD of Christian faith (both Protestant and Catholic) described using holy water and anointed oils in addition to prayers, while four people in my sample (all Protestant) described having attended crusades on healing or miraculous public healing services, which were held in charismatic churches. The following narrative describes a religious healing service I attended in the outskirts of Nairobi. It illustrates the popularity of these events, the promise of a "cure" or "solution" the pastor was able to provide when biomedicine could not (often attendees had brought medical diagnoses or scans) and the importance of "donations" for "healing".

> *Narrative 13: Church healing service*
>
> Amina had arranged for us to visit a healing service, a weekly event held at the church. The service started at 8am and ended at 2pm; we arrived at 11:30am. Inside the gate was a merchandise stand selling the pastor's teachings on DVD and calendars with his face on. On the outside wall of the church was a large banner with an artist's impression of the future church they hoped to build (*Image 7*). We stepped into the darkness of the church building and Amina was shocked by how many people there were. I had arrived with no expectations, but Amina thought it would be a small event with a handful of families.

The building had a low ceiling and the rows of chairs seemed endless. Floating around the aisles were ushers helping people find seats; there were thousands of people in the giant room. We could barely see the 'stage' from where we had entered at the back (*Image 8)*. Large flat-screen TVs hung from the ceiling, broadcasting what was happening on stage. The pastor began with an announcement informing the congregation that they needed to raise 6.7 million Ksh (£52,000) to pay off the loan for the land the church was built on. Attendees lined up to put their donations in the baskets on stage for (a) the pastor's TV channel, (b) funds to build the new church or (c) to pay off the current church loan. The pastor ensured only those who had paid their fee could be healed. A lady sat next to us explained that everyone in the hall wanted themselves, or someone they knew, to be healed. A section at the front was asked to line up and people were ushered on stage.

Image 7. Banner depicting an artist's impression of the future church to be built

There was no verbal exchange between the pastor and attendees, he merely touched them and said, *"get a job",* or *"you are cursed",* or *"your work has finished",* or *"you are going to be paralysed",* or *"you have demons".* The people then stood in a crowd on stage and were prayed for; several fell over. One woman had brought an X-Ray – the pastor held up the image for one second, explaining that he had already seen the disease and knew it was cancer. A pregnant woman approached the pastor with her baby scan. The pastor explained that the baby had not turned properly and prayed for her. The next person had a brain tumour. One woman explained she could not get a job, the pastor said it was because her family were tied up in spirits.

Image 8. View of one side of the inside of the church, showing a TV screen and members of the congregation on stage in the distance

> The next lady brought a young baby wrapped in blankets and said his legs were malformed. She explained that a doctor said the baby's leg required amputating. The camera focussed on the baby's swollen legs; they were turned inwards. The pastor insisted she should not amputate and pray instead. He began to rub anointed oil on the baby's leg; he sold this at his merchandise stand. A man in a wheelchair was brought on to the stage; he had a colourful scarf wrapped around his head, the dress of a particular sect of Christianity. He did not 'belong' to this church yet had come for healing. The man had been diagnosed with tuberculosis and handed the pastor an X-Ray. The pastor glanced at the image and proclaimed he did not have tuberculosis, merely mucus in the lungs. The queue of people continued.

Section 5.1.1 described how PWPD often tried out different neurologists in search of a more optimistic outlook. The church healing service seemed to provide people with an alternate, more hopeful diagnosis and solution compared with the prognosis biomedicine had given them. Several people had brought X-Rays and diagnoses to the service having sought medical care initially, demonstrating that biomedicine could still be the first port of call for many; as PWPD also suggested. The pastor also engaged with X-Rays, trying to demonstrate his "scientific" knowledge and discredit the medical doctors' diagnoses, illustrating the competitive landscape where pastors appeared to be competing with other forms of healing. However, the pastor was also giving inaccurate medical advice, which could have harmful consequences if PWPD attending these services were told to stop their biomedical treatment. The service also began with a collection of donations, indicating the importance

of money and the potentially large amounts attendees were donating, or paying, to be healed. In contrast to my experience, Louise explained that during the Christian crusades Norah visited, all attendees were prayed for at the same time.

However, several PWPD in my sample described not wanting to attend "healing services"; as Gideon explained, *"No, no, no, I can't"*:

> *"She [spouse] could bring some priest in the house, he could pray, then they go…they just pray. I couldn't go beyond there, I couldn't agree, because I knew what was affecting me. I had come to learn more about PD. So, I'd just agree so that they don't find like I'm rebellious" (Gideon, 33-year-old PWPD)*

Gideon explained that he knew he was suffering from PD, his diagnosis was correct and pharmaceutical treatment worked, and therefore knew that a healing service could not offer a solution; yet his wife believed he had been cursed. He was also concerned that he would seem *"rebellious"* for refusing a potential treatment option. Instead, for most Christian participants, prayers involved intimate events in their homes, for some this was to *"cast out demons".* For other more charismatic church groups, prayers were more eventful. Jasper described his mother's experience of prayer:

> *"There's a lot of singing and uhh, praying in tongues, umm where everybody is praying…People sort of switch to the state and everyone is in their own world" (Jasper, son of 78-year-old PWPD)*

Jasper explained that for his mother, her medicines were *"second rate"* to her faith; given the difficulties in obtaining medicines, they were often second rate. Jasper was not religious but did not dare disclose this to his mother for fear she would lose hope.

In addition to prayers, PWPD of Muslim faith described reciting Ruqyah[18], which was a way to hurt Jinn (supernatural creatures) in the body that could cause disease by 'attacking' people, as Imran, whose father had PD, explained:

> *"If you want to have Jinn, there is certain incantations you have to do…They ask you what you want and then they want something in return. What they want is your obedience, like instead of worshipping God, you worship me, do what I tell you…They*

[18] Ruqyah is a practice of treating illnesses caused by magic, the evil eye, or general physical ailments by reciting particular healing verses of the Quran.

[Jinn] can hurt someone for you…When they go into your body, then they can give you different problems" (Imran, son of 80-year-old PWPD)

Spiritual and faith healing could be used for treatment if Jinn or witchcraft were thought responsible for causing PD. Reciting Ruqyah was done in combination with drinking honey as well as consuming herbs and tree leaves that were known or mentioned in the Quran as having healing properties. However, Imran explained that his father's condition significantly worsened after using this method of healing for several weeks, and he began taking his biomedical treatment again. In contrast, Layla (79-years) described how her symptoms improved after a sheikh recited Ruqyah. Similarly, Noor (60-years) described visiting a sheikh for a week in Mombasa, adding *"After reciting (the Quran), I could stand up and go to the toilet"*. Noor believed God had given her PD, but she did not know why.

Although only one Hindu PWPD was included in this study, several participants of Hindu faith attended the support group meetings. They described attending temples and praying for themselves, as well as the importance of the powerful mantra 'Om' in prayers, chants and during meditation or yoga practice, which assisted with healing.

5.2.2 Herbal healing

Only eight PWPD in my sample used, or had tried, herbalism for the management of PD; this was usually in combination with biomedical treatment. No PWPD who attended the public neurology clinic (n=13) described accessing any form of herbalism, while those who did described it as being too expensive and potentially unaffordable for many. For example, Imran described how the *"glasses of honey"* a healer prescribed his 80-year-old father cost more than his PD drug treatment; although he added it was not very effective either. However, those who did access this type of treatment were given promises of a cure, guiding them to pay significant amounts in hope of a solution. The constrained access to, and affordability of, biomedical services and medication also appeared to be a key factor in PWPD seeking out alternative treatment.

One of the most important reasons for participants interacting with herbalists was their faith in a 'cure' outside of biomedicine. Tina, whose husband lived with PD for 16 years, described

her desperation to try *"everything"*, including herbal treatment, in hope of a miracle recovery:

> *"You know, when somebody is sick and you hear there is something which can help him recover, you listen attentively and the following morning you visit because you never know…We tried all we could to get him better" (Tina, spouse of deceased PWPD)*

Tina, like others, described seeking out treatment *"everywhere and anywhere".* While there were still treatment options, several PWPD, and their families, felt they were not allowed to give up and described their search for the "cure" they hoped existed. Usually, participants were surrounded by a vast and at times bewildering therapeutic landscape offering optimistic alternative therapies and "solutions", although often for a high cost and to no effect.

The types of herbal healing participants utilised varied. Some described using more "traditional" therapies, including herbs, leaves, roots, seeds, honey, oils, and teas. Tina described paying 100,000Ksh (£750) for a three-month supply of herbal medicine, including *"green leaves from the forest*", which were boiled and mixed with honey. She described how her husband used herbal medicine and drug treatment, which became very expensive; although the leaves gave him diarrhoea, adding more work to her caregiving role. Others described accessing more "commercialised" herbalists who incorporated the use of acupuncture, supplements, vitamins, Chinese medicines, and "modern" medical equipment into their practice. Constance's family showed me some "modern herbs" they had bought to *"stimulate the veins"*. On assessing the box, I realised it was instant coffee sachets, also illustrating the potential of unscrupulous herbalists to exploit desperate and vulnerable people. In most cases, these practices were used as adjunctive therapies to biomedicine.

I visited three different herbal clinics during fieldwork: a Chinese herbalist in Nairobi, a "commercial" herbal clinic (part of a well-known chain) in Central Kenya, and a more "traditional" independent medical herbalist in Nairobi. All three reported having seen, and cured, PD cases on a regular basis; as the Chinese herbalist described, PD was *"one of the easy ones [diseases]"* to cure. However, no PWPD in my sample described visiting a Chinese herbalist. The following narratives describe my observations of the types of "traditional" and "commercial" herbalists operating within the therapeutic landscape, which illustrate the

hope of a cure they could provide and the strategies they employed to legitimise their practices.

Narrative 14: "Commercial" herbal clinic

The clinic was set behind a metal gate in a small, dark shopping complex. In the room, there was a large glass cabinet covering one of the walls filled with various well-packaged medicines (vitamins and supplements). The 'doctor' in the clinic wore a lab coat. She explained that they used a 'Quantum Magnetic Resonance Analyser' to analyse *"every aspect"* of the body, including the brain, heart, kidney, liver, amino acid levels and so on. The analyser looked like a small computer and had a metal rod, which the person held. She explained that because the blood flowed in different directions in men and women, they had to hold the rod in different hands. Treatment would involve five supplements to detoxify the body, boost the immune system and finally, add vitamins and minerals. She said she had recently seen 20 patients with PD and had treated them all.

Narrative 15: Independent "traditional" herbal clinic

Dr Mwangi had his own website and twitter page. His office was situated in a gated compound. Dr Mwangi wore a flowery Hawaiian shirt and stood behind his medicine counter, the shelves behind him full of bottled and labelled herbs and supplements. As we entered his consultation room, he wore his white lab coat over his flowery shirt and donned a stethoscope. His office had scientific diagrams and posters on the walls depicting parts of the body. He also had an examination bed and curtain to cover it. Dr Mwangi had trained as a pharmacist, but his family were all traditional medicine practitioners. Several years ago, he said his wife became ill and he could not treat her with pharmaceutical drugs. After witnessing his grandfather treat her condition with *"concoctions"*, as he put it, he decided to retrain as a *"medical herbalist"*. However, he continued to maintain the appearance of a pharmacist. Dr Mwangi believed that PD was curable and said he used a *"holistic"* approach, adding, *"It's not like 'conventional' medicine".* He insisted that he knew all his patients well, in contrast to hospitals who *"don't have time for you".* He estimated treating someone with PD in three to four months, which would cost up to 80,000Ksh (£620). He asked if I would bring him a PD patient to cure to demonstrate his ability.

These accounts illustrate the "modern" discourses and strategies herbalists employed, for example the bogus analyser[19], bottled supplements and medical appearance, to legitimise their practices, gain clients' trust and attract customers. They appeared to be presenting

[19] The Quantum Magnetic Resonance Analyser is a fake, clinically invalidated machine that Hampshire *et al.* (2017) suggest has penetrated the herbal healing landscapes in Africa.

their practices to fit people's evolving expectations of herbalism. Marsland (2007) explored the emergence of "modern traditional" healers in Tanzania, who aimed to convince sceptical clients of their modernity in order to compete with biomedicine. Hampshire and Owusu (2013) also identified the combinations of "tradition" and "modernity" that healers in Ghana utilised to legitimise their practice within the aggressively competitive healing landscape. The herbalists also offered hope of a "cure", a crucial characteristic of their treatment, which could give people faith in a miracle recovery. However, their treatment was not cheap, and most participants described not having used herbal medicine; although they also may not have disclosed this to me. Dr Mwangi also stressed how much time he had in contrast to medical doctors; an important aspect PWPD in this study discussed.

The herbal healing landscape also appeared to be quite intimidating. Posters for herbal healers were plastered across towns and cities on utility poles, walls, bus stops and signboards (*Image 9)*. They advertised the range of problems herbalists, or "professors", could manage, including claims to help with love affairs and finding jobs as well as chronic and infectious disease treatment, and a mobile number to contact.

Image 9. Poster on utility pole advertising 'Professor's' specialist services

Although participants described actively seeking out herbalists, which was not difficult given the advertising seen in *Image 9*, some also explained how herbalists or traditional healers had followed them, approached them on the street or sought them out at home. Jacob (76-years) lived with his son, Simon, in a village in the Coast province. He described how a

"witchdoctor" approached him after hearing of his condition and invited Jacob to stay with him for one month during which time he would "cure" his condition; Jacob said he declined the offer. Eunice lived in Nairobi with her husband, Benjamin, who had been living with PD for 18 years. She described several encounters she had with herbalists trying to market their treatment in the city:

> *"Before we got even a doctor, we had so many people, herbal, herbal, herbal everywhere…to the extent that somebody will alight with him [PWPD] from the bus…He [PWPD] is a potential client…Follow him [PWPD] until he finds where he goes…then they will come to our house. When they explain that they saw him on the bus…I just turn them down. Others come and tell us we only need to stop the doctor's medicine, we start theirs…You know, they are just supplementary, it's nothing, there is no curing medicine there…and they cost a lot of money" (Eunice, spouse of 79-year-old PWPD)*

Eunice and Jacob's experiences illustrate the aggressive and competitive nature of the therapeutic marketplace where PWPD were actively targeted as potential customers. However, several participants described being dubious about herbalists' training and knowledge and the effectiveness of the treatment they 'prescribed' and were reluctant to succumb to these techniques. As Louise described in *Narrative 12*, she was concerned about them *"lying".*

Other participants explained that their families had put them under significant pressures to try ineffective alternative treatment. Eunice described how a relative had sold her husband expensive herbal medicines (£90 per month) that they saw no improvement from. Eunice decided to stop the treatment but added, *"He [relative] started talking bad about me…that I don't want my husband to get healed…maybe I want him dead".* If PWPD did not pray, see a healer, use an 'analyser', or pay for expensive herbal medicines, they felt judged by extended families and communities who may have thought they were not doing enough. Judith, a 69-year-old PWPD of Catholic faith, explained that a neighbour had advised her to see a herbalist, but Judith added, *"I say I better die clean"* and declined, suggesting that herbal medicine was 'impure' or could cause harm. Several others also described their worries about trying herbal treatment or "mixing" medication, as Jasper suggested, *"I'd be willing to try anything if there was no danger to her".*

However, it appeared that most participants associated “herbal medicine” with “traditional medicine” or *“waganga”* (“witchdoctors”). They often disregarded and labelled these practices as untrustworthy or associated with ideas of witchcraft, magic, superstitions or casting out of demons, which went against their religion (both Christianity and Islam). The daughter of Fatma, a PWPD of Muslim faith, explained, *“The ones who do juju, no, we don’t believe in that”.* Chris (51-years) was Catholic and often prayed in church; he suggested that in *“African culture”*, witchcraft and superstitions misguided people to see “*waganga”,* which he did not believe in. In Zambia, Sugishita (2009) found that “witchcraft” was seen as evil or ‘Satanism’, violating Christian values. In Ghana, Hampshire and Owusu (2013) described how Pentecostal and Charismatic churches denounced “traditional medicine”, claiming it was “antithetical” to their mission or associated with witchcraft. The authors also found that traditional practitioners often improvised their practice as a result, instead presenting themselves as “herbalists” to gain legitimacy; remarketing themselves within the therapeutic landscape to attract potential customers. This “rebranding” of “witchdoctors” as herbalists in Kenya could be why participants were reluctant to use their services and associated herbal medicine with magic, *“juju”* or demons.

Although some participants were aware that biomedicine could not stop the progression of disease, as described in Section 5.1, many other PWPD were not given an accurate prognosis about their *“disheartening”*, degenerative condition and believed that medical doctors could ‘cure’ them. Some doctors therefore presented an over simplistic picture of PD – in part to promote their own practice, but also in an attempt to maintain hope. Lewis *et al.* (2018) exploring healthcare professionals’ views of palliative care in Tanzania found that doctors did not disclose a prognosis as they believed it would lead to patients seeking out traditional and faith healers and in doing so, risking financial exploitation and deteriorating health. In addition, coupled with religious healers’ claims of the curative powers of prayer, several people in my sample described their faith in God to ‘cure’ any sickness, especially if the condition was given by God as a test of faith. As Aida (77-years) described: *“Since maybe the doctor said it is not curable, there is nothing like that in God…He can cure all”.* Furthermore, herbal healers marketed PD as *“one of the easy ones”* to cure, which could lead people to believe that biomedicine was failing to do what alternative practices could. All these factors

appeared to collude in the belief, for some, that PD was curable, or a miracle recovery was possible, even at later stages of disease.

Almost all PWPD in this study utilised the pluralistic therapeutic landscape in Kenya. It is possible that some PWPD only obtain treatment from non-biomedical sources because biomedical services are scarce, expensive and time constrained, and there is a belief that faith and prayer can heal PD. However, participants had to navigate the aggressive marketing and potentially exploitative nature of alternative healers, the limits of drug treatment and biomedicine, and their own beliefs about prayer, faith and the possibility of recovery while managing PD, an unpredictable and progressive disease with no information, educational resources and at times limited financial and social resources too.

5.3 Parkinson's disease support groups within the wider therapeutic landscape

Parkinson's support groups in Kenya played a role in filling in the gaps in information and services that the healing landscape was unable to provide. Consequently, the groups stood out because of the significant constraints of biomedical care, acting as doors to therapeutic possibilities and enabling access to services and often, medication. However, they also acted as another source of care and support for PWPD, other than the family, but also support for caregivers. In this sense, the groups acted as both sources of therapeutic support, while also enabling "sociality", providing camaraderie, a sense of belonging and emotional support to attendees – this aspect of care for PWPD is explored further in Chapter Six. This section describes how the groups were established, the benefits of support groups for PD, as I have touched on, but also the downsides, or challenges, of groups for degenerative conditions where people could see the inevitable progression of the disease.

Support groups for PD have been identified in high-income countries as a way of gaining information, providing a sense of belonging and enabling PWPD to continue interacting with people and partaking in activities, as described in Chapter Two. Rabinow (1996, p. 102) has described support groups as *"groups whose members meet to share their experiences, lobby for their disease, educate their children [and] redo their home environment"*, who should help their members *"experience, share, intervene, and 'understand' their fate".* In East Africa, the potential benefits of support groups have been documented for people living with HIV, specifically in Kenya (Gillett and Parr, 2010; Prince, 2012), Uganda (Whyte, 2014)

and Tanzania (Marsland, 2012); although groups can only benefit those who can access them. The support groups in Kenya operated outside of the state and were run on a voluntary basis by patients and caregivers. Of 55 PWPD included in the questionnaire survey, 16 had attended a PSG meeting in Nairobi, although they were recruited from the group. There was no support group anywhere else in the country at the time of the study. However, a group was started in Kisumu in July 2018 and I started a group in Mombasa in October 2018.

I begin this section with excerpts of fieldnotes taken during meetings I attended in Nairobi and Mombasa once the group was established. They demonstrate the range of activities that took place during monthly meetings and the kind of information and experiences shared.

Narrative 16: Excerpts from support group meetings

10th May 2018, Nairobi

One of the group members spoke of feeling alone today. Amina, a committee member, explained that one of the purposes of the group was to make sure that people were not alone. She also stressed how important exercise was for PWPD and provided some alternatives to dumbbells such as bottles of water. She then had everyone in the room hold their arms above them and 'call the rain' for a minute or so. Everyone began to laugh as it became more tiresome.

9th August 2018, Nairobi

Today the group had a visiting masseuse to teach massage techniques. She started with the head and neck, and moved to the arms, abdomen and then legs. A lady asked about why people shuffled and froze sometimes. Someone suggested using cues to help encourage movement to restart walking after freezing. The masseuse recommended marching to help with shuffling, lifting the legs up instead of getting into *"comfort zone shuffling"*. A pharmacist noted the stigma around people using a walking stick, but added, *"Who cares, dance like nobody is around".*

11th October 2018, Nairobi

Today was an art therapy session run by one of the group's family members. She spoke about dealing with depression, anxiety and aggression through art. She encouraged everyone to paint no matter how good or bad they thought they were. The pieces of paper were taped onto the small desks attached to the school chairs, so they did not slide off. People seemed unsure at first but grew in confidence. At the end of the session, PWPD were proud of what they had produced and seemed happy with their work; several members asked to take their artwork home. The pieces of art

were photographed and made into postcards to sell and raise money for the group *(Image 10)*.

Image 10. Example of the artwork produced by PWPD made into postcards

8th November 2018, Nairobi

The meeting today was a dance therapy session led by a dance group. The dancers played some local Kenyan music and led members through a seated dance routine first. They then asked everyone to stand, if they could, and partner up. I danced with Nzambi who was sat next to me. We held hands and danced on the spot, stepping side to side. He was a good dancer and in time to the music. After a few minutes I could feel he was getting tired, he was putting more and more weight on me until I felt as though I was holding him up. He sat down to rest. Other group members were laughing as they danced; they seemed to be having fun.

10th November 2018, Mombasa

We discussed what issues the members wanted to cover in future meetings. This included sessions on dosing, medication, how to prevent falls, the cause of PD (a popular topic) and how to manage comorbidities among others.

There was a discussion about urination problems. Somebody suggested using a catheter. Others asked about how to prevent progression. Suggestions included medicine, exercises, and diet. Someone mentioned how stubborn their spouse was becoming; others concurred. The son of one PWPD suggested that families should try to be more understanding as PWPD had experienced a huge change from their former selves and lost their independence. He suggested being there for them as much as possible.

While tea and sandwiches were handed out, attendees were engrossed in deep conversation with other members. Several stayed on long after the meeting had ended, just chatting.

13th December 2018, Nairobi

There was an occupational therapist at the meeting today, the relative of one PWPD. He gave tips about how to eat and avoid choking, including sipping from a full cup, or holding the Adam's apple when swallowing. One PWPD explained that he had begun to struggle eating *ugali* (polenta) with his right hand; someone suggested practicing eating with his left hand; the PWPD did not look happy about this[20]. After the meeting, attendees spent time with the therapist asking questions.

9th May 2019, Nairobi

We held a minute's silence today for the four members of the group who had died recently. The family of one PWPD had donated their medication and a walker to the group.

One of the pharmacists in the group carried out a mini 'study'. He asked the nine PWPD at the meeting if they experienced tremor, seven said they did. He then asked who had tremors in their dominant hand, four did; he joked that we could publish these results.

The excerpts illustrate the types of support participants received during meetings and the friendships they formed. Attendees could relate to each other and share experiences, although the idea of sharing was not for everyone. PWPD were given exercises and massage techniques to take home and given advice about their symptoms; something they did not receive from neurologists. Art and dance therapy sessions provided PWPD with a way to take part in activities, while visiting professionals provided practical advice to take home. However, PWPD were unable to access these services further because they were too expensive or unavailable.

5.3.1 Setting up groups

A group of people who had been directly affected by PD formed the first PSG in Nairobi in 2012. These individuals had experienced the lack of information available in Kenya. The group began meeting in the home of one PWPD whose spouse, Anya, felt that families should share their knowledge and experiences. She described wanting to help others and improve the awareness of PD. Anya's husband attended a private neurology clinic. They

[20] Ugali is part of the staple diet among Kenyans, and many Africans, and is eaten with the hands; specifically, the right hand. The left hand is used to wipe after going to the toilet and so, asking people to use the left hand to eat was seen as dirty. As van der Geest (2002b, p238) identified in Ghana as well, *"it is the left hand which does the dirty work".*

were of a high socioeconomic status and could host the group at their home initially. At a similar time, the daughter of one PWPD in Nairobi felt that she needed to do something about the lack of PD awareness and information availability and registered a non-governmental organisation (NGO). The organisation worked closely with the Nairobi group and other individuals, growing slowly through advertisements in newspapers and through the NGO's website and Facebook page, which is how many of the members found the group; although, excluding those without internet access. However, several neurologists I spoke with in Nairobi had no knowledge of the group's existence, as Dr A explained, "*How comes they are there, and we don't know about them?".* This suggests that awareness about the group was still very limited and they were not reaching a large proportion of PWPD accessing neurology services.

Through attending meetings in Nairobi and conversations with PWPD who did not know about the support group, it became clear that many participants wanted to gain more knowledge and meet others with the condition. One of the founders of the Nairobi group, William, had moved to Kisumu and begun meetings there. At a similar time, through my awareness of the value of support groups and the absence of one in Mombasa, I began holding meetings at a private neurology clinic with the help of the staff; the group was open to all PWPD, even those who were not clinic patients. Participants who attended the group described how much they learnt from meetings, how good it felt to meet others with the condition, while family members described how beneficial it was to share their experiences with other caregivers and learn from each other. However, there were also PWPD who did not want to attend meetings, for whom the groups threatened their sense of self and possibilities of hope for the future.

5.3.2 Positives of groups

One important aspect of the groups was the information members gained from attending meetings. The Nairobi group had established a committee made up of the family members of PWPD, who were all of a higher socioeconomic status. The committee organised meetings and often invited family members or friends (some of whom were healthcare professionals) to run sessions on a voluntary basis; the groups did not have funding. These included physiotherapists, speech and language therapists, occupational therapists, dieticians, yoga

instructors, masseuses and pharmacists. On rare occasions, a private neurologist attended by invitation (on a voluntary basis). Those who attended provided members with advice and exercises to manage their condition at home; crucially, this advice was free. In this way, the group took on certain roles the state was unable to provide, or people could not access. However, PWPD would unlikely be able to access these services again as they were expensive and scarce. Robert (62-years) was well represented by family members at meetings and described the benefits he received from attending group meetings:

> *"I find it useful information…Especially learning from other people's experience…but it also helped me see what possible stages, uhh, I might go through…If you stay isolated, you would think that your diet now, for example, will not affect you and you'll find out rather late in the day" (Robert, 62-year-old PWPD)*

Other attendees also described enjoying the educational aspect of meetings. Robert also described wanting to see how his condition might progress, unlike several other PWPD. As well as visits from allied health professionals, the group provided people with leaflets imported from PD foundations in high-income countries as well as advice on specialists and further resources – in this way, the groups provided access to information often not provided by neurologists. However, this information was often not tailored to the Kenyan context.

Crucially, the groups enabled members to share advice through their own experiences of living with and caring for someone with PD and tips for negotiating the Kenyan health landscape. Furthermore, through WhatsApp groups for each PSG, PWPD, family members and allied healthcare professionals shared ideas, experiences and posted news articles relating to PD in-between meetings, which ensured that the groups were always connected. For example, the Nairobi PSG WhatsApp group had 100 members. For older PWPD who did not have WhatsApp, younger siblings or offspring took part in these group conversations. However, several older and less well-off participants did not have smartphones and were unable to participate in these conversations.

The groups also acted as an important source of care and social support for attendees; one of the most important aspects for participants was the social relations they formed. PWPD

also described seeing that they were not alone. Christine was still employed part-time and travelled 150km (300km round trip) to attend meetings:

> *"It's very supportive. At least you get encouraged, you see you're not the only person with it…You see it's not only me, other people are having it, and if other people are having it, why not me?…If they can survive for so many years, I can also survive for so many years" (Christine, 55-year-old PWPD)*

Christine travelled almost three hours to attend meetings if she could afford to and felt able enough, because she thought it was important. Gideon, also a young onset PWPD, described how important the group was to him and the benefits of attending meetings:

> *"I started looking all over the internet, but I had not found a single Kenyan until I came to the support group…I said 'If there are some people in the same condition and they meet at a certain point in the month, I think I better join them'…I'd rather it was twice a month…I miss those talks, I miss those people, I miss seeing a person who is walking like me…when I am there, I feel at home" (Gideon, 33-year-old PWPD)*

Gideon described feeling at home among other PWPD who did not judge him. Several participants explained feeling that they belonged in the group, where people understood the frustrations, related to PD, they were facing. As Danny explained, it was a *"safe space".* Some informal family caregivers reported that they also benefitted from the groups by continuing to talk to other family members outside of the group setting.

Some participants described the group as a way to come to terms with having PD, where seeing similar symptoms in others confirmed the existence of the condition and their own diagnosis. Amanda described how her mother, Mildred, was unsure about her diagnosis and did not want to attend the meetings in Nairobi initially:

> *"I went and I was just like, 'Well, mum doesn't accept it'. And then she [PWPD] came and the Parkinson's meeting was so nice, because everyone was sort of kind and I could see my mum really did have Parkinson's because you can see it in other people…That was the beginning of feeling less alone with Parkinson's stuff" (Amanda, daughter of 66-year-old PWPD)*

Amanda suggested that the meetings enabled Mildred to accept that she did have PD and provided them both with emotional support. For other participants, it was seeing other PWPD worse off than themselves which spurred them on to attend meetings. Danny's

father, who was diagnosed with PD 18 years ago, initially did not want to attend the meetings but eventually agreed to go. Danny described his father's reaction to the group:

> *"After he [PWPD] had gone for a few of those meetings, he was like, 'Wow, there's actually people worse off than me'…Seeing that made him feel like 'I'm not actually as badly off as I thought I was" (Danny, son of 83-year-old PWPD)*

Danny's father was encouraged by seeing people in a worse state than himself, although a few years on and his condition had significantly progressed; he was now unable to attend meetings.

Finally, PWPD at the Nairobi and Mombasa groups were provided with 'PD alert cards' from an international charity. The cards could be kept in purses, wallets or pockets and read *"I have Parkinson's"*; although, they were all in English (*Image 11*)[21]. These cards had several functions. Firstly, PWPD described how the cards gave them a form of identity, a way to provide people with a legitimate item branded with 'Parkinson's', giving PD a legitimate disease status. Secondly, PWPD used them to educate others about PD if they commented on their appearance. Thirdly, the cards enabled them to inform doctors or emergency services about their condition.

The PD alert cards further demonstrated the importance of labelling, awareness, and legitimacy. Gideon explained that he wore his 'alert card' on a lanyard around his neck where it was clearly visible. He added that it was particularly useful on public transport and people often enquired about it; Gideon had fallen out of a bus and had been declared 'drunk' before he had acquired the card. Several PWPD who were still employed had used the card at their place of work.

[21] Parkinson's UK approved these donations. The alert cards are available to order for free on the Parkinson's UK website and I organised their transport to Kenya.

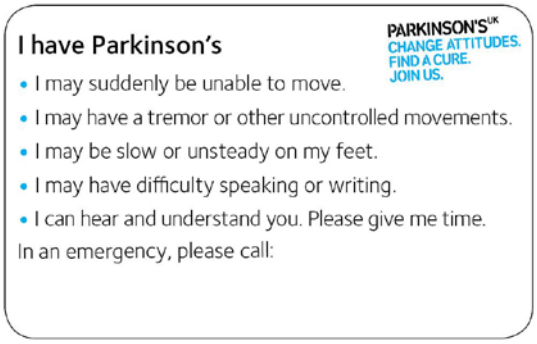


Image 11. One side of the PD alert card provided to PWPD in Kenya

5.3.3 Downsides of groups

Despite the potential positives of the groups for PWPD and family members, they also had several downsides. Most importantly, they were only accessible to those who knew about them, yet their reach was very limited, particularly for people with fewer resources, without the family support to attend meetings, or those who did not live in the city (and even then, neurologists were not aware of them). For example, Christine lived in Central province and despite enjoying the group, described how more recently she could not afford the bus fare or to miss work. The cost of travelling to meetings deterred many from attending, particularly if PWPD could not use public transport; Gideon also described his struggle affording the bus fare.

During the time of the study, most participants who attended the PSG had found it via the internet, which not everyone could do, and were generally of a higher socioeconomic status. As Esther suggested, the groups were not *"representing Kenya".* However, I was able to direct PWPD who attended the government neurology clinic to the group who would otherwise not have known about it. These PWPD and their family members described how useful the meetings were and, over time, outnumbered the previously existing members. This created an interesting group dynamic as attendees had very different social, educational, and financial backgrounds and often, different challenges, creating tensions in what they wanted to get out of meetings. For example, several struggled accessing basic levodopa while others wanted to learn about diet and what expensive foods they could buy. However, as Nzambi described in the opening narrative of this chapter, he enjoyed the dance session and making friends. Several PWPD from the public clinic also did not speak English, yet the groups were largely conducted in English which required translating.

Furthermore, attendees were often told *how* to manage their conditions, but the lack of available, and affordable, services meant that many were unable to access these, particularly those with fewer resources.

Although the groups allowed several PWPD to accept their condition and some were encouraged by meetings, others who described being in denial about their diagnosis indicated they were reluctant to attend meetings *because* it affirmed that they were ill. Stephanie was diagnosed ten years ago, although her condition had not progressed quickly. Her response regarding the support group was, *"No way would I do that"* and added she would rather pretend she did not have PD and carry on with her life – she did not want to know more about what might happen to her and so, the group was not desirable.

Other PWPD also described how attending meetings was disheartening as they would see the progression of those at more advanced stages, which gave an indication of what was to come. They described being concerned about hearing of the *"horrendous"* symptoms they might experience in the future. Several PWPD were wheelchair bound, could not talk, or had severe incontinence which some suggested was upsetting to see. Sarah described how her mother had stopped attending meetings because seeing the progression *"freaked her out".* Esther's mother, Leah, had lived with PD for nine years. Esther explained how she was worried about asking questions in the group about advanced PD that might scare or upset others, limiting the ability of the group to help the caregivers of members at more advanced stages.

Some PWPD described being put off attending meetings because they would see PWPD less disabled than themselves. Gloria described how she became jealous of PWPD at a dance therapy session the group held:

> *"This is when I get mad, I say 'Now, why me the whole body'…We were sitting down seeing people dancing nicely and I said, 'Why couldn't I also have…PD of one leg, instead of both of them'" (Gloria, 76-year-old PWPD)*

Gloria described being *"mad"* that her PD was *"worse"* than others – Gloria had tremors in all her limbs, she used a walker and had dyskinesia which meant she could not dance as she used to and so, she stopped going. These frustrations have been described by Stanley-Hermanns and Engebretson (2010) in the USA, where PWPD compared themselves to their

past ‘self’. This was also a downfall of group meetings where PWPD had to carry out activities they could no longer do. In addition, several attendees described wanting to learn; in this way, meetings with a focus on ‘activities’ such as painting or yoga were not as beneficial for some and may have deterred them, and more so caregivers, from attending. Several family members of advanced PWPD also described being disheartened by seeing others who could still walk. For example, Danny explained that his mother did not attend the meetings because seeing where her husband was headed was *“depressing”,* but she also did not want to be reminded of what he used to be like. These examples indicate how identifying around a disease is complex, particularly so for progressive conditions.

Despite these limitations, the PSG provided people with access to knowledge, camaraderie and specialist information that was otherwise unavailable, inaccessible, or unaffordable through government and private facilities. Crucially, they also acted as an extended form of kinship support for PWPD and those doing care work.

5.4 Discussion

“Constrained agency” and “improvisation”

The first of three themes this chapter raises is issues about the “constrained agency” (Farmer, 2001) of doctors in their practice and of PWPD who navigated the insecure and complex biomedical healing landscapes. Participants with hugely different resources struggled with the constraints of service availability, medication affordability and limited disease information, which resulted in both PWPD and neurologists having to make use of what was available to them rather than doing what was optimal. This has been referred to as “improvising” medicine by Livingston (2012) in Botswana, Wendland (2010) in Malawi and Rieder (2017) in Ethiopia on the part of doctors and by Whyte (2014) in Uganda with regards to patients’ “improvisation” of care. Mulemi (2017) referring to cancer in Nairobi suggests that actors engage in “therapeutic improvisations” to draw on available resources and knowledge to manage disease, although among participants in Kenya, the ability to improvise was constrained.

This chapter illustrated the limits of biomedicine in a lower-middle-income country like Kenya. Neurologists appeared to be ‘making do’, negotiating PWPDs’ limited resources and

undertaking an improvised form of care guided by structural constraints yet far from the *"best practice"* they described having learnt in their neurology training. However, they suggested that the training they had all received abroad did not detract from their practice but enhanced it. Improvisation takes on varying forms in different contexts to fill gaps in medicine and treatment. In Malawi, Wendland (2010, p.124) described how *"wards and clinics were spaces of bottomless need"* resulting in "compromised ideals" and "resourcing" faced by doctors through medical school, who had to cope creatively through adopting a *"transnational medicine"* (Wendland, 2010, p. 4). In Botswana, Livingston (2012) also describes the highly contextualised biomedicine undertaken within an under-funded, under-resourced cancer ward where "improvisation" and "innovation" were defining features of care. Public clinic neurologists in Kenya described putting patients *"through the process"* and providing a prescription as the key goal of clinic, a necessary "improvisation" in order to provide some form of care. In Kenya, Prince (2016, p. 454) described how doctors in a public paediatric oncology ward *"did what was expected of them";* they ordered tests, made diagnoses and prescribed medicines – similar to the situation at the public neurology clinic.

However, neurologists' ability to "improvise" was extremely limited, mainly in the public clinic, because of significant structural constraints, particularly regarding the availability of symptomatic therapy, which resulted in inadequate care. In rural Ethiopia, Rieder (2017) also described a situation where structural constraints outweighed physicians' abilities to improvise practice. Similarly, Muyinda and Mugisha (2015, p. 317) in northern Uganda refer to support and healthcare as *"more like a lottery than a systematic investigation of available choices".* There could also be an aspect of "learned helplessness" involved, where constant constraints in neurologists' practice resulted in the "making do" observed and described, and a reluctance to advocate change. Neurologists' were also limited in their ability to advocate for their patients, largely because of time constraints, but also because they were 'general neurologists', not specialised in movement disorders or PD – they could not advocate for every condition they came across. Again, neurologists were limited in their ability to improvise, advocate and innovate change.

PWPD and their families also undertook a form of "improvisation", using the resources available to them to negotiate biomedical services, similar to what Whyte (2014) has described in Uganda among HIV/AIDS patients. PWPD with more social and financial

resources (including pensions and insurance schemes) appeared to be less susceptible to constraints and better positioned to make choices about their care and optimise treatment; although options were limited for all. Mol (2008) argues that good care does not only result from individual decisions, care is something that develops through collectives – the supportive role of the family was crucial for the management of PD, particularly when health services were so scarce. Whyte (2014) has identified similar findings from Uganda among people living with HIV.

Farmer *et al.* (2006, p. 1686) describe "structural violence" as *"arrangements"* which are *"embedded in the political and economic organisation of our social world"* that constrain individual agency. Although structural violence and inequalities are relevant when thinking about PD in Kenya, poverty and social inequalities did not influence who did or did not get the disease, which is where PD differs from the infectious diseases Farmer (2004) and Parker (2002) refer to, and indeed, other non-communicable diseases. However, where structural violence becomes more visible is in the access to biomedical services and treatment that PWPD required. PWPDs' *"poor compliance"* was usually not deliberate; in reality, they experienced a "constrained agency" where maintaining dosing schedules was not possible. They therefore described "improvising" their treatment based on what was available or accessible, rather than what achieved the most desired health outcome. As Farmer (2001) argues, patient agency, guided by a biomedical focus on individual patients, can be exaggerated in low-resource settings. He instead suggests that 'treatment failure' is beyond patients' control and instead results from structural, environmental and operational factors. The poor availability of basic medication in Kenya, regular drug shortages, unaffordable private services and overwhelmed public clinics (aspects out of people's control) meant several PWPD were forced to stop taking any medication, instead trading off their health for their and their family's livelihood, or if the connections that initially gained them access to medicines were lost.

In contrast to the forced "improvisation" undertaken by many PWPD, some also described changing their dosing schedules to optimise treatment based on how they felt. Mol (2009) refers to this as "tinkering" among diabetes patients in the Netherlands in order to optimise dosing. However, she refers to patients in high-income countries who had effective options, something most PWPD in Kenya did not have. Guell (2009, p. 159) used the concept of "bio-

tactics" among Turkish migrants living with diabetes in Berlin to understand how people *"manoeuvred health advice"*, *"resourcefully adapting clinical frameworks to their individual and communal life circumstances on their own terms".* PWPD in this study in Kenya generally had little or no health advice to manoeuvre, while any adaptations were usually not done on their own terms or to achieve a desired outcome. Although "tinkering" and "bio-tactics" are useful concepts and capture some of what was occurring among participants, both assume a greater level of agency when in fact where resources were so limited and uncertainty so high, managing extreme constraint was negotiated each day; worrying about the future was not possible when expensive drugs often disappeared from pharmacies. Rieder (2017) echoes this view in the context of Ethiopia where she suggests "tinkering" is limited by the degree of structural constraints.

High levels of poverty, limited understanding of disease and the unaffordability and poor accessibility of treatment and services resulted in the constrained ability of participants (doctors, patients and family members) to manage PD effectively. Structural constraints made it difficult for participants to enact much degree of agency over their lives and treatment, which partly contributed to "medical pluralism" where several PWPD engaged with alternative therapeutic landscapes.

Medical pluralism

This chapter illustrated how PWPD drew upon a "therapeutic continuum" which changed over time and space and was highly dependent on social and financial resources and as Schoepf (2017) suggests, encouraged by the precarious health services and education available to the majority of African populations. Some PWPD were also exploited whilst trying to navigate the nexus of healing systems in Kenya; the therapeutic marketplace was complex, aggressive and at times took advantage of people's desperation and lack of knowledge. "Medical pluralism" can be used to describe the employment of multiple healing landscapes to address symptoms and has been widely demonstrated across SSA, as discussed in Chapter Two; Kleinman (2017) describes medical pluralism as the "reality" of African healthcare. Janzen (1978) described, with reference to Democratic Republic of the Congo (previously Zaire), how people in Africa living in poverty engaged in a "quest for therapy" including a range of therapeutic options.

The limited access to public health facilities and heavy reliance on the private healthcare system in Kenya resulted in PWPD's health being primarily determined by their financial capital but also their social capital and connections. The quality of connections and kinship networks among PWPD resulted in disparities and inequalities in care. Participants who could described *"shopping around"* for neurologists and interacting with alternative healing landscapes; Parkin (1995) describes this as "latticed" interactions. Mulemi (2017), describing the experience of cancer patients in Kenya, suggests that patients engaged in "therapeutic eclecticism" in order to meet their therapeutic needs and practiced "healer shopping"; as was experienced among PWPD. Manglos and Trinitapoli (2011, p. 120), referring to HIV/AIDS in Malawi, suggest that a complex interplay of different therapeutic landscapes results from *"individual experiences, social interactions, structural constraints and cultural flows"*. It appeared that for some participants, while there were still (seemingly endless) treatment possibilities and hope in a 'solution', they could not give up. However, herbal and religious healing practices were unaffordable for many; Schoepf (2017) suggests that healer therapies have increased in price, although adds that they often offer delayed payment schemes, something biomedicine does not. Having said that, alternative healing landscapes were not an option for many PWPD who instead relied on biomedical treatment and prayers.

Herbal and religious healers could offer PWPD hope of a "cure", something biomedicine could not, which participants suggested was important; hope, coupled with faith, ensured participants did not *"give up",* but also meant some PWPD were not allowed to settle for one treatment, resulting in substantial treatment costs. However, herbal and religious healers also appeared to be employing various strategies to seem more "modern", while participants suggested "witchdoctors" could be marketing themselves as "herbalists" to gain legitimacy. These actors appeared to be "improvising" their practices to keep up with and compete with medical advances and patient expectations. Studies in Tanzania by Marsland (2007) and McMillen (2004) have also described how traditional herbal healers have adapted and improvised their practices to appeal to wider audiences, challenging the boundaries of "modernity" and "tradition". Hampshire *et al.* (2017) discuss the use of 'analysers' among other "signals" used by healers in Ghana which they argue are used "strategically" to convince people of their trustworthiness and legitimacy.

Several participants also experienced healers' aggressive advertising and marketing techniques used to try to win over patients, while taking advantage of their hope and limited disease knowledge, illustrating the vastly overwhelmed healing marketplace. James *et al.* (2018) conducted a systematic review on the use of healing practices in SSA and identified aggressive advertising as a driving force for people interacting with alternative therapeutic landscapes. Adegoju (2008) discussed the "persuasive" and "propaganda" techniques used by herbal practitioners in Uganda who also challenged the value of "Western" medicine to attract patients; similar to what I observed by the pastor in Nairobi. Healers also seemed to be exploiting people and profiting from their suffering. Moshabela *et al.* (2017) explored medical pluralism among people living with HIV in Eastern and Southern Africa and identified the exploitation by opportunistic healers for financial gain. In Kenya, Kigen *et al.* (2013) suggest that the use of traditional medicine will rise as biomedicine continues to face barriers to successful treatment; although, they add that many healers are "frauds" who con desperate patients. Several participants in Kenya acknowledged the potential for healers to *"lie"* or not be *"trained"* and consequently, many did not use their services or succumb to their marketing. However, medical pluralism, particularly the use of prayers and biomedicine, and at times herbal medicine, was common among PWPD in my sample.

"Biosociality" and "anti-biosociality"

The final theme emerging from this chapter is the role support groups played in filling the gaps in information, care and support within the Kenyan healing landscape. Parkinson's support groups stood out significantly because of the extensive limits of the wider therapeutic landscape and the otherwise scarce practical information and social support. However, some PWPD had less positive experiences.

Support groups enabled attendees to share knowledge, learn, carry out group activities and exercises. However, one of the most important aspects of the groups was the social networks attendees developed and the sociality formed around PD. Rabinow (1996) described the socialities and identities that could form around biological conditions as "biosociality". The groups, combined with WhatsApp discussions, offered a way to emphasise the "social" aspect of "biosociality". Marsland (2012) in Tanzania argues that a more nuanced thinking of "(bio)sociality" is required where "sociality" is taken as seriously

as “bio”, especially in the absence of ‘high-tech’ technologies around which Rabinow’s concept was first developed.

Literature around biosociality has been largely positive whereby people can form kinship and a new identity around their diagnosis, although in West Africa, Nguyen *et al.* (2010) have suggested that self-help groups for HIV can monopolise resources and contribute to exclusion of those not in the group. In western Kenya, Prince (2012) described how people learnt to live positively with HIV through attending support groups, forming identity around their diagnosis, while also striving to normalise the disease in society. However, literature on the experience of PD support groups in SSA is lacking. In Ethiopia, Walga (2019) recruited caregivers of PWPD through a patient support group but did not discuss the experience of the group. The benefits of PSGs in Kenya were largely similar to those Prince describes, although the two conditions are very different; PD is progressive and associated with ageing. Prince also described the visibility of HIV support groups to organisations and potential funders, which was not the case for PD. There was minimal politicisation and bureaucracy surrounding the PSGs and, in this regard, “biosociality” was restricted to the group itself and members’ social networks.

Several PWPD who attended the groups in Kenya reported undertaking what Festinger (1954) has proposed as a “social comparison” of others. These comparisons had both positive effects on self-esteem and well-being but also negative and disheartening effects. Participants in Kenya described “downward comparisons” with people who fared worse than they did and reported feeling more optimistic because they were doing better than others were. “Upward comparisons” with those who were doing ‘better’ seemed to encourage some PWPD to be more optimistic about their lives and try to improve their condition through exercise or diet. However, for some, “downward comparisons” highlighted the daunting possibility of progression where PWPD could see where they were heading. Similarly, others described how “upward comparisons” left PWPD feeling disheartened because others were better off than they were, which deterred them from returning to meetings.

These negative experiences illustrate a form of what might be called *“anti-biosociality”* where participants actively chose not to identify through their illness and were deterred from attending meetings or forming sociality around their diagnosis through a comparison

with others; although for some, it was merely the idea of sharing experiences within a group setting that did not appeal to them. The progressive nature of PD partly explained why some were reluctant to attend meetings. Several attendees were in the early stages of disease and experienced few complications while low doses of symptomatic treatment worked. However, progression was very evident in the physical manifestations of the disease. A handful of PWPD attending the group meetings were wheelchair bound, unable to move their limbs or speak and this glimpse into the future seemed to be worrying for some. Although attendees shared the same biological diagnosis, the severity of disease varied hugely and, in this respect, PD differs from other non-degenerative chronic diseases for which support groups exist. Literature on the negative effects of support groups in Africa is lacking. However, Williamson *et al.* (2008) observed similar findings regarding upward and downward comparisons among caregivers of PWPD in England which were used as coping strategies. Solimeo (2009) also observed similar comparisons in her ethnography among PWPD attending support groups in the USA. In Australia, Hudson *et al.* (2006) found that although several PWPD and caregivers found support groups beneficial, others reported how unbearable it was to see PWPD at advanced disease stages, while discussing the experience of symptoms was deemed depressing.

PWPD and their families also described learning at every meeting, although many recommendations came from countries with advanced healthcare systems and may have limited use in Kenya when diagnosis is so delayed and access to drugs so limited. Knowing how to live well with PD and learning what *should* be done was more difficult in practice when family budgets were constrained, particular foods were expensive and therapists largely inaccessible or unaffordable. Meetings that involved exercises and activities also appeared to be distressing for some, just as Gloria experienced. “Biosociality” in resource-constrained contexts could have limitations where often people cannot do anything to stop the disease, particularly if it is degenerative and symptomatic therapy is inaccessible.

Finally, for many participants, attending the support group and seeing others with PD enabled a legitimacy that was not possible at the individual level; seeing PD in others confirmed PWPDs’ own diagnosis. Not knowing what a disease should look like meant that attending meetings was a way to legitimise illness, which in this context was another level to the “biosociality” achieved through the groups. Marsland (2012) described similar findings in

Tanzania among people living with HIV where recognising one's symptoms in others reinforced "biosociality". Furthermore, the distribution of 'PD alert cards' demonstrated the importance of labels, which enabled a way to externalise the legitimacy a label conferred to others outside of PWPDs' family and the support groups, including co-workers and passers-by.

In the context of Kenya where formal social support is lacking and information largely inaccessible, PSGs become important components within the therapeutic landscape, providing people with information, support and sociality, although this was only for a limited number of people. Chapter Seven shows how "biosociality" and a sense of community prevailed even after death where support group members were remembered and the relatives of deceased PWPD still played active roles in group meetings.

5.5 Chapter summary

PWPD experienced numerous challenges with the accessibility and affordability of biomedical services (both private and public) and medication, as well as the potentially exploitative nature of healers throughout their journeys. Financial and social resources became defining features of almost all PWPDs' journeys through the vast and bewildering therapeutic landscape. This chapter described the role of PD support groups as sources of information, acting as doors to the (limited) therapeutic possibilities described in Section 5.1. However, the groups also enabled sociality, playing an important role for some families as sources of 'care'. The section on support groups begins to explore the levels of support available for PWPD in Kenya and experiences of *being cared for*; the following chapter (Chapter Six) describes the experience of *caring for* someone with PD.

Chapter 6. Living with Parkinson's disease

Chapter overview

This chapter seeks to explore how PD is lived and negotiated within the home and community and the social relations and resources required to manage the condition. I look at the impact PD has on people's lives as symptoms progress, how this affects "personhood" (Degnen, 2018) and how PWPD learn to live with their condition and negotiate the stigma resulting from symptoms. I explore informal family caregivers' experiences of caring for someone with PD and the emotional, physical, and financial toll of doing care work, and finally, how concepts and beliefs around gender, generation and social change in Kenya influence PWPDs' resources for care, examining ideas around "reciprocity" (van der Geest, 2002a).

The chapter is prefaced with the accounts of Robert and Martin; PWPD with very different resources and support networks. Robert, aged 61, had been living with PD for ten years. Robert had never married, did not have children, and lived with an employed caregiver, although his seven siblings played a key and active role in his disease management. Robert also received a private pension after working in the formal sector. Martin, aged 65, was diagnosed with PD three years ago. Martin had been abandoned by his family because of his condition. He lived alone in a slum, was not engaged in paid work, and had no savings or pension from his work as an informal 'hawker'. Martin did not have any support from his wider family and largely relied on donations from 'well-wishers'.

Narrative 17: Robert

Robert was a teacher and he and his family had been well educated. Robert lived in the outskirts of Nairobi and would regularly stay with his siblings when attending clinics and appointments. Before moving to his current home, Robert said he spent time moving between their homes, adding, *"While I was with them…they got involved [in care]".* Robert had a stooped posture and struggled to walk without a walker. He had retired a few years ago but kept busy at home and had several hobbies. Although at one support group meetings, he told the group about how he missed playing sports and being active.

Robert said his family had always been close and he had many friends. He added that his siblings were supportive when he was diagnosed: *"I got some quite good support*

from them. They must have been…broken hearted, yah. Because I had never been admitted to a hospital". Robert's sister had come across the PD support group during her online research and Robert always had good representation at meetings: *"There have been few support group meetings that I haven't had me present or a family member".* I had also not attended a meeting where he did not have at least one family member present.

Robert explained that his siblings had begun to help run the group and supported other PWPD as well. At one meeting I attended, a member commented that Robert looked well, Robert joked: *"My siblings give me no breathing space".* At another meeting, Robert attended with eight of his family members who took part in the activities. Robert's father had also attended one session. Robert explained that he enjoyed the meetings because of the information he gained as well as listening to others' experiences, adding that there was no point in reinventing the wheel when it came to managing PD. He suggested that for him, the group meetings were more about learning than social support as he had his large family. Although, Robert did nonetheless mention that he felt like his social life had shrunk, despite his robust family network.

Narrative 18: Martin

Martin had attended the public neurology clinic since 2015, although he did not know he had PD. Martin shuffled when he walked, dragging his ill-fit tattered shoes. He wore a woolly hat and an old, discoloured blazer, which was missing the lapel and collar on one half. Martin was 65-years-old but looked much older and his hair was going grey. He said he had lived in Kibera most of his adult life and used to be a 'hawker' in the slum. He did not speak very good English. Martin explained that he had a sofa and radio where he lived but no electricity, running water or sanitation.

Martin lived alone in Kibera slum after his wife left him because of "*conflict*". His two young children went with their mother. Martin said he could not cope with his work because of his symptoms and had no income. He had a nephew who he sometimes visited and friends who brought him food or gave him a few hundred shillings (few pounds); he depended on well-wishers for food, bus fares and medicines. He also said his relatives had distanced themselves from him; they were not willing to be close to, or associate with, him because of his condition. He thought his family did not want to know what was wrong with him. Martin said he had chosen not to be bitter that his family had abandoned him and added that being sick was not his will.

These narratives highlight the extremes of family support and the effects of socioeconomic status, education and material resources in care for PWPD.

6.1 Experience of living with Parkinson's disease

6.1.1 Experience of symptoms: "It's a disease which destroys"

This section describes PWPDs' experiences of symptoms that progressed over the years, often resulting in loneliness, isolation and reduced independence. Both motor and non-motor symptoms affected PWPDs' abilities to carry out daily tasks of living or partake in social occasions. However, PWPD reported that it was usually non-motor symptoms that affected them the most in daily life and had a significant impact on who they were before the disease; although they often did not know these were caused by PD.

Findings from the non-motor symptoms questionnaire are shown in *Table 10*. The questionnaire allowed for further exploration of PWPDs' experiences of symptoms during informal interviews – the impact of symptoms on PWPD and caregivers' quality of life has been reported globally (Barone *et al.*, 2017). The most common non-motor symptoms experienced in this study were "a sense of urgency to pass urine", and "getting up regularly at night to pass urine" with 39 PWPD (out of 52) experiencing these (75%). The least reported non-motor symptom was "bowel incontinence" experienced by six PWPD (11.5%). Findings from my sample in Kenya are compared to data from selected HICs (Martinez-Martin *et al.*, 2007); there are no data from low-/middle-income countries. Disease duration among PWPD in Kenya was identified using date of diagnosis, which was often delayed. Data in *Table 10* shows the variability between countries. However, NMSQ values are similar to those identified in Israel, suggesting that symptoms of PD are similar between populations.

Country (number of patients)	Age (mean ± SD)	Disease duration (mean ± SD)	NMSQ (mean ± SD; range)
Kenya (52)	66.4 ± 9.45	4.85 ± 4.05	12.90 ± 5.8 (2 – 29)
UK (209)	67.66 ± 10.5	5.92 ± 4.9	9.99 ± 5.3 (0 – 28)
USA (42)	64.36 ± 10.7	7.92 ± 7.5	10.10 ± 5.8 (0 – 27)
Israel (51)	70.20 ± 9.8	9.22 ± 4.9	12.71 ± 5.7 (2 – 26)

Table 10. Comparison of data collected on non-motor symptoms from Kenyan sample and findings from a study by Martinez-Martin et al. (2007) of non-motor symptoms among PWPD in selected HICs

The symptoms experienced by PWPD in Kenya were largely similar to reported biological manifestations of PD (Jankovic, 2008; Park and Stacy, 2009) as well as those reported in qualitative and quantitative studies globally (Ford, 1998; Larsen and Tandberg, 2001; Sapir *et al.*, 2001; Wang *et al.*, 2002; Miller *et al.*, 2006b; Miller *et al.*, 2006a; Martinez-Martin *et al.*, 2007; Reijnders *et al.*, 2008; Menza *et al.*, 2010; Mshana *et al.*, 2011; McClurg *et al.*, 2016; Jonasson *et al.*, 2018; Pedrosa Carrasco *et al.*, 2018; Richard, 2019). Consequently, the difficulties PWPD experienced are briefly discussed but what this chapter focusses on is the impact of symptoms on relationships and resulting care opportunities, and the changes PWPD made in their lives as their conditions progressed, which was largely dependent on social and financial resources.

The non-motor symptoms that participants explored in detail included: memory loss, low mood, apathy, depression, constipation, drooling, incontinence and falls. The impact of motor changes on speech, communication and mobility as well as disease progression were also discussed. Some participants described how their symptoms resulted in them feeling *"sad"*, *"lonely"*, *"bad"*, *"terrible", "frustrated"* or *"hopeless"*; many PWPD described having lost their independence as a result. Similar findings have been identified by Bramley and Eatough (2005) in the UK, where PD disrupted PWPDs' sense of self and agency. However, some symptoms, including hallucinations and delusions, that are common among PWPD and have been related to increased disease burden globally, were not reported by many PWPD. This may have been because of the stigma and shame associated with seeing something, or someone, that is not there, such as a dead relative. Furthermore, several mood disorders, such as anxiety, impulse control disorders and dopamine dysregulation syndrome were not discussed. This was likely because PWPD did not know about them or were not aware the symptoms were associated with PD, and these aspects are not part of the non-motor symptoms questionnaire. Although mental health problems are increasing in importance in SSA, challenges exist with stigma surrounding depression and anxiety, as well as with the availability and capacity of mental health services (Sankoh *et al.*, 2018).

Memory loss was often reported as a concern but was also evident during interactions; several PWPD appeared to forget questions or words or their thoughts would trail off. For some, memory loss manifested in other ways such as forgetting to take, or losing,

medication, losing money or confusing people and things from the past. Pauline described how her mother, Leah, would "hide" her medication:

> *"One day I was making her bed, then I realised she had hidden her medicine…We realised her medicine should last a month, it is ending after 21 days. So, what happened to the nine tablets? She took them, she repeated, because she forgot. So, now we had to take them" (Pauline, daughter of 78-year-old PWPD)*

Memory loss resulted in some family members becoming more active in PWPDs' routines, for example, to ensure their medication was taken. Some participants also described how PWPD found it hard to accept not being able to do certain things such as walking or driving or not having the capacity to manage their medicine, feeling like they had become a *"burden"* on their families.

Many family members reported trying to let PWPD do as many things as possible for themselves; although several viewed the extra help they needed as a *"weakness"* or symbol of how *"helpless"* they were, often denying assistance. For example, Leah repeatedly tried to fire her employed caregiver, despite being unable to walk or as Esther, her daughter, described, make a cup of tea. PWPD did not discuss memory loss as much as caregivers did, although some did and noted the worry this caused them for the future.

Several participants also described how PWPD no longer wanted to participate in social occasions, leave the house or talk to people. Aliya described how her 70-year-old mother, Zahra, who lived in Mombasa felt sad about not being able to move, adding, *"She feels lonely, doesn't want to speak to people and feels sad when she has to do something"*. Many PWPD in my sample who were less able to leave home reported feeling sad, lonely and depressed, yet preferred to meet at home for an interview rather than venturing out. Gideon, aged 33, described how he felt *"alone in the world"* and talked of his battle with depression and how he had attempted suicide three times. Joseph was diagnosed three years ago. He described how he did not enjoy being around people:

> *"I feel sorry for myself. I used to communicate with people. I'm a church pastor…I can't concentrate on my job or what I used to do. I feel hopeless…I feel like I want to excuse myself [in social situations] and avoid questions" (Joseph, 65-year-old PWPD)*

This sadness and apathy also affected family members who had to negotiate sleepless nights resulting from PWPDs' restlessness, inability to turn in bed and incontinence as well. Many participants reported experiencing incontinence during the questionnaire survey – some PWPD had to wear adult diapers, have a bucket near the bed or a catheter if bed-bound.

Several participants reported the impact of PD on their speech and communication, which resulted in difficulties participating in 'normal' social occasions or phone calls, where someone would have to speak on their behalf. Many PWPD with advanced symptoms were completely unable to talk. Some described using coping strategies such as avoiding social occasions where they could be left out of conversations or could not be heard. I observed this during support group meetings where some PWPD were reluctant to contribute to discussions.

Participants also reported issues with swallowing and chewing where mealtimes became prolonged, while others described feeling shy or nervous about spilling food or drooling, preventing them going out for meals or to events. I observed these challenges during support group meetings – tremor would cause tea spillages or PWPD would drool because of swallowing difficulties. Constipation was also described as *"a big problem"* which contributed to significant pain and discomfort but also affected PWPDs' ability to carry out daily activities. However, families described difficulties making *"special food"* solely for PWPD to combat constipation. As the wife of Jared, aged 70, explained: *"We don't have money, we are buying drugs, we are not buying fish[22]".*

Several PWPD described having fallen in their home or in public, which resulted in some feeling fearful about leaving the house or doing exercise, contributing to feelings of isolation and loneliness. Gideon described his experience:

> *"I tripped and I fell on the road when a matatu (bus) was coming…Some people understand and they help, others think I am drunk…I feel bitter, especially when someone says, 'Let him sleep he's drunk'…It's a sad thing for me" (Gideon, 33-years-old)*

[22] Animal protein can decrease the effect of medication, fish does not have the same effect and is also healthier than red meat (but more expensive).

Gideon also had his phone stolen by onlookers during the chaos. Others described avoiding leaving the house because they were concerned about people's perceptions of them. For example, Gloria (76-years) thought people would say, *"Who is this lady, look at how she's walking"* if she went outside, so she did not; although, she said this made her feel lonely. Some PWPD continued to venture into society, despite what people thought of their symptoms.

In addition to broken bones, scrapes and bruises resulting from falls, PWPD also reported experiencing a general and worsening pain, stiffness and 'slowing down', where getting out of bed was a *"crisis"*. These symptoms prevented some from partaking in activities or socialising outside of the home. During fieldwork, I noted that rigidity and stiffness were evident through physical assessments; observing that several PWPD were immovable. Stiffness and progression led to some PWPD being bedbound and/or unable to walk. Some continued to venture outside despite these difficulties, often, as I observed, with the assistance of a walking stick, caregiver's arm or wheelchair in more advanced cases.

With progression came the *"terrible"* symptoms, *"hopeless"* conditions and *"more problems".* Participants described the increasing effect this had on PWPDs' independence and ability to do the things they used to. Constance described her husband, Jared's, experience of progressing symptoms after 14 years of PD:

> *"Ribs are squeezed, the backbone is stiff, you cannot turn this one...The head comes down, you cannot sit up, you cannot even swallow a tablet of medicine because of the throat…There's no movement…If you want to stand most of your energy is going to be spent on the standing action only…that's the end of everything" (Constance, spouse of 70-year-old PWPD)*

The obvious yet uncertain progression of PD contributed to great worry and uncertainty for many participants; as Gloria described, *"Since I started there has been no end…I have to suffer".* Gideon had two young children and had to consider how his condition and progression would affect his career and future.

Several PWPD described feeling that whatever independence they had left was of great importance and allowed them to live as 'normal' a life as possible. On visiting Paul (70-years), a retired lecturer, I became acutely aware of this:

8th June 2018

Paul appeared annoyed about his condition. He explained, "*This disease cannot allow me to do many things"*, adding it was disheartening having to watch as people did things for him. Paul described struggling to turn over in bed or stand up from the sofa: *"I want to be independent; I don't want to keep calling people".* Paul proceeded to stand up from the sofa and struggled. Throughout my time with him, he continued trying to stand, insisting on getting up independently and demonstrating how he could walk. At times he looked like he might fall but made it back to the sofa. My arms were constantly outstretched in anticipation of a trip. Later, he dropped down to the ground and performed two push-ups on the carpet. He proudly confirmed that he did two every day.

Paul wanted to demonstrate the independence he still had, showing off to me how he could walk and do push-ups, yet reluctantly acknowledged that there were things he could no longer do. Several PWPD also reported wanting, and trying, to reduce the burden on their families to allow them to continue living their own lives.

Most PWPD in this study, where possible, reported finding ways to adapt to their situation, work around symptoms or develop coping mechanisms. For some without families this was more difficult. However, getting used to life with PD was a continual, evolving journey of self-management discussed in the following section. Although the biology and physiology of PD was similar to reports globally, the different sociocultural and political-economic circumstances within the context of Kenya resulted in different perceptions, understandings and experiences of treatment and disease.

6.1.2 Adapting and getting used to life with Parkinson's disease

PWPD and their families learnt to manage and get used to PD, making changes to everyday life. This section examines the complexity around acceptance and denial of PD, the resources and support networks required to allow PWPD to negotiate their condition in the home and within society, and the experience of changing roles, from both PWPD and caregivers' perspectives. Living with a chronic condition like PD requires that people manage their symptoms, daily lives, social roles and families; Corbin and Strauss (1988) suggest this is linking "illness work" and "everyday life work".

Acceptance and denial

Many participants described their upset and frustration at having PD, expressing that *"things are not going right".* However, some also expressed how they had come to understand, come to terms with or learnt to live with PD. This usually involved support from family or seeing others living with PD, knowing they were not alone. Christine had been diagnosed eight years ago whilst still employed in Nairobi; she described how she managed her condition:

> *"At first, I was scared, but after some time, I was used to it…You know, I have to live with it. I have to get used to it…and make yourself happy. That's how I've managed it. If it is not a life-threatening disease, then I can live with it" (Christine, 55-year-old PWPD)*

PWPD often described becoming more accepting of their condition as they began to understand it better. Some acknowledged the drive and determination they had to live well with PD as long as they could continue with their daily lives. Jacob lived with his eldest son in a village near Mombasa; he described how he had incorporated his condition into his life:

> *"I took it [PD diagnosis] lightly, because there's nothing I can do…We eat food daily, so if I am to take medicine daily, it's the same thing…So, I've accepted it, it's part of my life because it doesn't prevent me from doing my work" (Jacob, 76-year-old PWPD)*

Jacob was still able to work on his *shamba* (plot of land for farming) thus maintaining some continuity. Although many PWPD described having accepted their condition, learning to live, and coming to terms, with a changing self was complex. Several PWPD described being in denial about their diagnosis – they believed it was incorrect or someone had made a mistake. James, a 59-year-old civil servant, was diagnosed by a private neurologist in Nairobi six months before we met:

> *28th November 2018*
>
> James arrived straight from work in a blue pinstripe suit. He shuffled as he approached the table and his facial expression looked absent. Before we began the questionnaire, James made sure I knew that he did not think he actually had PD yet continued to take medication for the *"sake of it"*. I noticed a slight tremor in his left hand. James talked slowly and kept building up saliva in his mouth. At one point, he knocked a glass of water over himself as he reached for his phone. James explained

that he initially thought his symptoms were to do with his diabetes, which he had had for 20 years. He admitted that he was also in denial about his diabetes diagnosis and did not start medication for years.

James explained that his 'symptoms' got worse in social situations which he said was embarrassing. He added that he had started needing help doing his tie up. If someone asked him about his condition, he told them he did not know what was wrong. James explained, *"There is nothing better in this world than denial"*.

James acknowledged his 'denial' despite having accepted needing medication; this was a common experience among other PWPD, particularly the men in my sample. Anya also described how her husband believed that the two private neurologists he had seen had made a mistake and denied his diagnosis. Yet, Anya said he still took his medication and did his exercises daily – studies in HICs have identified similar findings among PWPD (Eccles *et al.*, 2011; Soundy *et al.*, 2014). Several participants also described not wanting to learn about PD. For example, Stephanie, aged 75, did not want to carry out the NMSQ for fear of learning about the symptoms she might develop, adding she would rather continue pretending she did not have PD.

Some PWPD reported feeling more accepting of PD and positive about their future when medication improved their symptoms, particularly after spells without treatment. However, acceptance and denial are two of many fluid responses to chronic illness that can change over time. Chronic illness is a disruptive event where people can adapt to life but also have periods of *"classic sick-role behaviour"* during episodes of worsening symptoms (Bury, 1982, p. 168). In these cases, PWPD may feel more able to be dependent on others.

Younger-onset PWPD in their *"youthful years"* described their expectation to be productive and *"useful"* and the difficulties they faced suffering from a disease of 'older people'. They described how difficult it was to relate to others' experiences during support group meetings or online (where accessible) because they were at different stages of their lives. As such, some younger-onset PWPD found their condition more difficult to accept – as Gideon admitted, he had contemplated suicide.

The ability of PWPD to accept, or come to terms with, their condition and a changing 'self' appeared to be made achievable through support from kin networks. PWPD described

becoming increasingly dependent on family members for care as their condition progressed and the following section explores the changes made within the household and in daily life.

Changes to the home and everyday life

Families had to make significant changes to their lives, including where and with whom PWPD lived, but also adaptations to their routines and activities, allowing PWPD to maintain some independence and 'normality' in their lives. In the context of HIV in Uganda, Whyte (2012) describes the importance of sociality, kinship and friendship in enabling people to control their condition.

Where and with whom PWPD lived was highly dependent on family networks and the availability and proximity of biomedical health services. Many PWPD described having migrated from villages to cities when young in search of job opportunities, starting families and building their new lives away from their ancestral homes. Several described anticipating moving back to their villages after retirement. However, this became less 'practical' after the onset of disease – PWPD needed to be closer to services and care resources in cities.

Other PWPD who had lived in rural Kenya all their lives had relocated to the city to live with their adult offspring once they required more care. Relocations were often dependent on whether offspring could support them. For example, Louise described how she, and her sisters, were able to relocate their mother, Norah, to Nairobi and care for her, adding, *"It's been much easier for everyone, including herself".* In some cases, PWPD had little say in this decision. Gloria lived in rural Kenya and had moved to Nairobi to live with her daughter nine years ago in search of a diagnosis and treatment. Gloria wanted to return home, but her daughter wanted her to stay close to the services she believed she needed. Noor (60-years) had travelled across the country to Mombasa to get the treatment and care she required:

> *6th August 2018*
>
> Noor was staying with her nephew in Mombasa, but she was from a village 570km away. Noor had travelled 18 hours by bus (costing 3000ksh (£23)) to Mombasa to see a neurologist and collect her medicines. There was no hospital near her. Her nephew said she was in bad health when she came, so he asked her to stay longer, although added, *"She wants to go back".* In Noor's village, she had no electricity, running water, sanitation, toilets, TV or sofa. She lived with her husband and nine children.

Like several others, Noor had relocated to access medication and services – PWPD often called on and negotiated social networks and connections for care. In contrast, some (generally younger) PWPD who lived in the city described having to return to their village because of the high costs of city life and reduced ability to work. For example, Christine returned to her family's rural home in Central Kenya where she had a small plot of land because she had begun working part-time and could not afford her rent in Nairobi.

Within the home, participants described making changes to enable PWPD to better manage and negotiate life. Several PWPD had acquired a new 'hospital' bed, added a railing to the wall to help them get out of bed, moved their bedroom altogether or created pathways across the house to manoeuvre their home. All these changes were contingent on families' financial situations and their ability to make adaptations. PWPD who did not have this support described not being able to make appropriate changes to their homes.

Many PWPD described the importance of establishing routines, which made their day-to-day lives 'easier' to manage, incorporating aspects such as: dosing schedules, mealtimes, drinking water, exercise, social visits, appointments, naps and in some cases, working hours. Some also described cutting down working hours, using their skills in different ways, or negotiating ways to allow them to continue working. For many, routines also had to fit into their family's schedules; Gideon described how he and his wife negotiated daily life:

> *"By 6am I am at the shop. She [wife] is left behind preparing the son for school…I work with her, helping each other until the end of the day…I am the one who goes for the boy [son] from school. [Routine] keeps me busy. It keeps my mind from thinking about negative whatever" (Gideon, 33-year-old PWPD)*

Several PWPD stressed the importance of keeping busy and active, or trying to maintain some normality and independence. Some participants described how PWPD tried to carry on partaking in social occasions or doing activities they used to enjoy, including: going for walks, attending places of worship, going out for meals or visiting friends and family, although this was often dependent on filial support. For example, Tina described how she would help Steven, her husband, cut his birthday cake and feed a piece to someone, a birthday tradition he enjoyed. However, other PWPD described situations where their family had not adapted to their needs. William (64-years) explained that he had become a slow eater, but his family

would not wait for him to finish meals, which resulted in him never finishing his food and losing weight.

PWPD with less advanced symptoms described being independent enough to carry on with some aspects of their lives. Christine described how she was happy she could still do things she enjoyed without assistance:

> *"I'm happy; I can do so many things. I even go to the shamba (plot of farming land) down here…I can pick coffee…I can do so many things…I can skip, I can walk very far…I don't go to work every day" (Christine, 55-year-old PWPD)*

Although some PWPD reported trying to maintain their past lives and sense of self, others found it more difficult and reported feeling physically unable to do certain activities, as one PWPD explained, *"You want to do that thing, but you can't because you are unwell".* Other reasons for withdrawing from social occasions or activities included: having moved away from friends, finding it difficult to be in certain situations, being unable to go out without assistance, struggling to walk or use public transport, worrying about what others would think of their appearance or feeling down or depressed. Some family members described how difficult it was to take PWPD outside in a wheelchair; the roads were bad, there were no pavements and places were largely inaccessible, which resulted in many rarely leaving home.

Adapting to life and negotiating PWPDs' daily needs were dependent on financial resources and social support, which varied greatly among participants – socioeconomic status, family size, educational and cultural resources influenced opportunities for care.

Shifting roles in the family and society

Participants described how PWPDs' roles as wives, husbands, mothers, fathers and siblings had changed as their condition progressed. PD affected the whole family, particularly when resources were pulled together to provide care. In a village in rural coastal Kenya, Constance described her husband Jared (70-years) as the metaphorical 'driver' of the family home and how he could no longer lead his household. Constance said she had to take charge instead and, like other wives, make decisions for the family as their husbands' conditions progressed.

Several participants described how PWPDs' relationships with offspring had also changed. Adult children suggested their roles had reversed and they were now looking after their parents; although this is also part of "normal" ageing. Simon had recently moved to live with his father, Jacob, who struggled to accept that he needed his son's help:

> *"When you try to be very persistent, he [PWPD] now gets very angry…He tells you, 'I'm not a child, you're my child'…The role has changed…the son bit has to be there, because you just need to, 'OK, OK dad, yes, yes dad'. But I think the other part is…Just let him be a dad, but you have to be a bit pushy sometimes" (Simon, son of 76-year-old PWPD)*

Many participants described the difficulty accepting and balancing their new roles, for example, as a son and caregiver. Several daughters described feeling more like the 'mother' in their relationship and the pressure this put on them:

> *"Since I was 19, I'm the mother; I'm the one who makes the decisions essentially…But it's sort of tough because my mum will be like, 'You don't respect me, I'm your mother'…Mothering your mother is very difficult, but it's also hard when I need care and she doesn't recognise that" (Amanda, daughter of 66-year-old PWPD)*

Amanda began to cry as she spoke; she felt as though she had lost her mother. Other adult offspring also described the many different roles they had taken on – Sarah explained how her roles created tensions in her relationship with her mother:

> *"I'm the daughter…Then I'm the caregiver…The other thing that we've had to straighten out, I am not the primary caregiver, I am the provider but not the caregiver…She wants me to be both…There's that part as well where I'm still fighting for my space to be a daughter…and every now and again I get it…and it's very special" (Sarah, daughter of 78-year-old PWPD)*

Participants reported how PWPD also found it difficult to accept their new roles and negotiate their new relationships and capabilities.

Younger onset PWPD described how their school-aged children would help them get ready in the morning or rush back from school to check on them during the day. Amina cared for her father while at University and explained, *"My first year I failed miserably"*. Gideon had two children under six-years-old at time of the study; he described his relationship with his 6-year-old son:

"I think he [son] was also affected by the condition I was in. He was sad all the time…He used to be there for me, anything…like wearing on the socks, putting on a sweater. He could always ask 'Dad, what's wrong, what happened?' Such questions…I'm still complaining…until I can work and provide for my family, because that's like my core responsibility…Just recently my son was out of school because of fees…I can't manage to pay fees for my son and also go to hospital at the same time…now food to eat, food on the table" (Gideon, 33-year-old PWPD)

Younger onset PWPDs' responsibilities as fathers and husbands appeared to be greatly affected by their symptoms; as Gideon suggested, he struggled to provide for his children as well as afford care. How PD affected gendered roles is explored further in Section 6.3.1.

Several participants also described difficulties maintaining their social roles within their communities. Sarah suggested her mother was a *"generous person"* and had always *"fixed people's problems"* but struggled not being able to anymore. Gideon also described how he struggled to maintain his social life and his role as 'friend':

"I changed completely. I lost hope…I used to keep by myself all the time, I always wanted to be alone…I stopped everything…I did not want to be with people, I felt bad about my condition. Secondly, my movements are limited. I really try very much to get back my social life…Most of them [friends] left me…Not many people want to associate with you when you have a strange condition" (Gideon, 33-year-old PWPD)

Gideon's wife worked because he could not, and he did not have extra family support to help him keep in touch with friends or maintain his social roles.

Many PWPD described how their symptoms resulted in them feeling like a different person than who they used to be. PWPDs' roles within their families had reversed, many could no longer engage in social occasions and experienced difficulties coming to terms with a changing 'self'. Families described trying to make the transition as easy as possible for PWPD; although also described the physical and emotional toll this took on them, explored in Section 6.2.

6.1.3 Experience of stigma

The limited knowledge about PD resulted in participants being "judged" in day-to-day life outside of the home. PWPD of all ages described how their visible, *"strange"* symptoms

often led to assumptions, including: that they were cursed, drunk or a wizard, their symptoms were caused by witchcraft, given by Satan, were *"out of this world",* or that they had a disease of *"white people"* or *"rich people"*. Christine described peoples' perceptions about her condition:

> *"You know, there are other people who think it's a witchcraft or something…Then I told them, 'If it's a disease and the doctors are saying it's a disease, so other people had it or other people are having it. And I'm a person; I'm a person like any other'. So, they're telling me that all those other people who have it have some issues…It's just a disease that came" (Christine, 55-year-old PWPD)*

Christine also described the difficulties she had explaining how she could run one day but needed a walking stick the next, which was dependent on her 'on' and 'off' periods. She also joked that she had *"joined those rich people"* with PD across the world because of the perception that it was a disease of *"white people"*. Danny echoed Christine's experience where his father required a wheelchair at times yet could be *"up and about"* shortly after. He thought that this could be shocking for people and created conflicting reports of his father's condition, including witchcraft as a possible explanation. This contrasts perceptions in HICs where fluctuations are seen as PWPD malingering or pretending (Sunvisson and Ekman, 2001; Maffoni and Giardini, 2017). Perceptions regarding supernatural causes and witchcraft have also been identified among people living with dementia in SSA (Adebiyi *et al.*, 2016; Mkhonto and Hanssen, 2018; Spittel *et al.*, 2019; Brooke and Ojo, 2020), resulting in stigmatising perceptions towards the person with dementia.

Several participants described experiences of stigma in society. Nzambi recalled how people would avoid him on the street or cross over the road when they saw him:

> *26th October 2018*
>
> Nzambi told me about the times people had taken a wide berth around him on the street or vacated the seat next to him on the bus. Nzambi laughed, adding, *"People think they could get sick like me".* Nzambi told me about one day when the bus was delayed for a long time because people did not want to sit next to him, but the bus would not leave until it was full. Again, he was giggling, *"They don't talk to me even".* Nzambi said he was used to this behaviour now and did not mind it so much. As we spoke, it was obvious he tried to hide his face with his hand to cover the head jerking. Maybe it did bother him. *"People who don't know think I was born like that",* Nzambi sighed.

Participants not only reported experiencing stigma in society but also in their own homes and among their families. Danny described how members of his extended family thought his father might have been cursed:

> *"They're like, 'I don't want to go to that house because you know, like whatever spirit is there might get into me'. There's some people I don't expect to ever see coming to visit because they believe…my dad is bewitched and if they come anywhere near him the same thing might happen to them…It's not uncommon for people to think that" (Danny, son of 83-year-old PWPD)*

Danny felt quite strongly about the stigma surrounding PD and, like other participants, tried to explain the condition to others, particularly in his family's rural home. Gloria also described how she thought people might respond to her condition in her village:

Gloria:	Let people go and see me at home; they can say what they want.
Natasha:	What do you mean? What will they say?
Gloria:	I left my house and I came to Nairobi to get better and be healed. 'Why has she come back when she's not healed?' 'We thought you went to Nairobi to be better, to be healed. You came back again with the disease, then the disease you never got it here, you got it where you went'. I'll have to explain to them, if they have time, because I'll be feeling annoyed.
	(Gloria, 76-year-old PWPD)

Gloria felt that people would not understand why she had not recovered after nine years of treatment and consequently, think she had been cursed. However, several other PWPD also described wanting to teach others about PD to prevent being *"cast out"* from their community or perceived as 'drunk':

> *"Like a place like [slum], nobody has ever heard about it…I wish I could get a platform to make people know that there are people like that, there's a condition like that and they can get help and can live a normal life like normal people. Yah, so that…they could not be jilted, they could not be like, cast out" (Gideon, 33-year-old PWPD)*

Gideon expressed his frustration that he was suffering from a condition no one knew about but also his distress that his wife did not believe PD existed – he asked if I would explain to his wife that PD was a *"real disease".* Pauline also suggested that when community members visited her mother in rural Kenya, she would try to educate them about PD and what signs to

look for. From their experience, Pauline and her sister, Esther, felt strongly about raising awareness about PD, as Pauline explained, *"Like the way we used to create [awareness] for HIV".*

Several PWPD described not having experienced any stigma in the community or suggested that their friends were understanding and supportive. However, some PWPD often did not leave the house because of the range of symptoms and issues discussed in Section 6.1.1. As Wanjiku explained, her father was not *"out and about"* and spent almost all his time at home, hidden from the outside world and any opportunity to be judged. Although not all PWPD experienced stigmatisation, almost all participants were aware of 'other' peoples' perceptions. PWPD endured various comments made about them, often resulting in exclusion from their communities, but also tried to educate people and rid any negative perceptions.

6.2 Experience of caring for someone with Parkinson's disease

6.2.1 Family care for people with Parkinson's disease: "It becomes your life"

Care opportunities

In the earlier stages of disease, informal family caregivers described their role in helping PWPD but not 'caring' for them – several recently diagnosed PWPD did not identify a 'main caregiver'. However, PWPD began to require more assistance as symptoms progressed and care became more complex. The filial support available to PWPD in this study varied. Some families took on the caring role as a *"team"*, as Constance described, the family worked together to ensure her husband took his medication on time. PWPD with larger kinship networks usually had more opportunities to receive care. Eunice described her family's role in caring for her husband, Benjamin, who had been living with PD for 18 years – nine people lived at home with Benjamin:

> *"We had agreed with the family, he [PWPD] will never, ever be left at home alone…This is more important than what you were going to do...everybody understands. So, what happens is if you wake up and find you are the only one in the house, you take up the responsibility of him…You have to be there, whether you had a heavy burden…When somebody else enters that house, you just tell that person, 'Take over, I have gone"' (Eunice, spouse of 79-year-old PWPD)*

Benjamin's family saw it as their responsibility to care for him – they understood him and believed they were best equipped to provide his care. As Eunice explained, *"You want to help him because…you know what he's been through".* Larger families, like Benjamin's, described being able to split caring roles between themselves, having opportunities to step back and find outlets to deal with the toll of care work (described in the following section).

In contrast, others reported not having support networks to rely on which impacted on their ability to cope with their new role. As Amanda described, *"There's no one else in the family…it's all on me".* Informal family caregivers who also worked full-time described the burden of caring on top of their paid jobs and the tensions this caused in their relationships. Amanda lived alone with her mother:

> *"I kind of realised I can't take care of my mum and it's really hard living with her because I think my mum thinks I've come from a holiday when I walk through the door…Because the moment I get in, 'Can you do this, can you do that, I've been in pain all day'" (Amanda, daughter of 66-year-old PWPD)*

Some participants described how trying to find a balance between the caregiving role and their own life was a struggle, particularly those who did not have additional support networks. Several discussed how they had *"given up"* or *"sacrificed"* their own lives, family lives and work to take on the caring role. Spouses described not being able to go out to the shops or to see friends in case PWPD needed them at home:

> *"I was not going out because when somebody is paralysed, he needs you all the time. 24 [hour] service…all the years. Staying in the house throughout, just taking care of him…How can you leave somebody in bed suffering and then you go out…can you really be happy? So, I never used to go…Because if I didn't do that, my children could not go to school…I had to sacrifice myself" (Tina, spouse of deceased PWPD)*

Full-time informal family caregivers often described having little time to concentrate on their own wellbeing, particularly in more advanced stages. Several also reported being less able to participate in social occasions, visit friends, *"be spontaneous"* or travel. In Tanzania, Dotchin *et al.* (2014) identified a higher caregiver burden among caregivers of PWPD than dementia. Yet globally, caregivers of PWPD tend to neglect their own wellbeing and often do not have, or do not accept, respite from their role (Bhimani, 2014).

Several adult offspring described making the decision to give up their jobs and responsibilities to care for their parent full-time. Pauline described how she transitioned into her role as caregiver:

> *"I used to have a shop…and then my mum got sick and now we started going to the hospital for clinics…At that time I could still run the shop, but nowadays I am forced to close because most of the times I'm in hospitals, I'm going for clinics. I have to make sure she gets the right dose at the right time. So, I had to close the business…So basically, that's my life" (Pauline, daughter of 78-year-old PWPD)*

Although Pauline described how this was her own decision, other offspring were 'chosen' by the family to take on the role because they had more flexible work patterns, fewer commitments, the most resources, they were the eldest or because of their gender. However, the commitment to take on the caring role was still a sacrifice. In contrast, young-onset PWPD with school-aged children, like Gideon, described their limited care opportunities:

> *"I'm the one who's supposed to support them, not the other way around. So, that's what I'm missing…I don't expect anybody to come through for me. So, I have to really work hard for myself…even my mother will not be there for me always, she also has her responsibilities" (Gideon, 33-year-old PWPD)*

Gideon was married but felt that he, not his wife, should provide for the family. Other younger PWPD also described how they were supposed to be looking after their families, not receiving care.

Most families reported doing everything they could to care for PWPD, paying for medicines, physically assisting them in the home and taking them to appointments. However, in some cases this was deemed *"not enough"* by extended families. PWPD had often lost weight, become more rigid and stooped and this image of their physical body was seen as a reflection of the care they were receiving. Judith was 69-years-old and lived with her husband. Her son, Moses, drove 45 minutes every day to see her and attended monthly support group meetings. However, Judith discussed how her eight siblings thought she had *"been neglected"* by her children because she had lost weight and was not 'healed'. Moses added, *"We are doing our best".* Judith's experience reveals the challenges of caring for

someone with a progressive condition like PD and the emotional burden of care work, particularly when people did not understand the nature of the disease.

Several family members described feeling like expert caregivers having learnt various tricks and skills over the years, including: how to lift PWPD, turn them in bed, what foods reduced their constipation, when they were able to go out or how to stop freezing of gait. Tina explained: *"I am a PhD on Parkinson's caring".* During support group meetings informal family caregivers often shared tips they had gained through their own caring experience. In contrast, others believed they did not know enough about how to care for someone with PD:

> *"The biggest struggle, I suppose, is that I'm not a caregiver. It would be nice to have one, because I'm not. I don't know how to manage my mum is the biggest thing…I'm not a caregiver, I'm just the default person" (Amanda, daughter of 66-year-old PWPD)*

Several participants discussed the challenge of learning how to care for someone with PD. This role was overwhelming for some who had the role thrust upon them. Gideon (33-years) said he wished there was more information available for caregivers to learn, adding, "S*o that they can be able to help their people".* Despite this, caregivers reported the constant learning *"on the job"* and need to adapt to the progressive requirements of PWPD. PD constantly brought up new challenges to negotiate, with the most stressful period towards the end of life. This experience is explored in Chapter Seven.

In the questionnaire survey, 30 PWPD identified having a 'main caregiver' (*Table 11*). However, what became evident was that care networks were often complex and multi-layered. Care involved input from several family members (as discussed), as well as informal domestic arrangements where paid help were involved, in some cases instead of or as well as full-time caregivers. In addition, just because PWPD did not identify a main caregiver did not mean they did not need one. Some did not have the family networks or financial support required to have a caregiver. The majority of identified main caregivers in this study were female – of 15 spouses, 13 were wives of male PWPD (*Table 11)*. Section 5.3.1 explores the idea of gendered roles in care.

Although family networks are crucial in the management of chronic disease and for older people, in particular in SSA (Apt, 2001), it was not only PWPD with larger care networks who received good care. Participants appeared to be negotiating care and constantly learning.

Care networks were messy and fluid and for some families, several actors contributed to different aspects of care for different needs, which varied temporally. A study in Ethiopia by Walga (2019) identified similar findings where families of PWPD shared the caregiving role, reducing the burden.

Demographics of main caregivers	No. of PWPD
Identified caregiver	
Yes	31
No	24
Type of caregiver	
Informal/family	27
Formal/employed	4
Relation of informal family caregiver to PWPD	
Spouse	15
Daughter	5
Son	3
Grandchild	3
Niece	1
Sex of caregivers	
Male	9
Female	22
Age range of informal caregivers	13-72 years
Median age of informal caregivers	53.5 years

Table 11. Demographic characteristics of main caregivers of PWPD (n=55)

Physical, emotional and financial support and the burden of care work

The roles of caregivers encompassed physical, emotional and financial support for all PWPDs' care requirements. Larger families described sharing caring roles between them – some took on physical care while others contributed financially. Several offspring who were in full-time paid work could not physically care, but instead provided for them financially and supported their needs in this way. However, the various forms of support also resulted in significant burden for many caregivers and families. This section describes the support families provided and the challenges of care work. Similar challenges relating to financial stress, social isolation, physical and emotional stress has been identified in neighbouring Uganda among informal caregivers of people living with dementia (Owokuhaisa *et al.*, 2020).

The physical assistance required by PWPD became more complex over time and included: helping PWPD stand up, sit down, turn over in bed, go to the toilet, get dressed and washed, brush their teeth, eat, drink, walk, shake someone's hand and so on. Constance described the responsibility she had after 14 years caring for her husband:

> *"The whole night, in fact I'm a nurse, night duty...When you go back to your bed and try and settle, he calls you back. Sometimes you have to shout at him. I am very tired because of the day's work. I want to rest, wewe (you) after every 5 minutes you want urinate, then urinate there on the bed then I will wash the bed sheets. So, we quarrel over night. Then I wash and remember, ehh, washing the bed sheets is more difficult than lifting him up. So, we have a story every night" (Constance, wife of 70-year-old PWPD)*

Constance described the toll of caring for her husband and the tensions this created in their relationship. The constant lifting, moving and turning of PWPD contributed to back aches and pains. In Uganda, Ainamani *et al.* (2020) described similar physical challenges associated with care for people with dementia resulting from constant assistance with activities of daily living. Among participants in Kenya, the physical strain of carework sometimes resulted in the need for extra help for those with extended family or the resources to employ a caregiver.

Caregivers also described the emotional support required to ensure PWPD engaged in everyday activities. Esther explained how buying her mother a wheelchair meant she could see her whole house for the first time in years after not being able to walk very far, which she believed made her very happy. Tina described how she cared for her husband:

> *"When you have a patient with Parkinson's disease you have one thing, to be very caring, very kind…You have to take him with a wheelchair by the road so that he can see the road and see the people…You even talk to him so that you can see whether he is talking today...You see, when you have a patient you have hope" (Tina, spouse of deceased PWPD)*

Tina described how looking after her husband gave her hope for the future and a miracle recovery but added that she had very little time to herself. Sarah also described how important it was to provide emotional support to her mother and remain strong for her:

"To watch the transition…to watch her, you know, deteriorate and just lose functionality in the way that she is, is extremely difficult…You just have to keep going…Just be there to support her and if you need to cry, go somewhere else" (Sarah, daughter of 78-year-old PWPD)

Several family members described a similar experience and the significant emotion of watching PWPDs' deterioration.

As well as providing emotional support, carework was suggested to take an emotional toll on caregivers too. As Eunice suggested, *"I have dedicated my social life to him [PWPD]".* Consequently, some described feeling sad, stressed and depressed, falling sick and not looking after themselves. Similar issues have been described globally (Solimeo, 2009; Mosley *et al.*, 2017) with regards to PD and more recently among caregivers of people living with dementia in Uganda (Ainamani *et al.*, 2020). Yvonne and Jenny looked after their mother with PD who was bed-bound:

"So, literally, we don't have our lives. At some point your life has to stop, so that you can take care of her" (Jenny, daughter of 77-year-old PWPD)

Other family members described trying to negotiate their roles and not give up their own lives, although this was difficult. Amanda, who was in her thirties, described the tension she had between negotiating going out and looking after her mother:

"I need us to live our own lives but separately. And that's how the guilt has to go as well. Because she'll be like, 'It's fine, you should go out', but I'll come and she won't sleep and if she doesn't sleep that night, she'll be miserable the whole of the next day" (Amanda, daughter of 66-year-old PWPD)

Amanda, as an only child with no other support, described the significant burden she felt from her caregiving role. Other adult offspring described how they had adjusted to their new lives and reported having learnt to deal with sleepless nights and constant demands, although still needed to escape their role sometimes:

"At times, I feel I don't want to come back here [home]. I feel better when I go to take tea; I want to take more time there" (Yvonne, daughter of 77-year-old PWPD)

Caregivers who lived with PWPD described their reliance on them for everything, while those who did not described the worry and guilt they experienced when they were apart.

However, others described feeling guilty about not earning an income when they were at home with PWPD. Tan *et al.* (2012) identified similar worries among caregivers in Singapore who described their "guilt" when leaving PWPD at home or in someone else's care.

Participants with large kinship and support networks described having opportunities to *"release"* their emotional burden; although many still reported the worry and stress of caring. Several described the outlets they used to manage their stress and opportunities to step back from their role:

> *"You can't just keep it all in...I do music…I write...I have to find ways of releasing that, because it can, man it can choke you...I think that's how I've dealt with it...That's the benefit of the support group, there's people who are in a similar situation as you, who understand your frustrations. At this point, this is our life, you know, it's just become part of our life…Mum I think, there's the farm, she has a church group, she has her sisters" (Danny, son of 78-year-old PWPD)*

Like Danny, other family members also described using the support group to express how they were feeling. Sadia, the wife of one 72-year-old PWPD, had attended a support group meeting in Mombasa alone; as she introduced herself, the emotional burden of her caring role overcame her:

> *13th October 2018*
>
> Sadia said her husband had PD and they lived together in Mombasa; her children lived abroad. She talked about her husband's deteriorating health and how hard it was to care for him. He could no longer walk well, and she said he had fallen this morning. She went on to say it was straining her health. After saying this, she quickly went to sit down and started sobbing in her seat, wiping away her tears with a tissue. The lady next to Sadia comforted her, putting her arms around her as she cried. They had just met today.

Not only were groups important for supporting PWPD but also appeared to be a way for caregivers to find social support from others going through similar experiences.

All families discussed the high financial costs associated with PD and usually, family members were all required to *"chip in"*. Only 20 of the 55 PWPD included in the questionnaire stage and none of the 13 PWPD attending the government neurology clinic said they received a pension, which varied vastly in amount. The financial burden of care

appeared to fall completely on families who reported using up savings, selling assets, borrowing money and holding fundraisers to source funds. Amina, the daughter of one PWPD explained, *"It drains you completely".* Jared lived with 15 family members in a large but unfinished house; there was no ceiling below the roof and no glass in the windows. There was a small TV on the wall, but they had no electricity. The family had sold *"a great cow"* to afford his consultation fees. Jared's wife explained their situation further:

> *"In fact, people are wondering how we are surviving because…the income is too low and again you have to cough that money…In fact, if it were not for this problem [PD], maybe we would be in a better place than this one. Even we look at the TV, but we don't see because things are not doing well" (Constance, spouse of 70-year-old PWPD)*

Jared's large family struggled to pay for his care – this huge financial burden was usually because of the costly medicines, health services and consultations described in Chapter Five. As another spouse described, *"Treating a disease is very expensive".* In Tanzania, Mshana *et al.* (2011) also described the significant financial burden PD had on families, while in Uganda, Ainamani *et al.* (2020) identified similar financial costs associated with care for older people with dementia. Managing these costs was easier for some larger families who all had an income, as Wanjiku described:

> *"I have siblings, we pay for it together…They [siblings] pay for the insurance. They have monthly contribution to his care. So, it's not that difficult really…on the financial side it's very low" (Wanjiku, daughter of 71-year-old PWPD)*

In contrast to Wanjiku's experience of sharing the costs, some PWPD relied on one family member for all their financial costs. Esther had a relatively good job in Nairobi, which meant she was expected to pay for all her mother's care needs in rural Kenya, instead of physically caring for her:

> *"Imagine. 'You are there working in your big office and I am slaving here for your mother'…That's the way it works in Kenya. If you are in Nairobi, you are the slave of the family" (Esther, daughter of 78-year-old PWPD)*

Esther identified herself as a caregiver and although she did visit her mother often, her main 'role' was to send money, medicines or 'adult diapers', while other family members did the hands-on caring.

Overall, PWPD with more resources and care opportunities received more physical, financial and emotional support and this did reflect on their appearance and wellbeing as I witnessed. In addition, the physical, emotional and financial burden of doing care work came out strongly during this study, particularly for those who took on full-time caring roles – several caregivers cried during interviews when revealing the toll PD had taken on their lives. The burden of caregiving on caregivers of PWPD has been reported globally and there are clear parallels with the experience described in Kenya and those seen in HICs (Martínez-Martín *et al.*, 2007; Tan *et al.*, 2012; Bhimani, 2014; Mosley *et al.*, 2017; Tessitore *et al.*, 2018). As identified Martínez-Martín *et al.* (2007) in Spain, time spent on the caregiving role is significantly associated with caregiver burden. However, where experiences between HICs and LMICs might differ is in the support mechanisms available for caregivers and family members through charities, groups and online forums; although challenges with caregiver support have been reported in HICs too. Despite this, several participants described wanting to spend as much time as possible with PWPD and hinted at a sense of failure if they left them alone or guilt if they passed on responsibility to someone else.

6.2.2 Experience of employing caregivers

This section explores family members' experiences of employing caregivers and the resources required to do this. Only four PWPD who completed a questionnaire identified having a full-time employed caregiver. However, as fieldwork developed, several family members of PWPD also reported employing caregivers. Almost all families reported having some form of paid domestic help in the home who assisted with the cleaning, cooking and sometimes caregiving roles, although PWPD who lived alone, and young onset PWPD, usually could not afford this extra help.

Several family members described their struggle to find and keep 'good' employed caregivers. Jasper described his experience; his mother had had over ten:

> *"So, we've had caregivers…As we went along, they would disappear, in case she needs to get up at night…and she has to be lifted out of bed...So, at times she can get up at night like three, four, five times and this is murder if you're trying to rest, if you're a caregiver. So, some you know, say 'No, it's just too tiring' and they're gone. But someone always comes to fill their place...It is family networks...I train them" (Jasper, son of 78-year-old PWPD)*

Even though Jasper called on kin networks to provide paid care, they were still unable to manage the burden; these were poorer family members who assisted in return for wages. Others reported similar situations where caregivers could not 'handle' the tough role. One daughter described the *"nightmare"* trying to find caregivers with experience but who were also kind and compassionate. In rural Kenya, Esther explained that formal caregivers from Nairobi would *"get bored"* resulting in a high turnover.

Other families described how paid domestic helpers in the home had transitioned into a caring role. These informal, yet paid, caregivers were different to employed full-time caregivers. Danny explained how the gentleman who helped around their house transformed into his father's caregiver:

> *"At first, he was just, you know, he'd just be a general helper around the house. But then…he seemed to have a good understanding of what somebody in that situation needs…He's not trained…He seems to understand my dad better than a lot of doctors" (Danny, son of 83-year-old PWPD)*

Although Danny's father was largely cared for by his wife, the family required additional help as his condition progressed. However, other participants reported that paid domestic helpers were often reluctant to take on the caring role, adding it was not in their job remit or they were too busy.

Several family members suggested never having thought of the idea of an employed caregiver, while others wished they had another person to support them but could not afford this. The ability to employ formal full-time caregivers was usually only an option for upper-and middle-class families who welcomed the opportunity for assistance. Having said that, others resented the extra help they needed and often families took on the caring roles themselves despite being able to afford to employ caregivers.

6.3 How gender, generation and social change influence care

Previous sections in this chapter have outlined the experience of living with and caring for someone with PD in day-to-day life. This section examines how social change and concepts around gendered roles influenced ideas about reciprocity and the role of communities in care. Participants reflected on Kenyan and African 'traditions' and the shifts in care

structures over time as a result of modernisation and urbanisation and how these changes impacted on PWPDs' resources for care.

6.3.1 Negotiating gendered roles in care

The 'traditional' and 'cultural' expectations of men and women within the family, and how gender influenced care was discussed by several participants during interviews. Most caregivers in this study were female and literature on caring roles in Africa, particularly around HIV/AIDS, has identified that women are more likely to take on informal caring roles (Schatz and Seeley, 2015). In addition, research globally has found that daughters are more likely to provide more 'traditional', personal care than sons (Campbell and Martin-Matthews, 2003). Studies in Africa have also demonstrated that men take on more 'normative' roles including financial or managerial assistance (Oppong, 2006; Schatz, 2007; Akintola, 2008). In Ghana, Atobrah and Ampofo (2016, p. 176) highlight the difficulties husbands who care for their sick wives experience in a culture where *"caretaking functions typically are performed by women"* but also how constructions of masculinity might obstruct their caregiving role. Some participants described having to negotiate gendered taboos to provide the complex care PWPD required.

Several family members described the expectations of women in society to care, to be 'strong', be wives and 'not work', roles that were partly influenced by 'tradition' and religious beliefs. Esther described her perception of women being expected to care for their husbands and how this affected the care her mother received:

> *"If the man is alive and has also health issues…the woman herself ignores her own issues…Society basically ignores you. The man gets preference. You notice his health issues are given more priority…Her [PWPD] issues were ignored because she was taking care of the husband…It's just in the mind of Kenyans…It's just entrenched that I'm in charge of my wife's whatever. I can decide whether she can go to the doctors or not…the women's health is never considered…You can spend the whole day taking care of him and no one takes care of you" (Esther, daughter of 78-year-old PWPD)*

Several participants acknowledged how the role of caring for an ill parent was thrust upon women. The expectation of women to care spilled over to younger generations as well,

where it was suggested that daughters were expected to care for their own children, their parents and parents-in-law, either physically or financially.

What became evident from the questionnaire data was the high number of female PWPD who identified as being 'unemployed'. Of 23 female PWPD, 11 had not been in paid employment beyond the household throughout their lives, yet often identified working within the home; this is reflective of gender and paid work roles of this age group. All male PWPD in this study had been in paid work; either in the formal sector, informal sector or self-employed – male unemployment rates in 2018 in Kenya (aged 15+) were estimated to be 2.5% (4.4% in urban areas) (ILO, 2019). This data resonates with male PWPDs' view of themselves as providers of the family, while women were more likely to stay at home and be *"housewives".* Women's roles were also governed by religion. For example, the daughter of Zahra (70-years) in Mombasa explained, *"Arab women don't work";* although the norm of women not in paid work extended to other groups.

In contrast to the role of women, men's roles as caregivers were described by some participants as *"totally useless".* Esther said that her brothers "*demanded a payment"* for looking after their parents when their employed caregivers took time off. In Ghana, Atobrah and Ampofo (2016) also found that husbands of women with terminal cancer were not willing to take on caregiving roles within the home and did not perform any physical or emotional care. However, some male participants in this study in Kenya described taking on very active roles in their parents' care. For example, Moses visited his mother with PD every day, arranged and took her to appointments, paid for her medication and attended support group meetings on her behalf – a more managerial role but still very involved.

Maintaining roles as husband and wife also became difficult when spouses were PWPDs' main caregivers. Many PWPD could no longer sleep in the same bed as their spouse. Others described having no choice and continued to sleep together, despite the risk of being *"boxed"* at night[23]. The wives of some male PWPD described how their intimate relationships had changed and they felt more like caregivers than partners – male PWPD did not discuss this with me. Benjamin (79-years) had undergone deep brain stimulation surgery.

[23] Rapid eye movement (REM) sleep behaviour disorder is a common condition among PWPD where they act out dreams that are intense and often violent, which can result in someone sharing the bed being hit.

Eunice, his wife, described that Benjamin had not been *"sexual"* but the operation allowed him to be intimate again; she described how happy she was to have her husband back.

Some participants also described how male PWPD had difficulties accepting their changing roles where they were no longer responsible for the household, able to provide or be the *"man of the house".* Danny explained his interpretation of his father's resistance to physiotherapy in front of his wife:

> *"We realised if we take him [PWPD] for physio, mum shouldn't be in the room, because if mum is in the room, he won't do anything…Like he doesn't want mum to see him struggling to do all this stuff…Maybe he wants to feel like the man of the house" (Danny, son of 83-year-old PWPD)*

Several family members suggested that male PWPD, who had always been providers, struggled with their evolving roles and increased dependence.

Most older male PWPD in my sample were cared for by their wives (who described relishing the status still having a husband brought them), had reached retirement age and had older offspring (who also did not require care themselves) or pensions to shoulder the financial burden. In contrast, several young male PWPD described how their wives had left them:

> *26th October 2018*
>
> Nzambi explained that he could no longer provide for his children (aged 13 and 15) or pay their school fees because he could not work anymore. Nzambi's wife had taken his children back to [hometown] earlier this year because they could not afford to send them to school in Nairobi – he said they no longer visited him. I asked how he felt about this. He said he did not think about them too much because they did not want anything to do with him.

Nzambi's experience was similar to that of three other young male PWPD who were not *"strong"* or able to support their family – their wives appeared to prioritise care for their children over their husbands.

Several participants also described the 'traditional' taboos they had to negotiate which acted as barriers to PWPDs' care, where only certain people could take on specific roles – issues with intimate personal care between opposite sexes occur globally. Jenny explained that in her culture, her mother could not live with Jenny's husband but admitted, *"When such a*

thing [PD] happens, it's not important anymore". Several families described negotiating these *"old school"* traditions to make care work, despite unorthodox living arrangements. Jenny's sister, Yvonne, added: *"You cannot continue following those cultures when someone is suffering".* In contrast, several family members described the importance of adhering to traditions such as men not taking their mothers to the toilet or bathing them. Eunice also described not allowing her daughters to bathe or dress their father. In other families, certain roles were conditional on who was in the house at any time:

> *"There are things that you cannot do to your father when your mother is around. Because, if he wants to go help himself [use the toilet], he has a daughter, you can't if he [son] is around" (Constance, spouse of 70-year-old PWPD)*

Although women did take on more caring roles, there were still taboos around daughters carrying out intimate care for their fathers. A masseuse attended one of the support group meetings in Nairobi and discussed how PWPDs' core muscles needed to be massaged but also acknowledged that *"with cultural upbringing, your mind is so blocked on touching your naked father".* Similarly, in Tanzania, Obrist (2016) found that daughters were restricted from performing intimate tasks for their fathers, which she referred to as "avoidance rules".

Despite men tending to take on more passive or 'managerial' care roles, some, like Jasper, also appeared to be taking on physical care roles and negotiating gendered taboos around care:

> *"There's some things in my culture are taboo. For instance, taking her to the toilet…It would be easier, I guess, for a girl. But these are things that need to be done…As she says, 'God knows us, so don't worry'…We've sort of gotten into a routine…I put her on the toilet, she's able to undress herself and I get out and when she's done she calls me and I take her out" (Jasper, son of 78-year-old PWPD)*

Jasper, as an only child, had to take on these roles as they had no other options. Families with more care opportunities negotiated caring roles, cultural beliefs and taboos to fit around care requirements. Some beliefs were adhered to, more often if families had larger networks, while others were more flexible and conditional on who was available. However, it appeared that some men were taking on additional caring roles, although research on the roles of men as caregivers is lacking in SSA.

Female employment in Kenya has increased in recent years because of urbanisation and improvements in education. Many female participants, particularly in cities, described having responsibilities as wage earners and were increasingly becoming less able to physically care for older parents. For example, both Esther and Sarah worked full-time – they instead described providing financial care for their mothers or employing caregivers, creating a shift in the care resources and structures available. It seemed that gendered roles were being negotiated by families and care work was becoming more blurred and fluid in the face of increasing requirements and changing female employment patterns, illustrating the pragmatic decision making around care which could result in less conventional care structures.

6.3.2 Intergenerational roles and reciprocity in care

Participants explored their roles as caregivers and recipients of care, as well as the changing expectations of care for future generations. Several PWPD described not expecting their children to care for them in old age or sickness, rather, their children wanted to. However, it became clear that reciprocal care was ingrained in some families who had observed the care their grandparents had received from their parents, as well as the care they had received as children. Daughters and firstborn sons described feeling *"obliged"* to care for their parents or took on the role out of *"respect"*. As Jenny, the daughter of one 77-year-old PWPD described, *"We feel obliged. She did this [cared for them], we do this [care for her]".* Jenny and her sister also added that their own offspring *"should do the same for their parents"*, demonstrating how the idea of reciprocity was still being passed down through generations – as the sisters explained, their children needed to witness this care and learn. The obligation of adult children to care for their parents was evident in families of different socioeconomic status, both those who could afford care and paid for employed care, and those who had to physically care for their parents themselves or struggled financially. Many offspring explained that no one could ever provide the same standard of care as they could.

In other cases, adult offspring described how their parents had not anticipated needing care. Some PWPD received small pensions (usually civil servants) or owned their homes, which would have seen them through later life. However, the additional costs associated with a

condition like PD, including medicines, clinics and incontinence pads, became overwhelming for some who required extra help.

Although many adult children cared for their parents themselves, few also described relying more on formal employed care. The obligation to care was still there but for some wealthier, urban families care was changing form. Some adult offspring working and living in cities believed their parents could no longer *expect* the same physical care they might have given their own parents. Others suggested that the ability to care for their parents was changing because of changing material and financial circumstances:

> *"It's not reasonable to expect, like, your kids to support you in old age…They're like, 'Yeah, when you were a kid, I did this for you…So, now it's your turn to'. OK, a lot of us feel that obligation, but life is expensive now…People are living longer now, and you have kids who are struggling to get by in the city…They also have their own future to think about. So, then they have that added burden of now having to take care of you…I think it was just ingrained in us, we saw all the stuff they did for their parents. So, even if they don't say, you just feel like you need to do it. There's just a cultural thing…It's just like kind of an expectation" (Danny, son of 83-year-old PWPD)*

Although the *"obligation"* or *"expectation"* to care for parents was still present, families described how in reality, this was becoming more difficult. Despite this, the idea of care homes was seen as shameful; although they are largely private facilities and not an option for all but a minority. As one participant explained, older people would *"rather die than be sent to one of those places".* Jasper described his view of care homes:

> *"I think it is as it should be [that family care for older members]…Would I mind going into a home when I'm at that age…not at all…People that era, it's different. It's not even something that you'd suggest. It's like 'OK, you're throwing me away, OK, you're dumping me'. We do have old people's homes, but they're not very popular…sort of stigma associated with them. 'So, your kids dumped you here?"' (Jasper, son of 78-year-old PWPD)*

Wanjiku, the daughter of another PWPD summed up the idea of care homes in Kenya, explaining, *"well I haven't heard of anyone who's done it"* – care homes are still scarce and often, unaffordable.

The expectation of "reciprocity" (van der Geest, 2002a) is embedded in complex cultural and historical systems. However, literature suggests the ability of families to care for older

people is deteriorating (Apt, 2001; Aboderin, 2004b; van Der Geest, 2016). Among participants in Kenya, urban migration, 'Westernisation', economic challenges, shifting family networks, improved opportunities for education and increased female employment were described as contributing to unstable care resources and eroding opportunities for intergenerational care. However, reciprocal care still appeared to be expected and respected.

6.3.3 Community networks in care and returning 'home'

Participants in this study spoke of the historical role of the community in care and support for 'the sick' or older people in cities, but more so in villages:

> *"You know the best thing in rural Kenya…you are here in your house but my brother and his family are somewhere there, my sister is somewhere there, my grandmother…even the small kids…It helps, that community thing helps" (Esther, daughter of 78-year-old PWPD)*

Several participants explained how the community played a crucial role in maintaining social networks for PWPD, staving off loneliness, providing support and often for '*Harambee'*, a Kenyan tradition of fundraising which literally translates as 'all pull together'. As Tina described, *"We are in Kenya, when things are bad, we do fundraisers".* Although the community role was important and ensured PWPD were included in social gatherings, participants also highlighted the work it took to host visiting groups (friends, family and religious groups) in the home, which involved substantial tea-making in addition to care work.

Several family members also described how PWPDs' social networks had begun to dissolve as they could no longer uphold expected social roles, like attend weddings, church or visit friends at their homes. Consequently, some PWPD reported having fewer visits from friends and family and experiencing a *"shrunken"* social life. Some participants reported how the 'masked face' of PWPD often led visitors to believe they were not happy to see them; this was also identified by Stanley-Hermanns and Engebretson (2010) in their study exploring the experience of PWPD in the USA. Facial masking and the inability to 'communicate' resulted in society questioning PWPDs' intentions, contributing to feelings of isolation. For other PWPD, their social life situated around their extended family in the home:

7th August 2018

I took my shoes off as requested and entered the living room where five ladies were sitting on sofas around the room, all wearing 'deras', loose-fitting floor-length dresses, and head scarves. I was unsure whether they were there by chance or as support. Maryam, the PWPD, was 67-years-old and had 12 grandchildren. Maryam had divorced and remarried but her husband had recently died. Her three daughters and three of her grandchildren lived with her. Her friends stayed in the room for the duration of my time there. Other women kept arriving, kissing Maryam on the cheek and taking a seat wherever there was space. Her daughter explained that Maryam never went outside anymore and so, her social life took place in her home. Having several guests during the day was common.

As well as the community's role in visiting older people in their homes, participants often described the respect for older people in general where people would help if the family were struggling. This positive experience seemed to occur for older PWPD who received more respect as per traditional customs, because they were old. Wanjiku reported positive experiences while she was out with her father:

"People will just think he [PWPD] is old. And in this part of the world, people have respect for older people…If you're driving the wheelchair, you'll find someone coming to help you…nobody will come out and you know, say, or point" (Wanjiku, daughter of 71-year-old PWPD)

On the other hand, for younger PWPD and those with more obvious, serious, outward symptoms, participants reported people in the community avoiding or judging them.

Participants living in cities reported trying to maintain ties with their villages and return 'home' as often as possible. The strength and support of the community in villages was one of the reasons some PWPD wanted to move back, although others acknowledged the changes happening to 'rural life'. As Gloria described, *"In my village, all the women who are there of my age, they are all dead…all these people have gone".* Several participants acknowledged the reduced number of people living in villages, with older people dying and younger people moving to 'the city'. Reduced income generating and care opportunities because of migration and economic challenges resulted in issues with PWPD being able to return to rural life. Danny explained the situation in his ancestral village in Western Kenya:

"Nowadays, it's not like before where you go to the village and there's tons of people…there's a lot of urban migration…a lot of people have their roots there, but they don't live there anymore…There's almost no one there…The older people have…passed away. Because before, like a lot of those kids never used to go to school, now everyone goes to school. Younger people…what are you sitting around in the village doing. Probably makes more sense to go and get a job…If you stay in the village, how are you going to support them [parents]. A lot of them [children] left to go find work in the city and send money back…Sometimes there's a relative who's there and they just send money for food and sustenance…I think that's the new dynamic…it's happening all over Kenya" (Danny, son of 83-year-old PWPD)

Extended, multigenerational families situated within large close-knit communities are, or used to be, the norm in rural Kenya, providing social capital and large care opportunities for older people (Cattell, 1993). However, these networks are shifting (Aboderin and Hoffman, 2015). Factors such as urban migration, older people dying, and the push for children to go to school instead of staying at home appeared to be influencing the community networks and multigenerational family structures that once existed. This in turn influenced the potential care for PWPD in rural areas and resulted in many either staying in the city closer to care or moving to the city with adult offspring to be near biomedical services, as discussed in Section 6.1.2.

6.4 Discussion

"Personhood", interdependence, and the burden of care

As symptoms progressed, PWPD became less able to engage in activities, communicate, venture outside or do tasks for themselves; affecting their sense of 'self'. PWPD often became completely dependent on others for care – although developed from "Western" societies, Scheper-Hughes and Lock (1987) suggested that social disharmony can occur around the body in sickness, while increased dependence also affects caregivers. The first of two issues this chapter raises concerns the impact of disease on PWPDs' "personhood" (Lamb, 2014; Degnen, 2018) and interdependence, and how families made changes to their lives to preserve PWPDs' autonomy.

Comaroff and Comaroff (2001) suggest that among the Tswana in South Africa, "personhood" is intrinsically socially constructed whereby people are known in relation to

others. Degnen (2018) also argues that the personhood category is constructed through social relations. It is not only how people perceive themselves but how a person is treated by others that informs how they are positioned in society. PWPD in this study maintained or preserved personhood through family ties and connections they had formed over their lives – being able to adapt was dependent on "social capital" or connections and "economic capital" or financial resources (Bourdieu, 1986).

Whyte (2012) has also described, in the context of HIV in Uganda, the importance of sociality, kinship and friendship in enabling people to control their condition and manage everyday life. Chapter Four described the importance of older people in Kenya being amongst kin and *partly* dependent on their assistance; what Whyte (2017) and McIntosh (2017) refer to as "desired interdependence" in later life. Elder (1994) also discussed the idea of "linked lives" or "interdependent lives" that people create across the life course – the lives of PWPD in my sample were intertwined with their families, particularly as their condition progressed. However, PWPD in this study also experienced an accelerated trajectory towards *complete* dependence, which became problematic for many. This loss of interdependence caused by the progressive nature of PD resulted in challenges for families regarding care, and the ability to ensure PWPD could maintain personhood for as long as possible.

PD appeared to not only affect PWPD themselves (in terms of symptoms) and a changing 'self' (Charmaz, 1983) but also their relationships and roles within the family, community and society. Progressing symptoms resulted in PWPD falling, forgetting, and becoming isolated and lonely. Advanced symptoms resulted in some no longer being able to communicate and Harris (1989) suggests that without language, people cannot participate in social discourse and so, are not conceptualised as persons. Several PWPD were also described as having a "masked face" (indicating no emotion), they could not shake someone's hand (customary tradition), eat *ugali*, go to the toilet alone and could no longer socialise or attend events. This disengagement with society and *"erosion of personhood"* (Luborsky, 1994, p. 240) resulted in exclusion for many and contributed to what Taylor (2008) refers to as "social death".

Furthermore, several PWPD experienced stigma both in the home and in society because of their *"strange"* appearances and consequently, were denied opportunities to participate in

the community. In Tanzania, Obrist (2016) describes how older people continued to engage in activities through having visitors who kept them up to date with events. For PWPD in my sample, not being able to engage with their community affected their external agency and ability to maintain personhood through social relations. PWPD themselves also described feelings of embarrassment because of their symptoms, an experience identified by Nijhof (1995) among PWPD in the Netherlands. These judgements and perceptions (by self and others) contributed to further social exclusion and isolation for some, especially when PWPD could not explain the cause of their condition or people did not understand; reiterating the importance of 'naming' disease discussed in Chapter Four.

Family members in Kenya described different ways of providing PWPD with emotional support, reinforcing personhood. In contrast, PWPD without adequate social support instead reported withdrawing from social situations, affecting social identity – Luborsky (1994) suggests that withdrawal is one strategy to maintain an identity critical to personhood. In Canada, Roger and Medved (2010) found that PWPD and caregivers established "cooperative identities" rather than "autonomous realities" where their daily lives were intertwined in order for PWPD to maintain a sense of personhood. Although developed in a very different context, as described, the symptoms of PD are comparable globally; similarities may exist in the role of families in care. The reluctance of PWPD in my sample to be completely dependent on others for care calls into question the revered idea of "desired interdependence" (McIntosh, 2017) among older PWPD who could no longer engage with or contribute to the family or community.

Family was the main source of care and support in this study, despite shifts in practices around reciprocity, community networks and care. However, many families described the overwhelming and financially devastating care requirements of PD, which appeared to result in significant emotional suffering, isolation and stress for some. The care PWPD received was thought to have gone above and beyond the expected care requirements of older people (without a chronic, degenerative disease), requiring more input from additional family, more pooling of resources and fluid care arrangements. This raises issues when thinking about the epidemiological transition occurring in SSA, the increase in chronic disease associated with later life and the burden of care that older people may require for longer. In Botswana, Livingston (2003) described how elderly women no longer had the socio-economic power

they used to as chronic illness became part of “normal” old age. Livingston (2003, p. 207) suggests that an increasing emergence of chronic disease among older people has resulted in changes to *“socio-cultural norms around care, money and work”* where older people must negotiate old age as a new, dynamic “bio-social state”.

The reduced ability to care for older people with chronic disease or the overwhelming nature of care requirements participants described could be a result of several factors, including the new “bio-social state” to which Livingston refers. Firstly, Lamb (2014) suggests that as societies (India in this case) become more “developed” they may adopt “Western” ideals which place an emphasis on independence in later life instead of interdependence and reciprocity; several participants in Kenya described struggling to care for their children and parents. Secondly, biosciences and medicine continue to suggest potential cures for terminal illnesses in order to prolong life and have succeeded in improving life expectancy (although often added years are not disability-free); life expectancy in SSA is increasing faster than anywhere in the world but people are living for longer with more disease. Thirdly, an increase in the incidence of diseases associated with later life, such as PD, have contributed to additional years of increased dependency where older people may require more intense care for longer, calling on more social and financial support. Fourthly, modernisation, urban migration, increased education and literacy levels have resulted in younger generations moving to cities and older people being ‘left behind’ with fewer care opportunities, while more women, who usually do care work, are engaging in paid formal work. Participants in this study described how “desired interdependence” was disappearing and a combination of these factors made it more difficult to care for older PWPD, although they still did.

Lamb (2013), drawing on ethnographic research from India on old-age security, suggests that as countries develop, older people will increasingly rely on the state, market or self for care rather than family. For PWPD in my sample, connections and social resources enabled care and ensured they maintained facets of “personhood”. However, some connections were precarious or non-existent because of changing kinship networks, shifting places of care, the burden of care work, as well as the lack of independence, choice and as a result, agency that PWPD had over their lives, while other connections appeared very strong.

Intergenerational care and "reciprocity"

This chapter also raises issues around care and "reciprocity". Regardless of their resources, family members often described their "*obligation"*, *"responsibility"* and "*duty*" to care for their parent, spouse or sibling with PD, while the expectation of adult offspring to reciprocate the care they received as children seemed to be ingrained in families. As (Aboderin, 2004b, p. 131) quoted from her three-generational study in urban Ghana on the material support available for older people: *"If your parents look after you when you are growing your teeth, you must also look after them when they are losing their teeth".* Most participants in Kenya described drawing on kinship networks and resources in order to negotiate PWPDs' care needs – care structures were interconnected. However, some families described being less able to care (physically and financially) as care requirements increased, which appeared to put a strain on the deep-rooted expectation of "reciprocity" (Aboderin, 2004b; van Der Geest, 2016); care structures appeared to be becoming more fluid as a result.

Several adult offspring described difficulties providing indefinite, complex care to a standard they thought PWPD deserved, and suggested that their parents could no longer expect the same physical care older people received in the past – care work was becoming more difficult to negotiate and appeared to change form for some. Some offspring provided financial care or employed formal caregivers, although still upholding their expectation. In urban Ghana, Aboderin (2004b) identified the changes in support available for older generations caused in part by an increased focus on nuclear families, dwindling resources and decreased help from extended families and communities. In India, Lamb (2013) found that the growth of nuclear families, migration of children and improvements in gender equality resulted in uncertainty surrounding reciprocity. Although Apt (2001) suggests that the change in the ability of families to care for older people is due to urbanisation and the perception of older people as a 'burden', Aboderin (2004a) posits it is more the decline in resource capacity and increased costs of living combined with changes in societal values. It is not that families do not want to care for older people, rather they are less able to. In rural Kenya, Cattell (2008) found similar situations where families had to choose between caring for parents or sending children to school. A reluctance to care for older PWPD was not

apparent among participants in Kenya (except for younger PWPD whose families had left them), care work was just becoming more difficult.

Participants also described the changes occurring in rural communities where there was *"almost no one there",* resulting in reduced care networks for those who remained. The decline in support for older people in rural villages has been observed elsewhere in Kenya (Cattell, 2008), Ghana (van der Geest, 2002a) and Botswana (Dintwat, 2010). Adult offspring in my sample described how they would send monetary remittances to their parents in villages. Similarly, in Ghana, Aboderin (2004b) found that adult offspring were increasingly migrating to cities, leaving parents with less support. van der Geest (2002a) also identified the increasing act of "care from a distance" in Ghana by adult offspring. In coastal Tanzania, Obrist (2016) refers to "kin-based carescapes" where kin provided care from a distance, including: monetary contributions, advice, material help or medication as was observed in Kenya. This financial mechanism of care was more absent than the physical care enacted by those living with PWPD, although Livingston (2003) suggests financial contributions to care can affirm connections between people. However, what became clear from several participants was that PWPD were being moved to cities to live with and be cared for by their adult offspring. Obrist (2016) identified similar situations in Tanzania where older women moved to live in cities, often without any consultation or choice. Other offspring employed caregivers in the house; a very different approach to the 'traditional' community care received in villages in the past and a change some PWPD were reluctant to accept. Many families in Kenya seemed to be making pragmatic decisions to make care work in the face of societal change.

Younger PWPD in this study required care at a point in their life course that led to significant disruption. Oppong (2006) suggests that it is the "maturity" and "wisdom" accumulated over one's life that is revered in many African countries rather than old age. In return for a life of raising generations, providing and caring, older people are respected and cared for; younger people had not yet reached this stage in life. They instead described having to negotiate care for their children and maintain a livelihood, while negotiating their own care – the parents of this generation would have required care themselves. However, Gideon (33-years), for example, moved to live with his mother in rural Kenya for a period when he was struggling with his symptoms, leaving his wife and young children in Nairobi. Other young-onset PWPD

described not having this opportunity for care. Research in SSA is lacking regarding the experience of working-age adults living with chronic disease who require care. There are examples of older people caring for their adult children with HIV/AIDS, although the conditions are not comparable.

The perceived challenges of families to care for older PWPD in this study could be explained by two theories: a) modernisation and ageing theory, and b) political economy perspectives (material constraints argument) (Aboderin, 2004a). Modernisation theory draws on the weakening of filial obligations and extended families, suggesting an unwillingness of families to care for older people as society "develops" (as was experienced through industrialisation in HICs) (Aboderin, 2004b). However, what I observed in Kenya was that although families were also focusing on care for their own children, they still felt obliged to care for their parents. Yet, this was becoming difficult, often resulting in significant worry, stress and isolation, and frequently taking on different forms. The material constraints argument (Aboderin, 2006) highlights the increasing hardship faced by people in developing countries as the cause of the perceived decline in family support. Participants discussed the constraints in care provision they experienced, including financial constraints, but also time constraints. However, families may have been more willing, or felt more responsible, to care because of PWPDs' condition but also because many simply had no alternative for care – neither theory alone can describe the changes occurring in Kenya and SSA with regards to urbanisation, demographic change and the care available for older people. Furthermore, most participants lived in cities; PWPD living in rural villages could have different experiences of care.

6.5 Chapter summary

Parkinson's disease resulted in significant challenges for PWPD, as they came to terms with progressing symptoms, increasing dependence, shifting relationships and stigma, but also for family members who often struggled with the substantial financial and emotional burden of their caregiving role. Care work was becoming more difficult, and families negotiated social change and their expectation to reciprocate the care they received from their parents. The following chapter (Chapter Seven) explores the progression of PD and how participants

navigated complex care for PWPD with limited information and social support through to the end of life.

Chapter 7. End-of-life care

Chapter overview

This chapter presents an analysis of family members' experiences of end-of-life care. Five narratives are presented which encompass three main themes. Firstly, I explore the reluctance to talk about death and dying and the hope and denial surrounding the end of life. Secondly, I discuss the idea of "good" and "bad" deaths (van der Geest, 2004b; Howarth, 2007) and how resources, kinship networks and place influence this. Finally, I look at how people come together around death and the continued "sociality" enacted by family members after PWPDs' death (Marsland, 2012; Whyte, 2014).

The first palliative care hospice in Kenya was opened in Nairobi in 1990 and there have since been minimal improvements in both the number of hospices and awareness of palliative care (Ali, 2016). Kenya Hospices and Palliative Care Association work on establishing hospices and training staff in Kenya – Hospice Care Kenya (2020) has identified 30 hospices and palliative care units across the country, although all have a focus on cancer (similar to the UK). The week before death was estimated to cost up to 200,000Ksh (£1,500) in a private hospital while government hospitals had no palliative care facilities. As a result, end-of-life care largely fell on families as hospitals were unaffordable for the majority. Therefore, the ideas discussed in this chapter are situated within the context of scarce and inaccessible palliative care services.

This chapter is prefaced with Esther's account of her mother, Leah's, end-of-life care. Her narrative encompasses several themes and issues that arose among the experiences of other participants. Leah died in hospital and Esther could afford this care; although, Leah did have health insurance[24]. End-of-life care in institutional spaces was something most could not afford. Leah's story illustrates the complexities of comorbidities (in Leah's case, cancer) towards the end of life in addition to PD.

[24] Only five PWPD in this study, all of a relatively high socioeconomic status, had private health insurance schemes in Kenya or abroad.

Narrative 19: Leah

I met Esther exactly one year after I had first interviewed her. When we last met, Esther told me about Leah's quest for a diagnosis. This time, Esther discussed Leah's death and their experience of end-of-life care. Leah had been experiencing bouts of pneumonia where she was admitted to their local hospital, treated and discharged several times. At the same time, she had been vomiting after eating. Esther described how the hospital had reprimanded Esther and her family, blaming them for not looking after Leah. She explained, *"The doctors…they were very cross with us, 'How come you guys when she's here [hospital] she's well, when she goes home, she is sick"'.* Esther said she attributed Leah's worsening symptoms to her PD progressing, although she realised the medication Leah was taking must not have been effective because she was constantly vomiting. She explained Leah was *"just bones".*

Leah underwent further tests in hospital in rural Kenya where they discovered she had oesophageal cancer. However, Esther described how the doctors would not tell her or her family about the cancer, explaining, *"They go around in circles, Kenyan style…The doctors can't tell you straight".* Esther also suspected that Leah had not been given her PD medication while she was in hospital. She explained, *"Now, the symptoms came, she became very weak, skinny, the face changed, it became like a mask…She wasn't sure she was in hospital or in the house".* Esther explained that they had to counsel people before they visited Leah because of the shock of her appearance. She continued, *"She's reading your face. Mercifully, she never saw a mirror. If she had seen how she looked, she would just have died sooner than that. So, it was horrific…It was literally starvation".* Esther said she was unsure whether Leah knew she had cancer. She added that she thought the doctors had done well considering the circumstances and she believed they were doing palliative care, although they may not have said it. Leah's church group prayed for Leah every day.

Esther explained the doctors would *"skirt around the issue"* of chemotherapy while Leah was in hospital, suggesting she was too weak and did not tell the family that Leah was going to die. Esther explained, *"At some point I just wanted to ask him [doctor], 'Just blurt it out"'.* Esther suggested that doctors do not talk about death and avoid telling the family that death might be imminent, suggesting, *"The about-to-die thing, death, after, it's just not talked about".* Esther explained, *"You can't deliver bad news to Kenyans just like that…you start a long story".* She added that doctors would rarely suggest that the end of life was near and even if they did, no one would believe them: "*In fact, they will just move to another doctor".* Esther also did not tell Leah's husband that she had cancer, explaining, *"You don't tell old people things".* Esther said people had suggested taking Leah to India for treatment, but she added, *"For what. What's the point? Where do I go getting loans for millions of shillings? Then I have to even wonder how to bring her back as cargo".* She laughed as she said this.

Esther said that Leah died over night in hospital, *"One day we went, and she was gone. It was as simple as that".* She explained that it was *"horrific"* to watch her mother suffer with PD and cancer. She explained that the hospital called her sister in the morning and told her that Leah was *"very sick"* but had not disclosed that she had died over the phone. Esther explained, *"No one knows how she died, no one told us. We just went in the morning we were told, 'Oh, she went to the mortuary"'.* She added that she was grateful the hospital had called them, she added, *"Other hospitals…you just go find an empty bed".* She added, *"In Kenya I've learnt, when the doctor tells you your patient died at 5am, it means anything from 10pm because nobody found her. So, they find her at 5am…And they don't even know themselves why she passed away".*

Esther described not taking much interest in Leah's death certificate because she was overwhelmed with funeral preparations. She explained that death certificates came from the government, not the hospital: *"When you die, it's sensitive who has your ID…You look like you want to get an advantage or something…You give the ID to get the death certificate…those documents become very important. So, if you start snooping around them, 'Ah, why are you interested?"'.* In addition, Esther explained that if she did *"too much"* to Leah's grave people would suggest that she would join the dead. If Leah had been cremated, which is becoming more common, Esther said that *"no one will carry your ash".* She explained that people who cremated bodies had ulterior motives such as *"getting rid of the body"* so there was no DNA for a potential mistress and their children to demand inheritance. She also suggested people might feel uncomfortable keeping ashes in the home; adding *"what if they morph into ghosts"*.

Esther explained that their community had been very supportive: *"The funeral had like 2,000 people".* Leah had taken out health insurance at a young age. Esther suggested she was ahead of her time and joined various circles: *"You hear something, 'poof' she's joined".* Leah's insurance covered most of her hospital and funeral costs, which Esther was very grateful for. She added: *"In other families, what they do, they discharge you. You just die. It's either you die, or you're all burnt out. So, we had that luxury of keeping her in the hospital".* Esther explained that her family had prepared themselves for Leah's death because they knew she was *"chronically sick".* Esther said her father was upset at first because Leah was his 'eyes' (he was blind) but had come to terms with her not being there; she explained, *"Life moved on".* After our interview, Esther confirmed that Leah's death certificate did not mention PD.

Leah's experience of end-of-life care, as narrated by her daughter, is of course unique. However, it illustrates some themes common to the experiences of other research participants that I develop in this chapter. First, there is a deliberate avoidance of discussing

death or acknowledging its inevitability – a complex interweaving of hope and denial that characterised several end-of-life experiences. Esther said her family had prepared themselves emotionally for Leah's death (something other families were not able to do), although her church group were still praying for her recovery. Second, there is a strong concern about the way that dying happens, as well as the aftermath – a theme I explore in the second part of this chapter on "good" and "bad" deaths. Both happen in a context where institutional end-of-life care is limited and even basic concepts like receiving medication on time can be challenging (incidentally, this has also been reported in HICs (Parkinson's UK, 2019b)). Like many other PWPD, Leah's final months were also made more difficult by comorbidity.

7.1 Hope and denial at the end of life

Hope of a miracle recovery through faith, prayer or a new treatment option was important for family members; however, it could also make death more shocking when it came. Doctors described their reluctance to discuss prognosis as seen in Chapter Five, while family members experienced doctors' avoidance of death-talk. The narratives in this section illustrate the consequences of this for end-of-life care.

Previous chapters have described the hope and faith participants had in recovery despite the progression of disease. Tina, the wife of Steven, a PWPD who had died eight years ago at the age of 58, explained that while Steven was alive, she still hoped and prayed that he might recover despite knowing that PD was *"just maintenance"* and could not be cured by biomedicine:

> *"In fact, I thought he would get a miracle, because I had even some preachers who were coming to pray for him. Yah. I was expecting a miracle from God'' (Tina, spouse of deceased PWPD)*

Tina's daughter, Amina, had a similar hope, explaining: *"I used to dream of maybe one day I'll come and just find him [Steven] walking around".* Hope was an important tool that kept participants optimistic about the future but also in denial about the possibility of death. Amina described how she vividly recalled the day her father, Steven, died and this was 'unexpected' after 20 years of living with PD:

"I even remember the spot where I was standing…I'm looking at him [brother] and that's when he tells me, 'You know what, dad passed away today'. I can't, I've never forgotten because it was, you know, there are those things you'd expect but that one came, I think it just hit me so hard, I screamed" (Amina, daughter of deceased PWPD)

Amina described the shock of her father dying, despite knowing he was close to the end of his life, illustrating the power of hope and denial around death. Similarly, other participants described not thinking about the possibility of PWPD dying. As the daughter of Fatma (55-years) suggested when I queried about her mother's future needs: *"I haven't thought about that; she's going to get better"*.

The power of hope was described from the perspective of family members but also became apparent through the narratives of participants' interactions with healthcare professionals. Participants described the reluctance of doctors to admit the possibility of PWPD nearing the end of life. In *Narrative 19* Esther described the uncertainty surrounding Leah's worsening condition and cancer diagnosis which the doctors were reluctant to disclose, skirting around the certainty of death. Harris *et al.* (2003) experienced a similar issue in Tanzania with regards to cancer diagnosis and prognosis. They refer to the 'skirting around' as a "roundabout" approach ('*mzunguko'* in Kiswahili) which allowed doctors to gauge how well information about prognosis would be received to avoid older patients giving up hope. Several other participants in Kenya described a similar practice by doctors, as was illustrated by neurologists in Chapters Four and Five. Anya experienced the reluctance of healthcare professionals to discuss death and dying when her husband, Amit, was admitted to a private hospital in Nairobi after his third bout of pneumonia. Amit was 76-years-old and had lived with PD for 17 years.

Narrative 20: Amit

Anya described how Amit had experienced difficulties swallowing and would accidentally inhale his food and need to cough. Within one month, Amit was admitted to a private hospital twice with pneumonia, was treated and discharged after one week's stay. Anya added, *"The doctors still don't go deep, deep down that this will be really, really bad for him. They say you have to be careful, but they still don't put that panic in you".*

Amit was admitted again with pneumonia and stayed in a private hospital for ten days. Anya explained, *"Last time seven days he was better…I didn't expect that he*

won't recover". Anya said she had wanted to move her car from the hospital car park and told the nurse she would be back in ten minutes. She said the nurse tried to stop her from going: *"She's telling me, 'Wait, wait, wait. Don't go'. She's not warning me".* Anya continued, *"It didn't occur to me that he would be gone when I come. He's there and then suddenly he's taking his last breaths".* Anya said she was not ready for her husband to die but she was glad to be with him. Anya expressed her anger that the doctors did not warn her how serious pneumonia could be. She explained: *"I do agree, some people can't take it…but after having him for 16 years with Parkinson's, 17th year, I think we were ready for more…You are hardened"*. Amit's death certificate included 'respiratory failure, septicaemia due to aspiration, pneumonia due to severe advanced Parkinson's disease'.

Anya described her frustration that the doctors did not disclose the severity of Amit's condition. She described wanting to know as she thought it may have allowed her to better prepare herself for his death, which Anya believed happened too soon. However, Dr H, a palliative care specialist in a private hospital, explained that talking about death and dying was *"taboo"* and doctors tended not to discuss death – it was seen as a failure or giving up, antithetical to the power of hope many participants hung on to. As Julian described: *"When you go to see a sick person, you'll rarely discuss their health; you'll just go there and encourage them".* The power of hope and encouragement for people throughout their journeys, but particularly at the end of life, became clear. The avoidance of death talk raises issues when thinking about chronic conditions like PD that are progressive and for which death is an eventuality. However, as Esther suggested, even if doctors did suggest that a patient was dying, the family may not believe them, illustrating the duality around the idea of talking about, and preparing for, death.

Not talking about dying and the apparent inappropriateness of asking too many questions surrounding someone's death or discussing their deteriorating health made it difficult to talk to family members about the end of life. Many were not aware of the particulars surrounding PWPDs' deaths, especially if they were not there at the time. As Christine (55-years) described about someone she knew: *"We were just called that she's dead. When you are just called, it's very hard to ask those people".* Downing *et al.* (2014) also found that death was not discussed among Kenyans in their survey on preferences for end-of-life care. Furthermore, death seemed to be a sensitive subject and something several people did not

want to discuss or delve into for fear of being seen as trying to gain something. The following section explores family members' recollections around the end of life.

7.2 "Good" and "bad" deaths

This section explores ideas around the different characteristics that appeared to contribute to "good" and "bad" deaths (van der Geest, 2004b). Aspects such as family resources, connections, place of death (home, hospice or hospital), hope and denial and the ability to say goodbye seemed to influence death among participants. On researching old age in Ghana, van der Geest found that those who made peace with people before their death, died in a peaceful manner, naturally, at home and whose death was accepted by family experienced a "good" death. However, he argues that categories of death are not fixed and are liable to ambiguity. Medical, social and financial components contributed to the rationality behind end-of-life decision making.

Jenny and Yvonne's mother was still alive but bed-bound, incontinent and refused to take medication. The sisters described having the time, financial resources and support from their own families to care for their mother at home, explaining: *"She is our mother; we felt it was an obligation…Nobody can do better than us".* However, their mother had developed bedsores and her increasing care requirements had made care more challenging – the wound specialist they required also brought additional costs. Despite this, the sisters described being glad they could pray and sing to their mother, which they believed made her happy. Gloria was 76-years-old and had been living with PD for over nine years. She described how she would want to be cared for at home, explaining: *"People had even been saying when you go to the hospital you are given medicine to kill you, people they don't want people to go to the hospital to disturb nurses there";* suggesting that end-of-life care in an institution may be associated with a "bad" death.

Tina looked after her husband, Steven, in their home until the day he died. Steven had lived with PD for 20 years and was bed-bound towards the end of his life. The following narrative describes Steven's "good" home death from the perspective of his wife.

Narrative 21: Steven

Tina explained that she had made sure Steven did not suffer and was kept comfortable throughout his PD journey. She described having to blend his food and feed him; he struggled to chew and swallow. She also described having to bathe Steven and lift him up onto the sofa so that she could make the bed. Tina also took him out in his wheelchair or moved him to his seat in the lounge; she showed me the plastic sheets she had put under the cushion for him. It was still *"his chair".*

One day, Tina said she had fed and cleaned Steven and left him to rest in bed but added, *"When I came back, he was not there".* Tina explained, *"You know, Parkinson's you will not know, the day you die you will just keep quiet".* She added that he did not say goodbye to her. Tina thought he may have gone unconscious but explained that when she called a neighbour to check, they confirmed he was *"gone"*. Tina explained, *"He looked happy even on his death bed…He looked happy because he knew somebody took care of him".* Tina smiled as she said this.

Tina described being very proud of the care she provided for her husband and happy that she was able to care for him. Steven had died peacefully in his sleep after he had been fed and cleaned without any medical intervention. Although Tina did not label Steven's death "good", van der Geest (2004b) found that to die peacefully and naturally was crucial to a "good" death in Ghana. Tina described that she *"gave all the service all the years"* and was happy that Steven *"died a happy man".*

In contrast, Nzambi's experience of end-of-life care within the home, without social and financial resources, was very different. Nzambi was 59-years-old, almost the same age as Steven, and had been living with PD for 16 years. His family had left him, although he had a sister who he sometimes saw.

Narrative 22: Nzambi

At the last support group meeting I attended in December (2018), Nzambi had lost his mobile phone again and asked me to save his sister's phone number in case I needed to contact him. Nzambi said he enjoyed the meetings and would continue attending. I returned to Nairobi in May (2019), five months after I had last seen Nzambi. On visiting the government neurology clinic, one of the information officers, with whom Nzambi had become well acquainted, asked whether I had seen him. She added that he was not well and had come to the clinic but could not afford the consultation fee and so, was sent away without being seen and given another appointment date. He had also not been attending the support group meetings. The information officer reiterated how sick Nzambi looked when he was last at the clinic.

> Concerned, I rang his phone number, but the call did not go through. I called his sister, remembering Nzambi had given me her number. She answered and seemed very confused about who I was. Eventually, she said that Nzambi had died last month. She explained that he was at home and had asked a friend to go and get him a fizzy drink. The friend brought the drink to Nzambi but said he did not drink it. Then, she said, he just died. I did not press for more details. I informed the support group in Nairobi about Nzambi's death and at the next meeting, we held a minute's silence for him and three other PWPD who had died in the past few months. The 'friend' Nzambi said he had made at one of the meetings expressed how sorry he was and recalled how he had spent one of the meetings with Nzambi and walked him to the bus stop.

Nzambi's story illustrates the crucial role of both family support and money in care for a long-term, chronic disease like PD. Nzambi could not afford a £5 fee to attend the neurology clinic, let alone be admitted to hospital if he was unwell and consequently, died at home unexpectedly. Nzambi had also died alone, relatively young and without his children who had left with his ex-wife; aspects considered to contribute to a "bad" death (van der Geest, 2004b). However, Nzambi was mourned and remembered by the PSG where he had become part of the community; the importance of this is discussed in the following section.

PWPD with more social, educational and financial resources were in a better position to receive care from kin networks but also to be cared for in hospital. Mary was 73-years-old when she died and had been living with PD for 14 years. In the following narrative, Mary's daughter, Jessica, describes the care her mother received in the last few months of her life, which was largely spent between private hospitals and a hospice, something not many families could afford.

> *Narrative 23: Mary*
>
> Mary lived in central Kenya with her husband but experienced ill health as she grew older; she suffered from hypertension, asthma, arthritis as well as PD. After ten years of living with PD, Mary moved to live with Jessica in Nairobi, closer to the services she needed. Mary had become increasingly *"unstable"* and required someone to be with her all the time. Mary's husband still lived in central Kenya, but Jessica said he would visit weekly. Jessica explained that she and her husband decided to *"adopt"* Mary and look after her in their home, adding that it was *"old school"* not to live with one's

mother-in-law[25]. Mary had become bedridden and Jessica and her siblings hired a caregiver to look after Mary all day and had a duty roster for her care at night.

Mary increasingly required more care and eventually had two nurses looking after her, which cost 140,000Ksh per month (£1,000). Jessica said Mary was *"in and out of hospital"* constantly and added how difficult it was to look after her at home. Eventually, doctors decided that Mary required palliative care. Jessica added that her family's resources had *"gone, gone, gone".* Mary spent two months in a private room in hospital. She was unable to swallow, and her PD medication had to be crushed. Jessica added that the nurses would not give Mary's medication on time; they could not keep up with her drug regime. Jessica felt that her mother was not being cared for in hospital and she was moved to a hospice. Jessica added, *"Resources were now finished".* After three weeks in the hospice, Jessica said the staff called to say Mary was ill; Jessica found out that she had died already when they called.

Jessica explained that Mary's last four months of life cost 1.7 million shillings (£13,000). Although, she added that Mary was well looked after in the hospice. Jessica explained that she would have preferred that Mary was cared for at home but could not manage this. PD was not included on Mary's death certificate, but Jessica added that she had destroyed all her mother's records after she died because they were of no use.

Jessica could not care for Mary herself because she needed to continue working to afford her mother's care requirements. In contrast to Tina who cared for Steven at home, Jessica and her siblings employed nurses and paid for Mary's institutional care. Her narrative illustrates the huge costs of palliative care in both hospitals and hospices but also the cost of formal care in the home. Mary's family spent all their resources on her end-of-life care, which required significant medical intervention. Jessica described the importance of Mary being pain free and comfortable at the end of life, aspects that contribute to a "good" death, despite undergoing medical intervention and not being at home or surrounded by family. This illustrates the ambiguity around categories of death as suggested by van der Geest (2004b). In contrast to Leah who had taken out several insurance plans, Jessica had to pay for all of Mary's care but was reassured she was well looked after.

[25] Several families described the "taboo" of an older woman living with her son-in-law (discussed in Chapter Six). In patriarchal societies, it is the norm for older adults to be supported by sons and cared for by daughters-in-law (Bongaarts and Zimmer, 2002). Lamb (2013) identified similar findings in India.

Downing *et al.* (2014), exploring peoples' preferences for end-of-life care in Kenya using a street survey, found that home was the most preferred place of death. However, almost a quarter of the sample included identified home as the least preferred place of death, opting for hospital care instead, illustrating the difficulties determining where a "good" and "bad" death should take place. Dr H suggested that families often wanted their family member to be admitted to hospital in the hope that doctors might be able to save them, which created hope - similar to what Prince (2018) observed in Kenya among children with cancer. Dr H described trying to discharge patients for end-of-life care at home to reduce the financial burden. Furthermore, Jessica described the difficulties getting Mary's medication on time in hospital, just as Leah experienced. Parkinson's UK started a campaign called "Get It On Time" to try and improve medication management for PWPD in hospital. In high-income countries, PWPD with dysphagia (swallowing problems) are given Rotigotine (dopamine agonist) patches (Hirano *et al.*, 2015) or drugs are administered through a tube. However, this was not reported among participants in Kenya.

In contrast to Esther, who was satisfied with the end-of-life care Leah received in hospital, Benjamin (80-years) was taken to India for treatment. Benjamin had been living with PD for 16 years and his family had the social and financial resources for him to travel abroad, which is where he discovered that he had cancer. Benjamin returned home to Nairobi and died two weeks later. His family described trying to rush him to hospital when he became very ill, but he did not make it; they chose to take him to hospital rather than letting him die at home. Similarly, Jared's family noticed a deterioration in his health and took him to hospital for further costly tests and scans. Doctors determined he had tuberculosis – he died the next day in hospital.

The complexities surrounding the end of life for PWPD resulted in shifting spaces and places of care as symptoms and requirements progressed. Families appeared to negotiate their resources and connections to provide care in whatever way they thought best whilst also navigating the biomedical landscape, which did not cater to palliative care needs or those with advanced PD. The end of life experience varied significantly between families, illustrating the ambiguity and challenges with achieving aspects thought to contribute to a "good" death. Steven and Nzambi's deaths both occurred at home but under very different

circumstances, while Mary experienced a pain free death in a hospice – in this case, medical intervention enabled her to die peacefully.

7.3 Life after death

Participants described how they mourned the loss of their family member and struggled financially after their death. This section also explores how people came together around death and continued to help other PWPD through the support groups by sharing their experiences, donating medicines and equipment, continuing to advocate for PD but also attending funerals and mourning.

All family members described the significant emotional trauma of losing someone close to them. Spouses and adult offspring described having invested all their time into care and treatment, learning all they could and sharing their PD journey with them. Some family members described being aware that PWPD were close to the end of life while others described the unexpected nature of their death. Esther suggested that her family had *"prepared"* themselves for Leah's death; she was 'old' and had been living with PD for ten years. In contrast, Anya expected her husband to recover and was not prepared for his death. However, all participants described their grief, whether they expected it or not.

Although some family members were able to talk about PWPDs' death after having come to terms with the event, others took longer to process their loss:

> *29th August 2019*
>
> I spoke to Jessica on the phone this morning (August 2018). She informed me that her mother, Mary, had died earlier in the year and she was still very upset about it. She agreed to speak to me in the afternoon over the phone. When I rang Jessica, she did not pick up. An hour later, I received a call from her apologising. She explained, *"I realised I wasn't ready to talk about it".* I apologised for bringing up her mother's death so soon and said she could contact me whenever she was ready, if she wanted to. She responded, *"Thank you for being so understanding".*

What became clear from Jessica's experience (once we met several months later) and other family members was the clarity with which they recalled certain aspects of PWPDs' end of life, even years later. As illustrated in Section 7.1, Amina described how vividly she recalled the day her father, Steven, died.

Tina, Amina's mother, described how lonely she felt after Steven died. Although he could not speak towards the end of his life, Tina felt that he kept her company:

> *"You need a partner, you are not happy as a widow…It's not a very good life and you get very lonely…When he went away, I found this place [home] empty" (Amina, spouse of deceased PWPD)*

Others also described the emotional trauma of losing their spouse. Anya explained that she felt lonely around the holidays when she was alone or her adult children had travelled, although she tried to keep herself busy. Eunice had finally retired after Benjamin had died and moved back to rural Kenya as she had planned, something she could not have done while Benjamin required care.

Family members also described the financial burden resulting from many years of care. In Chapter Five, Tina described how Steven's care had left the family *"empty".* She explained that she had to start working to be able to live or as she suggested, *"To get something to eat".* Jessica also described how her family's resources had been drained. Esther, in contrast, praised Leah for signing up to insurance schemes.

PD was generally not included on the death certificates of PWPD; some participants described how this was significant to them while others were not concerned. Amina described being *"angry"* about not knowing how her father died, while the rest of her family did not mind. She suggested that PWPD had experienced long and difficult journeys and to not have it included on the death certificate seemed like PD had not been acknowledged as part of their life and contribution to their death. Only Anya, whose husband died in a private hospital in Nairobi, and Jared's family (he also died in a private hospital), reported that PD was included on the death certificate. A review of death certificates of PWPD in the UK identified that PD was recorded as the primary cause of death in just 4% of cases (Hobson and Meara, 2018) and not reported anywhere (as a contributing factor) on 47% of PWPDs' death certificates. In the North East of the UK, Pennington *et al.* (2010) found that only 63% of PWPD had idiopathic PD recorded on the death certificate.

The role of the support group community was crucial even after death. Family members who attended meetings informed the group through WhatsApp conversations about the death of PWPD and always included details of funeral arrangements and prayers that members could

attend. Family members received countless messages of support and sympathy and referred to other members as their "PD family". Silences were held during group meetings and PWPD like Nzambi who had no contact with his family (except his sister), were mourned and remembered as part of a community.

For the families of those who had died, the groups acted as a way for them to continue to help others, share their experiences, have a purpose and stay connected to PWPD in some way; although, not all PWPD who died were members. The founder of the PD organisation in Kenya had lost her father, which spurred her on to help others. Anya had taken the Nairobi group under her wing after losing her husband and continued to share her knowledge. One pharmacist in the group continued to support PWPD in the group after he lost his cousin; he assisted families who had fewer resources with medication and took charge of several meetings. The group also became a way for formal employed caregivers of PWPD who had died to find new work.

7.4 Discussion

Hope and denial

The first of three key threads emerging from this chapter is a widespread reluctance to talk about death and dying and the role of hope, encouragement, and denial at the end of life. Hope and faith in a miracle recovery seemed to be important for family members throughout PWPDs' journeys which was further compounded by doctors, friends, and family avoiding discussion of death; admitting death was near was seen as "antithetical" to care.

Death was thought of as culturally "taboo", while family members did not want to accept that the end of life might be near, and death often came as a shock. They also did not want to discourage PWPD, while doctors and nurses were reluctant to take away hope of recovery – they instead "skirted around" the issue, similar to the "roundabout" approach to disclosure described by Harris *et al.* (2003) in Tanzania. Lewis *et al*. (2018) also found that doctors in Tanzania did not want to admit their 'failure' by admitting patients were at the end of life, or risk causing harm to them. These findings are similar to observations by Livingston (2012, p. 165) among cancer patients in Botswana where telling someone they were going to die was the *"antithesis of care"* and allowed patients to *"give up".* Similarly, as

Prince (2018) observed on a paediatric oncology ward in Kenya, healthcare professionals described having to give patients and their families hope and be seen to be "doing something", even though they knew patients were going to die. Prince also found that there was no communication about patient deaths.

As medical science has developed and succeeded in prolonging life, Howarth (2007) suggests it has set a challenge where death is a failing, which healthcare professionals are more reluctant to disclose. In Tanzania, Lewis *et al.* (2018) found that doctors were reluctant to break bad news and speak about death, which was identified as a barrier to delivering end-of-life care – doctors would instead keep the illusion of hope alive. Of course, healthcare professionals are also cultural beings and value the importance of hope and encouragement at the end of life. Both family members and healthcare professionals were responsible for the care of vulnerable PWPD and in this sense, "paternalism" (Livingston, 2012), or choosing to withhold information, was the practice adopted to comfort dying patients and their families. In Botswana, Livingston (2012, p. 165) found that Batswana people were shocked that people in high-income countries told patients they were dying; as Livingston suggests *"words can kill"* and cause patients to give up but can also comfort and bring hope of a miracle recovery.

Paternalism was still very present in the narratives of PWPD and patients, and often family members were shielded from the awareness of death. This seemed to be due to complex factors at the societal level (cultural "taboo" about death-talk) and individual level (doctors did not want to be seen as "failing" or family members did not want to accept that death was near). This has implications when thinking about the emergence of palliative care in the context of Kenya.

"Good" and "bad" deaths

A second theme emerging from this chapter is what constitutes a "good" and "bad" death, and how social and financial resources as well as 'place' influenced this. Families negotiated resources and connections to ensure PWPD were peaceful and well looked after and received the best care possible, although the particulars around this were different. Meier *et al.* (2016) also suggest that despite being popular terms in dialogues about death and dying, what constitutes a "good" or "bad" death is contended and complex. Seale and van der

Geest (2004) add that perceptions about dying "well" or "badly" vary across cultures and over time and should be understood within structural, political and economic contexts; these considerations are important for thinking about aspects such as communication at the end of life, place of death and degree of medical intervention.

Several participants described their preference for *"home is best"* at the end of life. Home care had the potential for PWPD to be peaceful, surrounded by family and given the best care possible – something they might not receive in institutional settings. Although, this was contingent on financial resources and the social support available for those doing the caring work. Broom (2015) who explores a social perspective on the end-of-life suggests that 'place' can shape the lived experiences of the dying process. In Tanzania, Lewis *et al*. (2018) found that home was the preferred place of death, unless patients had limited resources for care at home, in which case hospital was favoured. The contrasts in home care were evident from the experiences of PWPD with different resources, connections and support. Howarth (2007) suggests that caregivers' assessments of the quality of care they provided is important for a "good" death. However, a home death could also be "bad" for those without social and financial resources.

Participants' hope of recovery and denial about death contributed to some PWPD being cared for in institutional settings if they had the financial resources. Hospital was described as somewhere doctors were expected to prevent death. In Tanzania, Lewis *et al.* (2018) found that the act of taking a patient to hospital was a final "gesture" of treatment seeking where families demonstrated their care; as Benjamin and Jared experienced. Prince (2018) identified similar findings in Kenya where mothers brought their dying children to the oncology ward to be saved. However, in some situations, like Silvano's described in Chapter Five, families did not have the financial resources to provide any final medical intervention. Although van der Geest (2004b) in Ghana and Kikule (2003) in Uganda have suggested that "good" deaths occur at home without medical intervention, several participants in Kenya described wanting PWPD to receive care in hospital, particularly when they could not cope with complex care requirements or bouts of illness. Similarly, Gysels *et al.* (2011) in their systematic review of end-of-life care in SSA found that place of care was complex and differed greatly between studies; when the burden of care was unsustainable or associated with stigma, families reported preferring hospital care. However, the ability of several

participants in Kenya to afford expensive hospital care reflects the more urban, nuclear families included.

In the UK, Simpson (2001) has described the possibilities of making a "bad" death "good", in this case by posthumous conception where kinship was made possible after death, giving people hope after the sudden, premature death of a husband. van der Geest (2004b) writes that in Ghana, "bad" deaths could be made "good" by holding large, expensive and well-attended funerals, illustrating the ambiguity of these categories. Although rather different to Simpson's example of a posthumous change in death 'category', Nzambi's premature, lonely death was made better by the respect and acceptance he received from members of the PD support group; in some way this could make his death "better".

Most research exploring end-of-life care in SSA has focussed on HIV/AIDS while experiences of chronic diseases associated with later life are under-researched. The families of PWPD in this study described providing the best care they could with available services and resources. The end goal appeared to be to make PWPD as comfortable and hopeful as possible, whether this was at home or in hospital. End-of-life care required improvisation from family members as well as healthcare professionals who likely lacked the appropriate knowledge regarding the complex requirements of PWPD with multiple comorbidities, while palliative care was still under-utilised.

Sociality after death

This chapter illustrated further the "biosociality" generated through support groups that continued long after PWPD had died. Participants were brought together because of a shared biological diagnosis and these relationships between members endured even after the people who brought them together were gone.

All participants who died through the course of the study period were members of the Nairobi support group and relatives shared the news of PWPDs' deaths through the WhatsApp group, receiving condolences and prayers from members who had become friends. In Tanzania, Marsland (2012) suggests that people living with HIV associated with others based on pre-existing social relations and networks, not only on their biological status. She describes how support groups involved patients, family members and friends. In

Kenya, PWPD, their siblings, offspring, parents and friends came together at group meetings through a diagnosis of PD. What became clear was that for many participants these networks and friendships remained, suggesting that "biosociality" is important even after death. However, this camaraderie and sociality was only available to those who could access groups and I am aware that this may not pertain to others who were not. I observed part of the picture during fieldwork and was not aware of what happened to people who were not group members; relatively few PWPD had died.

Several participants continued to be active members of the group even years after PWPD had died, taking on responsibilities. Silverman and Klass (1996) suggest that interdependence is prioritised over independence when someone dies; people's lives are intimately involved in others, particularly after caring for someone for so many years. As such, when someone dies, Silverman and Klass suggest caregivers experience a "loss of self" (Charmaz, 1983) which they need to overcome. Participating in the activities PWPD used to, like support groups, or being surrounded by others who remembered them could be a way for caregivers to maintain self-identity and combat their loneliness and sadness through sociality.

Kim (2016), exploring how social relations are negotiated through bodily remains and graves in Japan, first proposed the term "necrosociality" to understand how sociality connects the living and the dead. Venbrux (2019) uses "necrosociality" to explore how communication and mutual care between the living and the dead in Tiwi is maintained through mortuary rituals. I propose that "necrosociality" could be used to understand the relationships and sociality maintained between the living through remembrance and connections with the dead. "Necrosociality" enabled PWPD to be remembered through interdependence and brought the group and family members together. In this way, support groups acted as an important place, and tool, for family members and friends to overcome their loss.

7.5 Chapter summary

PWPD and their family members suffered long, expensive and challenging journeys. The end-of-life experience appeared to be a culmination of their many years of struggling and navigating care resources, both in the home and outwith, while negotiating the uncertain nature of PD with very little information. PWPDs' social and financial resources changed over

time and space, while care was adapted to their constantly changing requirements. Considering the lack of available support, resources, and information available, participants managed as best they could and many PWPD lived long lives. However, as Constance suggested: *"I'm always praying he should be the last patient in my family and everywhere. It's a very bad disease".*

Chapter 8. Conclusions

Chapter overview

This study set out to understand the lived experiences of people living with Parkinson's disease in Kenya using an interview-based, ethnographic approach. In this chapter I provide a critical reflection of the strengths and limitations of this study and summarise its main empirical, theoretical, and practical contributions. In summarising the empirical contribution, I return to the original study objectives: (a) how the process of diagnosis worked and what challenges were experienced, (b) how PWPD and their families negotiated access to care and treatment, (c) PD in the home and society, and (d) care at the end of life. The next section, on theoretical contributions, seeks to draw together several core themes that are interwoven throughout the thesis, including: (bio)sociality, personhood, and interdependence; intergenerational care and reciprocity; improvisation and self-management; uncertainty and hope; and labelling and legitimacy. Finally, I provide practical and policy implications and propose directions for further research.

8.1 Strengths and limitations

To my knowledge, this is the first ethnographic study to be conducted in Kenya, SSA or any low or middle-income country exploring the experiences of PWPD; as such, it makes an important contribution to understandings of PD in low-resource settings.

One of the main strengths of this research was the ethnographic approach, which allowed me to understand, in a holistic way, how participants lived (and died) with Parkinson's disease and how they navigated care within and beyond the household. By combining in-depth interviews (formal and informal) with extended periods of participant observation, I was able to generate a grounded and deep account of people's lives. Although the study sample was necessarily limited to those seeking treatment or care in formal settings (see below), the variation in participants' financial, educational and social resources, along with different ages, severity and progression of the disease and residence (urban, semi-rural and rural), enabled me to unravel some of the contextual factors that shape the experience of managing PD at different stages (including at the end of life). The inclusion of family

members, healthcare professionals and alternative healers in the study generated different perspectives of life with PD, from the difficulties faced by caregivers in the home, to the challenges and complexities of diagnosis and management. It became clear that PD is a very 'social' disease, drawing in many people beyond the individual 'patient'; the role of different actors was crucial in exploring how the condition was lived and managed.

However, it is clear that the experiences described in this thesis do not capture the full range of people suffering with PD in Kenya. Although many of the participants had very little access to care, and some faced extreme poverty, they nonetheless included the more 'privileged' end of the spectrum, as I recruited participants largely through clinics in major cities. A major limitation of this study, therefore, is that I was unable to access PWPD who remained "un-diagnosed" or un-treated, a population that remains almost invisible and would be difficult to identify without, for example, a door-to-door survey. PWPD who do not receive any treatment or only access alternative therapies are likely to have very different experiences to those interacting with formal biomedical and associated services.

It is important to bear this limitation in mind when interpreting findings regarding the experiences, and management, of PD; by definition, all PWPD in this study were receiving (or had received) biomedical treatment. It is difficult to speculate how experiences of symptom progression and control, care and stigma or ostracization may be felt by those not diagnosed and not receiving biomedical treatment of any kind. That said, several participants did use herbal and/or religious healing, especially when biomedical treatment was unavailable or seemed to be ineffective, giving some insight perhaps into the wider context within which PD may be managed. In fact, many participants experienced periods without medication. This gives a brief glimpse into the potentially desperate situation of those receiving no treatment at all throughout the duration of disease; believed to be seven-eighths of PWPD across the continent (WHO, 2004) and possibly more considering basic antiparkinsonian medication (levodopa) is only available in 3% of primary care facilities in Africa (WHO, 2017). Indeed, Kenya has a relatively large number of neurologists (twenty) compared to many other countries in sub-Saharan Africa (for example, Uganda has four), again representing the relatively 'privileged' end of the spectrum. It would be important in future research to try to understand something of the experience of those – in Kenya and elsewhere – who have no access at all to biomedical care for PD.

Several people who attended private clinics or the Nairobi support group were of a higher socioeconomic status and largely lived in urban areas; a very select group. I tried to include PWPD from rural areas (16 of 55 PWPD), although this proved difficult given the expensive and challenging process of travelling to clinics in cities where recruitment took place. In addition, the delay to hospital ethical approval in Kenya resulted in less time for observations in clinics and recruitment of PWPD from the government hospital, who generally had fewer resources. This was a significant limitation of the study.

The study has also contributed to our understanding about ageing in Africa: a growing area of research. Given that much of the research conducted on the needs of older people in SSA has focussed on rural populations, it is important to understand the experiences of older city-dwelling people with chronic disease. Kenya, and many other African countries, are rapidly urbanising; informal urban settlements are continuing to grow and rural community ties eroding. This research has begun to address the needs of this population living in cities; the complexities of urbanisation with regards to intergenerational ties; and the significant care requirements of older people living with degenerative disease with very few resources and social protection. This thesis has also highlighted some of the challenges experienced by working-age people living with PD who do not necessarily have extensive family networks and may have caring responsibilities of their own. The needs of this group have not previously been explored.

Another strength of this study was my Kenyan ties. Conducting research 'at home' can be difficult, but many participants were more open with me because I had grown up in Kenya, and understood some of their challenges and the context in which they were navigating life with PD. However, my experience as a privileged white Kenyan was very different to many participants, which could have resulted in me having pre-determined ideas about how things in Kenya worked, for example, around health services or alternative healing. There was a limit to the extent I could share and understand their experiences. Furthermore, having relatively limited experience with PWPD allowed me to enter this research without pre-conceived ideas about the condition or what people's experiences should be, which is also a strength of this study.

The opportunity to observe and participate in support group meetings was a significant strength of this research, which the use of ethnographic methods enabled. To understand

the experiences of PWPD in Kenya without including the activities of the group and the support they provided to members (including the role of Africa Parkinson's disease Foundation in advocacy) would be to miss out an important component of the management of PD, although of course, only a very small proportion of PWPD participate in support groups. Furthermore, the group's existence enabled me to replicate their work and structure in Mombasa. However, almost all PWPD in Kenya do not, and will not be able to, access the groups and this requires consideration when thinking about their benefits and limitations (particularly for those with fewer resources and in rural areas) and the potential for replication elsewhere on the continent.

This thesis brought together literature and concepts from various fields, including PD specific literature, medical anthropology theory, ageing in Africa literature on intergenerational relations and care work, and theory on chronic disease management from low-resource contexts, a significant strength of this research. This range of disciplines and scholarship was required to understand the complexity of life with PD in Kenya and its specific social, political, and economic context. However, a drawback could be trying to engage with, and contribute to, a range of concepts and theories that emerged from the research. Little is known about how PWPD across the world (with the exception of high-income countries) manage, and live with, their condition and findings could help encourage others to use a similar approach to better understand the struggles and needs of the global PD community, which could influence international donor and local policy decisions.

8.2 Summary of empirical findings

This thesis has shown, in more detail than any previous study, how people living with PD in Kenya manage (for better or worse) their condition. In this section, I summarise the main empirical findings, addressing issues around diagnosis, therapeutic management, care in the home and at the end of life. I explore how findings fit into the global PD context and what learning from this thesis can be utilised to inform inclusivity and inequalities in healthcare provision in high-income countries.

8.2.1 Diagnosis

This thesis described the numerous misdiagnoses PWPD experienced, which has also been identified in Tanzania (Mshana *et al.*, 2011) and Ethiopia (Walga, 2019). The study's findings also corroborate those of Dotchin *et al.* (2007), who suggested that many PWPD in SSA are not diagnosed and, if they are, diagnosis is usually delayed. PWPD often believed their bodily changes were associated with ageing or comorbidities, only seeking help from non-specialist doctors (whose PD knowledge was extremely limited or non-existent) after acknowledging their symptoms were 'not normal'. However, similarities in challenges with misdiagnoses and PWPD delaying seeking medical help after the onset of symptoms also exist in HICs (Schrag *et al.*, 2018), perhaps to a lesser extent than was identified in Kenya. Awareness about PD needs to improve among the population and healthcare professionals in Kenya, and globally, to ensure PWPD are diagnosed before their condition progresses significantly. Issues with PD awareness, education and beliefs about the ageing process have also been reported among African-American and Latino populations in the USA as contributing to under-diagnosis of PD within these groups (Dahodwala *et al.*, 2009) suggesting that more needs to be done within underserved communities globally to improve timely and accurate diagnoses, including promoting awareness about PD and symptoms to look out for. Dotchin *et al.* (2014) propose that if PD is diagnosed earlier and treated effectively, the burden of care on families could be significantly reduced.

Misdiagnoses and referrals resulted in additional costs, while some PWPD almost gave up their quest before reaching a neurologist; others likely did give up, but they were not in my sample. If PWPD are to be diagnosed earlier, non-specialist healthcare professionals need to be aware of the existence, and symptoms, of PD, ensuring timely referral to neurologists and the provision of appropriate medication earlier. However, with the low number of neurologists, largely unaffordable private consultations, and overwhelmed public clinic, many may not be able to access or afford to see specialists even if referred. Dotchin *et al.* (2011) argue that providing access to movement disorder specialists is crucial for management in SSA.

For most PWPD, the information received at diagnosis was extremely limited – this resonates with the experience of PWPD in HICs (Schrag *et al.*, 2018). For example, a report by the Parkinson's Disease Society (2008) in the UK showed that 30% of newly diagnosed

PWPD had not been given clear information about their diagnosis. However, what differed in Kenya was that some never even learned the name of their condition. This had serious individual social consequences for some who were abandoned or not able to return home; it also contributed to wider issues around stigma, hindering the recognition of PD as an accepted, visible disease in society. Participants described their frustration that PD was not recognised by, or received little attention from, the government or international donors. Despite this, the incidence of PD will continue to increase as the population ages (Dorsey and Bloem, 2018). Findings have illustrated the need to improve awareness about PD, which stems from the information provided by neurologists at diagnosis, as well as improve communication around diagnosis. The need for improved communication by healthcare professionals about PD has been reported globally, although challenges with structural constraints and attitudes may present as additional barriers in Kenya.

8.2.2 Disease management

This thesis has highlighted the limited accessibility and affordability of biomedical services (both private and public), specialists and medicines for PD in Kenya. Similar findings have been reported elsewhere in SSA. In Tanzania, Dotchin and Walker (2012) have identified the high costs of PD medication, consultation fees and transportation. However, findings from this study have also illustrated the financial devastation PD can cause as the condition progresses.

Levodopa was unaffordable for most; similar issues have been reported in Tanzania (Mshana *et al.,* 2011) and Ethiopia (Walga, 2019), while Mokaya *et al.* (2016) identified the unaffordability of PD medication (including levodopa) in Kenya. Findings have highlighted the necessity for sustainable supplies of generic medication to be made available at lower costs – there are ethical dilemmas with improving diagnosis but not providing access to symptomatic treatment. Accessibility of medication was also a significant issue – no government hospitals stocked any levodopa despite it being an 'essential' medicine (Ministry of Health, 2019).

This study identified the significant costs of travelling to major cities to attend neurology clinics as well as the under-resourced, overwhelmed public clinic which resulted in *"prescription only"* consultations. Furthermore, very few PWPD had accessed any form of

additional services required for the holistic management of the condition, such as speech therapy, while the number of practicing allied health professionals remains low across the country. Findings have illustrated the need for improved access to these services for PWPD in addition to symptomatic therapy.

Although HICs have far greater numbers of neurologists and geriatricians in practice as well as well-established healthcare systems, reports of sub-optimal PD management also emerge from the UK. A community study identified that 18.5% of the 248 PWPD included were sub-optimally managed – poor cognition, worse mobility and lower education were contributors (Hu *et al.*, 2011) (similarities were identified in Kenya regarding information received from neurologists). Furthermore, less than a third had seen an allied health professional (e.g. physiotherapist (28%) or occupational therapist (14%)) at any point in their illness. A report by the Parkinson's Disease Society (2008) in the UK showed that 15% of PWPD had never been seen by a specialist in hospital and 25% had never seen a PD nurse. This suggests that challenges with effective, optimal PD management occur globally across country income groups. However, differences in why PWPD do not access services may exist, for example, in Kenya services were unaffordable and largely unavailable, yet in the UK services should be provided free of charge through the NHS. Perhaps there is a wider issue regarding knowledge and awareness about PD, what services can be accessed by PWPD globally, the importance of interdisciplinary and multidisciplinary disease management for PD (Bloem *et al.*, 2020) and the role of doctors in enabling referrals to these services.

Furthermore, findings from this thesis regarding poor information provision and the need for improved awareness among low-income populations to improve diagnosis and management may also be applicable for tackling inequalities and inclusivity in HICs, irrespective of access to services – with the right knowledge about PD, including symptom management, the role of speech exercises, physical exercise and dietary changes, the disease can be well managed in the home with the help of the family.

Although many participants in Kenya (excluding those employed in the informal sector) were enrolled on the National Health Insurance Fund, they received no benefits when accessing outpatient clinics and buying medication. However, the government has taken a step towards covering outpatient fees – this has been for civil servants in the first instance. Access to health insurance and coverage of outpatient public clinic fees could reduce the

devastating costs associated with PD management, although clinics may still be overwhelmed.

The limited availability and perceived ineffectiveness of PD medication (often caused by improper dosing schedules and side effects) coupled with desperation, beliefs about cause of disease, promises of a cure by herbal healers and people's faith in God contributed to several participants seeking out alternative therapies. Medical pluralism is very common in SSA (Kleinman, 2017), as identified among PWPD in Tanzania (Mshana *et al.,* 2011) and South Africa (Mokaya *et al.*, 2017).

Support groups played an important role for some PWPD and caregivers in filling in gaps in care and support. The reach of the groups was relatively limited, but they were successful because people had nowhere else to go, providing social resources and aspects of care not provided by the state (although I acknowledge that support groups can be problematic for some; see my remarks on "anti-biosociality"). This study has demonstrated the practicalities and possibilities of establishing support groups in Kenya and enabling PWPD to learn more about how to manage their condition. These groups have the potential to play important roles across the continent; notwithstanding their limitations. Walga (2019) has also identified the existence of a PSG in Ethiopia, while organisations also offer PD support in Uganda and Ghana.

8.2.3 Care in the home and society

PWPD experienced increasing challenges as their symptoms progressed, resulting in a gradual loss of independence. Motor and non-motor complications were similar to those experienced by PWPD globally and required continuous adaptation, including changes in where, and with whom, PWPD lived and shifting relationships within families.

This thesis illustrated similarities in stigmatising perceptions experienced by PWPD in Kenya and those in high-income countries, including a changing self, feelings of embarrassment and beliefs about PWPD being 'drunk', but also perceptions that have not been identified in HICs, including PD being contagious or caused by witchcraft/curses. Low PD awareness has also been identified among populations in Tanzania (Mshana *et al.,* 2011), Uganda (Kaddumukasa *et al.*, 2015), Ethiopia (Walga, 2019) and South Africa (Mokaya *et al.,* 2017)

resulting in social exclusion, isolation, anxiety and worry. However, PWPD in this study also experienced stigma within their own families. It is noteworthy that cultural context influences perceptions of PWPDs' experience. For example, fluctuations in 'on' and 'off' states were perceived by some as evidence of witchcraft, as described in Chapter Six, whereas in the UK or HICs, fluctuations can be perceived as PWPD malingering, yet still result in stigma towards PWPD, albeit in a different form.

Most participants had never heard of PD prior to diagnosis, which was further compounded by some not knowing the name of their condition. As Livingston (2012) suggests, linguistic translation is crucial in order to bring 'new' diseases into being. The study's findings have illustrated the need for improved awareness about PD in society in order to tackle these perceptions.

Many family members described struggling to come to terms with their new full-time caring roles which several believed had taken over their lives. Similarities in the physical, emotional and financial burden of caregiving previously identified in HICs (McLaughlin *et al.*, 2011; Tan *et al.*, 2012; Bhimani, 2014; Mosley *et al.*, 2017) exist in Kenya, with family members often reluctant to accept respite or take time away from their role due to perceptions about their responsibility to care. Since family appear to be the main source of care for PWPD in Kenya, as also identified in Tanzania (Mshana *et al.,* 2011) and Ethiopia (Walga, 2019), providing family members with information about how to manage PD in the home, as well as opportunities for support and respite, could have far-reaching consequences for disease management. The use of in-person caregiver-specific support groups, online forums, telehealth and online meetings could improve caregivers' wellbeing in Kenya, particularly as virtual methods of communication, including virtual support groups, have gained traction during the Covid-19 pandemic (Subramanian, 2020).

Families also negotiated gendered caring roles as well as their expectations around reciprocity and perceived obligation to care for their parents in old age; some wealthier families, particularly those engaged in paid work, relied on formal caregivers. Findings regarding families' perceived obligation and expectation to care for PWPD could be utilised to inform inequalities in HICs, for example, in understanding why some people from Black, Asian and Minority Ethnic (BAME) groups are less likely to utilise care homes or hospices (Greenwood *et al.*, 2015), instead taking the full burden of care upon themselves. In these

cases, families should be provided with additional support and respite, particularly as intergenerational households, and resulting support, may not be available.

Many participants acknowledged the challenges posed by urbanisation, economic difficulties, increased female employment and dwindling rural networks in providing complex, indefinite care. The experiences of PWPD need to be understood within the context of older people's resources for care and networks as PD is usually associated with later life. Pensions were quickly used up and many had no form of social protection, particularly those who worked in the informal sector, while full-time caring roles were often incompatible with paid work, reducing family income. As the population of Kenya continues to age with increasing morbidity (particularly long-term non-communicable diseases) and intergenerational networks shift, social protection policy needs to consider how people will afford care in later life (Aboderin, 2016).

8.2.4 End-of-life care

Finally, this thesis illustrated the societal reluctance to discuss death and dying. This requires consideration when thinking about palliative care for PWPD in Kenya, which Lennaerts *et al.* (2017) recommend at the end of life in HICs. Livingston (2012) suggests a focus on 'palliative care' is lacking within global health. However, services are scarce in Kenya (Ali, 2016), expensive and largely inaccessible. Palliative care requires an acceptance that the end is near and awareness of the proximity of death, although in Kenya, this was perceived as antithetical to care. Initiating discussions around death and dying and normalising death talk could improve the acceptance of palliative care among the general population and healthcare providers; although this requires access to palliative services.

PD was also rarely acknowledged on death certificates as contributing to PWPDs' death; a similar situation occurs in the UK (Hobson and Meara, 2018). Furthermore, findings hinted at difficulties determining preferences for place of death (between the home/institutional care), something also identified by Downing *et al.* (2014) in Kenya. However, as Ali (2016) suggests, the availability and accessibility of palliative care services in Kenya needs to improve, notwithstanding the challenges identified in this study. In the USA, ethnic minority groups have been reported to underutilise palliative care services (Gardner *et al.*, 2018).

Similar challenges exist among BAME groups in the UK where a combination of poor understanding, mistrust and lack of cultural sensitivity result in low uptake of palliative services (Calanzani *et al.*, 2013). Findings from this thesis regarding cultural barriers and taboos around talking about death, accepting death and awareness about end-of-life care could provide insights into inequalities in access to care for people with PD from BAME groups living across HICs, providing avenues to address these disparities. Furthermore, a report by the Parkinson's Disease Society (2008) in the UK showed that one third of PWPD admitted to hospital did not feel that staff knew 'anything' about PD, suggesting that awareness about PD, care at the end of life and the need for palliative care also needs to improve in HICs.

8.3 Theoretical contributions

8.3.1 (Bio)sociality

This thesis highlights the central importance of social resources and connections in managing life with PD in Kenya, from the recognition of symptoms to care at the end of life and beyond, contributing to theory around "biosociality". PWPD with more substantial, and better functioning, kinship networks appeared more equipped to navigate life at home and within the wider therapeutic landscape, where access to treatment and services, albeit limited, was highly dependent on levels of financial, educational, social and cultural capital (Bourdieu, 1986). Both Whyte (2014) in Uganda and Marsland (2012) in Tanzania have observed the reliance on kinship networks in the negotiation of everyday life with HIV and the "technical know who" that facilitated access to treatment. In a context where health services are scarce and formal social support non-existent, the role of family becomes evident. For almost everyone, PD care happened through social connections and this thesis has demonstrated the applicability of "biosociality", a concept used in SSA but largely developed around HIV/AIDS, to PD.

This thesis illustrates the crucial role of "sociality" in the management of PD as well as the "biosociality" (Rabinow, 1996) enabled through support groups. As Whyte (2014) proposes, sociality and kinship can act as substitutes for 'Western' notions of citizenship – PWPD in Kenya had no access to 'citizen-like' rights. In Tanzania, Marsland (2012) demonstrated how a nuanced understanding of "biosociality" could be used, given the lack of 'high-tech'

technologies available, considering people's social relations and networks. Findings from this thesis have illustrated not only the importance of family networks for the management of PD in Kenya, but how some PWPD form social connections and new socialities around their biological diagnosis through support groups. Groups also appeared to take on roles within the therapeutic landscape as sources of information, connections to services and sometimes, access to treatment, involving a somewhat "citizenship-like" role. This aspect of "biosociality" may be seen elsewhere in low-resource contexts for conditions with poor 'visibility' for which access to government services and support is non-existent. Groups in Kenya also provided a route to legitimacy, where seeing symptoms in others confirmed PWPDs' own diagnosis; Marsland (2012) identified similar findings in Tanzania among people with HIV. Furthermore, the groups could act as a 'surrogate family'; a role that sometimes persisted even after death, enabling "bad" deaths to become "good". However, the sociality of the groups could not fully make up for the inaccessibility of symptomatic therapy for a degenerative condition like PD.

Several PWPD undertook what Festinger (1954) suggests are "social comparisons" – I propose this gave rise in some cases to a form of "anti-biosociality", whereby PWPD were sometimes deterred from attending groups or forming sociality around their diagnosis. PD differs from other chronic conditions for which support groups exist because it is progressive, even with medication, and has very evident physical manifestations. Despite sharing the same biological diagnosis, the severity of disease varies. The nature and role of biosociality around PD, and possibly other progressive, degenerative diseases, may require more nuanced consideration. Similar challenges with PD support groups have been observed in England (Williamson *et al.,* 2008), USA (Solimeo, 2009) and Australia (Hudson *et al.,* 2006), yet this has not been considered in low- or middle-income countries. One of the most important aspects of PD management in Kenya was to maintain hope; seeing the inevitable progression in others could have quite the opposite effect.

Notably, the biosociality that groups enabled prevailed even after death; the term "necrosociality" coined by Kim (2016) can help us make sense of this experience. Silverman and Klass (1996) described the importance of interdependence when someone dies, which became evident among members of the Nairobi PSG. "Necrosociality" could be used to understand the sociality maintained between the living through connections with the dead

that was enabled through groups. The role of support groups elsewhere in enabling this kind of sociality merits further investigation.

8.3.2 Personhood and interdependence

Findings have contributed to theory on "personhood" (Degnen, 2018) and "desired interdependence" (McIntosh, 2017) with regards to PWPD and their resources for care. The visible manifestations of the disease and *"strange"* appearances often exposed PWPD to stigmatising perceptions, resulting in social disengagement and exclusion. Many also described increasingly feeling that they were a burden on their families, and experienced a form of *"social death"* (Taylor, 2008), becoming fearful of leaving their homes in case of negative judgement or falls and losing their independence and wider social connections. This thesis has described the consequences of progressing PD symptoms on the 'person' category and, as Comaroff and Comaroff (2001) described in South Africa, the social nature of personhood. Families' lives appeared to be interconnected and PWPD relied heavily on their social relations, posing serious challenges to personhood for those without robust social networks.

However, despite the importance of sociality, PWPDs' increasing loss of independence calls into question the "desired interdependence" that McIntosh (2017) identified as crucial and revered in old age in Kenya. Care went considerably beyond the expected care requirements of older people without degenerative disease, requiring more pooling of resources and fluid care arrangements. This study's findings have questioned the applicability of the revered idea of desired interdependence when thinking about a condition like PD, which progressively erodes personhood, affects people's sense of 'self', contributes to feelings of "enacted" and "felt" stigma (Scambler, 2004), creates tensions with family relations and communities and inevitably results in complete dependence on others for care. The consequences of an increasing prevalence of chronic disease on filial respect for older people, the reliance on families for care and inter-dependent family structures requires consideration in Kenya, and SSA.

8.3.3 Intergenerational care and reciprocity

This thesis has contributed to theory on 'ageing in Africa', particularly concerning intergenerational care networks and reciprocity. Findings have illustrated the continued *"expectation"*, *"responsibility"* and *"obligation"* of families in Kenya to care and provide for older people with PD, which differs from some existing research in the field. Apt (2001) queried whether the increased 'burden' older members might pose to families in the twenty-first century would erode the cultural norms of care in African countries – conceptualised as "modernisation" theory (Aboderin, 2004a). Similar ideas around the reluctance of families to care for older people and an increasing conditionality on reciprocity emerge from Ghana (Aboderin, 2004b; van Der Geest, 2016) and Kenya (Cattell, 2008), while research on "reciprocity" in several countries across SSA has highlighted shifting care patterns for older people (Hoffman and Pype, 2016).

However, reciprocity appeared to be deeply ingrained in the families I met who continued to care for older people despite the challenges they experienced; although, those without caring families may have been less likely to end up in hospitals and therefore, were not in my sample. Care was becoming more difficult, involved making more pragmatic decisions in the face of societal change and input from various actors who took on physical, emotional, managerial, and financial roles. Often care took place from a distance or PWPD moved to live with adult offspring in cities (leaving their spouses in villages). Obrist (2016) in Tanzania and van der Geest (2002a) in Ghana have identified similar findings. As countries continue to urbanise and rural communities dwindle, this may emerge as a new 'trend', creating inter-generational households in cities. Families with more resources also employed formal caregivers – the expectation to care was still very present yet was changing form for some. Care work was becoming more difficult and expensive, but this did not prevent families from doing everything they could with their available resources to provide care; the view of older people in SSA becoming a 'burden' needs more consideration.

This thesis has demonstrated the applicability of a political economy perspective, or material constraints argument (Aboderin, 2004a), for the structural constraints that can make care for PWPD difficult in Kenya. Among my sample, although social change and urban migration were important issues, they did not appear to be influencing the care that older people received. However, for those who might never have reached a neurologist, these constraints

may have indeed been completely disastrous. The impact of long-term chronic disease among older people needs to be considered when developing theory on intergenerational care and reciprocity in SSA moving forward.

8.3.4 Improvisation and self-management

This thesis has engaged with theory on "improvisation", a defining feature of life for PWPD in this study. Various forms of improvisation accompanied the uncertainty seen from the onset of symptoms through to the end of life both in the home and among healthcare professionals and alternative healers. Improvisation stemmed from and crucially, was limited by, the insurmountable structural constraints and resulting "structural violence" (Farmer, 2004) that many participants faced in daily life. Furthermore, improvisation may also have been limited by mindset; both healthcare professionals in terms of their approach to the care they provided and advocating for their patients, but also by many PWPD who did not interact with global information and support through the internet (where available, although this will also limited with digital illiteracy). This could be perceived as a "learned helplessness" which is exacerbated by poverty and structural constraints. Learned helplessness describes the "hopelessness" and "resignation" people learn when they perceive that they have no control over repeated bad events (Myers, 2008) – constant difficulties with accessing or affording biomedical treatment or gaining information, for example. This could in turn result in PWPD being less responsive to initiatives or interventions that could improve their lives.

Within the complex therapeutic landscape in Kenya, PWPD experienced a "constrained agency" where doing what was best for their care was not possible – most of the decisions made were not by choice, rather as a result of what Farmer (2004) describes as "structural violence", which was visible in access to services and treatment. Those without social and therefore, financial, resources were more likely to succumb to structural violence. Whyte (2014) described the improvisation of care by people living with HIV in Uganda who had to adapt recommendations to fit their daily lives. However, the improvisation and adapting observed in my study was more about manoeuvring structural constraints than making recommendations work. This thesis has identified what structural violence and constrained

agency mean for the management of PD, a chronic, degenerative condition, within under-resourced health settings.

Mol (2009) and Guell (2009) have described the ability of patients in HICs to "tinker" or use "bio-tactics" to self-manage conditions. Although these are useful concepts to think about PD management in Kenya, they assume a greater level of agency than most participants had. Resources were typically so limited that in most cases, no amount of tinkering could result in 'good' care, while "biotactics" did not result in making informed decisions about self-management – in this context, these concepts have significant limitations. van Olmen *et al.* (2011) proposed a shift towards 'full self-management' of people living with chronic disease in LICs. However, this study's findings have demonstrated that when reliable information is so scarce, poverty is so high, and medication and services are inaccessible and unaffordable, effective self-management is almost impossible. These severe constraints should be considered when thinking about people's ability to improvise and self-manage conditions in low-resource settings. In Kenya, Abdulrehman *et al.* (2016) identified similar challenges with diabetes self-management caused by severe structural constraints. The crucial role of connections and social resources and the extent to which structural constraints prevent the ability to improvise and 'make do' should be considered when conducting similar studies on chronic disease in SSA.

This thesis has also highlighted the improvised forms of care undertaken by doctors to provide a prescription and 'make do', while negotiating a societal reluctance to discuss the inevitability of progression, death and dying. A similar improvisation of medicine by doctors has been documented in Botswana (Livingston, 2012). However, the ability of healthcare professionals in Kenya to improvise was extremely limited and often resulted in inadequate care – Rieder (2017) and Wendland (2010) experienced similar constraints and suffering in Ethiopia and Malawi respectively. Herbal and religious healers also undertook forms of improvisation, using strategies and altering practices to 'keep up' with biomedicine and technology and appear more "modern" and legitimate. This improvisation or use of strategies has been observed among 'traditional healers' in Tanzania (McMillen, 2004; Marsland, 2007) and in Ghana (Hampshire and Owusu, 2013; Hampshire *et al.*, 2017) who used such techniques to try to increase their client base.

In short, improvisation by PWPD, families, healthcare professionals and 'alternative' healers was a defining feature of life with PD in Kenya yet restricted by substantial structural constraints. However, PWPDs' ability to "tinker", use "bio-tactics" or effectively self-manage was almost impossible. These concepts may not be relevant in a context of extreme constraint and scarcity of disease information.

8.3.5 Uncertainty and hope

PWPD and family members constantly negotiated the deep and multifaceted uncertainty surrounding PD. The withholding of information, including diagnoses, prognoses, and the inevitable progression of disease, generated further uncertainty and worry but also hope for the future and a miracle recovery. Although many families stressed their desire to get reliable information at diagnosis and throughout their journeys, it also became clear that faith, encouragement, and at times denial, were sometimes more important. This thesis has illustrated the duality around uncertainty and 'knowing', which enabled both hope for the future and access to services and treatment; albeit limited.

Findings have also highlighted the challenges with both paternalistic (which characterised many participants' experiences) and patient-centred (giving patients autonomy) views of biomedicine in the management of chronic, degenerative diseases with no cure in Kenya. Livingston (2012) suggests that the paternalistic doctor-patient relationship is often central to healthcare in low-resource settings; patient 'choice' or autonomy assumes that there are effective options to choose from, which is not the case in Botswana where Livingston's research took place, nor from my observations in Kenya. The reasons for healthcare professionals in Kenya withholding *"negative"* or *"disheartening"* information were complex. Importantly, they wanted to avoid delivering bad news and risk the patient 'giving up' – there appeared to be a general reluctance to discuss, or accept, the certainty of disease progression or the inevitability of death, which had several implications. First, it provided hope of recovery and possibilities for the future, even at the end of life. Second, it generated further uncertainty about how to live well with the condition and develop meaningful social connections. Third, it potentially contributed to stigmatising perceptions.

However, Whyte (2009) proposes that uncertainty can be a basis for exploration, not necessarily a negative thing to eliminate; in reality, it often cannot be eliminated and in

some cases, living with uncertainty might be better than living with the certainty of a negative outcome. The benefits of withholding disheartening information require consideration; the hope that uncertainty could generate seemed to be more important for some than knowing about the progressive, incurable nature of PD and had a beneficial impact on both PWPD and family members' outlook and wellbeing. In Sri Lanka, Sariola and Simpson (2011) have described the "heteronomous" nature of families as 'decision-making units' where personhood is not necessarily rooted in the individual. Assuming that patient autonomy is preferred, as is suggested in HICs, may not be applicable when resources are so constrained, treatment unaffordable and families play such an important role in decision-making. This also spills over to ideas around end-of-life care and awareness of the imminence of death.

Throughout PWPDs' journeys, both PWPD and their family members continued to strive for the 'cure' they believed, or hoped, existed – even at the end of life. This could partly be attributed to challenges with effective and sustainable disease management which, if optimally managed, could negate the need for a 'cure'. However, the focus on finding a cure was also at odds with 'palliative care' in HICs which centres around symptom management, exemplifying the challenges of delivering care in SSA without taking into account the values and beliefs described in this thesis around the end of life. Perhaps 'palliative care' in its current form needs repackaging in Kenya if doctors are to be equipped with the necessary skills to deliver effective end-of-life care, considering the role of hope and reluctance to accept death.

8.3.6 Labelling and legitimacy

This thesis has engaged with theory on diagnosis and labelling and the consequences of "biolegitimacy" (Fassin, 2009) for PWPD. In line with the issues discussed in the previous section around the duality of uncertainty, similar challenges exist regarding legitimacy. Giving a name to symptoms and suffering had important social implications and allowed PWPD to justify their illness to themselves, family, friends, and society. As Kleinman (1977) proposed, illness must be validated for someone to be legitimately sick. However, it should be noted that there were limits to PWPDs' "biolegitimacy" because of constrained access to

services – in this context, labelling may not be beneficial if PWPD cannot access life-saving medication.

Anthropologists and social theorists have argued that labelling and diagnosis can be crucial in the social construct of disease, validating illness experience. However, without any additional explanation of disease or signposting to further resources, a name may not mean anything and could instead eliminate hope, an important aspect of PWPDs' journeys. PD, in the context of Kenya and perhaps other low-resource settings, differs from other conditions which have been the object of political organisation (for example, HIV or even diabetes). Knowing the name 'Parkinson's disease' does not automatically provide access to claims, services, or treatment; connections and networks were far more important in the Kenyan context. Consequently, the importance of diagnostic labels requires consideration in constrained healthcare settings when it could risk people 'giving up'.

However, labels can reinforce the existence of diseases in society and withholding the name PD could have significant social consequences, for example in moving towards an acceptance of the condition. PWPD also wanted 'alert cards' that labelled and legitimised their illness and had the potential to prevent stigmatising perceptions. As such, labelling is important in this context and without the validity it ensures, PD will remain "invisible" from government and donor support.

8.4 Policy implications

The Sustainable Development Goals (SDGs) have set key global policy objectives in line with the 2030 Agenda for Sustainable Development. With regards to health, SDG3 is aimed at "ensuring healthy lives and promoting well-being for all at all ages" (United Nations, 2015c). The Kenya Health Policy 2014-2030 aligns with the government's long-term development agenda, Vision 2030 (and other global commitments), which aims to transform Kenya into a middle-income country. One policy objective is to 'Provide essential healthcare', specifically *"affordable, equitable, accessible and quality healthcare"* for all (Ministry of Health, 2014b, p. 33). Furthermore, Kenya's National Hospital Insurance Fund was reformed in 2017, aligning with the country's quest for universal health coverage (Barasa *et al.*, 2018). The policy implications outlined in this section are set within the backdrop of Kenya's own policy objectives, ultimately aimed at achieving universal health coverage (Chuma *et al.*, 2012), and

the SDGs more broadly, while acknowledging the associated difficulties with achieving these ideals, which are beyond the scope of this thesis.

The first policy implication concerns the awareness of PD among the general population (through the use of education campaigns) and healthcare professionals (by improving the exposure of PD within curricula), which affects PWPD throughout their journeys. Raising awareness could have significant implications for PWPD and their families, including: ensuring early recognition of symptoms and timely diagnosis across Level 2, 3 and 4 public facilities, reducing costs associated with referrals and misdiagnoses, combatting stigmatising perceptions within communities, and enabling people to manage PD well (both healthcare professionals within a clinical setting and families within the home). Coupled with this, awareness among community health workers in rural Kenya about PD could enable more timely diagnosis. However, improving diagnosis needs to be in the context of providing affordable drug treatment and somewhere people can learn about their condition.

The second implication concerns the establishment of support groups, and findings regarding the possibilities of groups and their potential role within the wider therapeutic landscape. This study identified the information and support the groups provided; albeit to a select group. However, if PD awareness was to improve, the groups could play an important role in providing people with aspects of care that already over-burdened neurological services might not be able to deliver. The support these groups provide could considerably improve with backing from local government. This might then mean that neurologists would be more prepared to disclose a PD diagnosis if they could signpost people to the groups for further information and support – negating some of the challenges associated with information provision at diagnosis described in Chapter Four. On a larger scale, collaboration of the groups with international PD organisations could generate more awareness and enable existing educational resources to be adapted to the Kenyan context. The success of the 'PD alert cards' from 'Parkinson's UK' among participants illustrated the benefits of such materials.

A third policy implication concerns findings regarding the high costs of medication in Kenya, particularly the financial devastation many families experienced. On a local level, reducing the costs of drugs, specifically levodopa, could have significant implications for families, who often had to pool resources together, and PWPD, who often suffered during periods without

symptomatic treatment. Levodopa is included on Kenya's Essential Medicines List (Ministry of Health, 2019) yet is often not available or affordable, aspects intended by the acknowledgement of a medication as 'essential' (WHO, 2017). A short-term solution could involve support groups 'bulk-buying' levodopa. However, in reality, government registration of levodopa needs to occur. Government recognition of the high costs of accessing levodopa could develop as the awareness of PD improves, although this would require on-the-ground advocacy.

The above 'basic-level' implications are attainable without significant high-level policy amendments. However, in an ideal world, considerable changes would have to be made to improve the situation for PWPD in Kenya, and SSA more broadly. For example, possible next steps could involve training more neurologists to reduce the current burden on neurological services, although this would require complex decisions to be made and re-prioritisation of health budgets. Improving the availability of levodopa in government facilities would also reduce the high costs of buying levodopa from private facilities. Furthermore, policy needs to address the poor coverage of pension schemes in Kenya and the implications of social protection for older people, as well as poor health insurance enrolment and the consequences for achieving universal health coverage. However, these would require large scale, complex decisions to made and consideration about how these might be funded, including further thought about whether universal health coverage aims to provide all people with basic care or care for all conditions. Although these are important issues to consider, they sit beyond the scope of this thesis.

Table 12 outlines possible policy recommendations drawing on the more 'basic-level' implications and the considerable 'large-scale' changes that would be required (in an ideal world) to improve the situation for PWPD in Kenya, and SSA more broadly. However, I acknowledge the huge scale of some of these ideals, which would involve consideration at a high policy level both locally, and possibly, internationally, and would be much more difficult to implement. Although these recommendations would considerably reduce the financial implications of PD among families in Kenya, significantly improve diagnosis, treatment and care, and reduce stigma, they would also require substantial amounts of government, or donor, funding and support, and a possible re-prioritisation of resources within an already over-burdened healthcare system.

Policy area	Recommendation	Implementation
Awareness	Educational campaigns by the government for (i) general population, and (ii) healthcare professionals	Ministry of Health and support groups
Training	Neurology and geriatrics Community health workers Allied health professionals (e.g. occupational therapists and physiotherapists)	Universities and Ministry of Health
Resources	Registration of levodopa Amendment to essential medicines list Supply of levodopa in government facilities Neurology clinics in Level 5 and 6 facilities Information packs at diagnosis and signposting to PSGs	Pharmacy and Poisons Board and Pharmaceutical Society of Kenya Ministry of Health Support groups
Social/health protection	Universal pension enrolment Reconsideration of health insurance premiums for informal workers	Ministry of Labour and Social Protection

Table 12. Summary of policy recommendations

Much of Africa now suffers from a double burden of disease, yet funding tends to focus on specific disease control rather than care: *"socialised for scarcity"*, where one priority loses as another wins (Farmer *et al.*, 2013b, p. 336). However, global health has largely focussed on infectious disease, not non-communicable disease, or the needs of older people. Farmer *et al.* (2013b) propose that the theory of "limited good", which would result in one's gain and another's loss, within global health must be avoided as it is built on an assumption of scarce resources. Development assistance funds have increased from US$5.59 billion (1990) to US$21.79 billion in 2007 (Farmer *et al.*, 2013b), and continue to increase, suggesting that budgets may not be fixed. In this regard, one could argue that funds need to be found to strengthen all aspects of health systems. As Yong Kim *et al.* (2005, p. 856) propose, *"Rather than assume a fixed universe of limited resources that makes only the simplest and least expensive interventions possible in poor countries, we must search for a more appropriate share of rapidly expanding global resources".* Moreover, the Kenyan public health sector

budget has expanded from $1.4 billion to $1.9 billion over the last three years (Ministry of Health, 2020).

Increased funding to specific healthcare issues could take away resources from other areas. However, conditions that primarily affect older people are under-prioritised or missed within health budgets. In Kenya, for example, 40% of the population is under 14 years (World Bank, 2019d), although morbidity associated with increased life expectancy continues to increase. If Kenya is to achieve its local policy objectives, accomplish 'Vision 2030', and align more broadly with the Sustainable Development Goals, further consideration is required about how to address conditions associated with later life. Although these challenges require recognition as wider policy issues, I acknowledge that they are beyond the scope of the implications of this study.

8.5 Directions for further research

Findings from this study have identified several areas which require further research. One of the limitations of this research was the limited access to "un-diagnosed" populations. A future project incorporating a prevalence study with recruitment to an ethnographic study could explore how PD is managed within untreated populations at different stages of disease. Further research could seek to understand how the experiences of this group differ from PWPD with more resources and access to biomedical care, including their use of alternative therapies. Similar ethnographic studies conducted in different locations in SSA (and other low to middle income countries) could provide insights into the particular challenges of other populations in under-resourced healthcare contexts.

This thesis has illustrated the importance of medical pluralism in the management of PD. How prayers, faith and herbal medicine can be incorporated into the holistic management of PD requires exploration. However, this clearly needs to be within the context of providing more affordable, accessible, and effective PD medication. Furthermore, the potential to treat PWPD with a low cost, naturally sourced, sustainable, levodopa-containing legume called *Mucuna pruriens* merits further investigation (Cilia *et al.*, 2018; Fothergill-Misbah *et al.*, 2020a).

This study's findings highlighted the limited awareness about PD among the general population and healthcare professionals. Future research exploring the potential for educational interventions to improve knowledge, and consequently the diagnosis and treatment, of PD is required. Studies should also investigate the role community health workers could play in identifying PWPD in villages and urban informal settlements (in Kenya and the wider continent). However, without access to affordable, effective treatment, education and early diagnosis may have a limited effect and could raise false hope.

With regards to end-of-life care, this study identified the varied preferences for place of death (which were highly dependent on resources) and attitudes towards discussing death. It cannot be assumed that suggestions from HICs regarding use of palliative care can be replicated straightforwardly in Kenya or elsewhere. Research is required to develop culturally specific guidelines for end-of-life care for PWPD, considering the importance of hope and a reluctance to discuss dying, as well as the limited availability of palliative care services.

Schemes such as the universal *Inua Jamii* have great potential and the benefits recipients experience with regards to healthcare costs should be considered. Future research investigating the impact of chronic, degenerative disease on families and the benefits of social protection schemes for people in later life is required; Barrientos (2008) suggests that non-contributory pension schemes can reduce poverty and inequality in low-income countries. The impact of long-term chronic disease on working-age populations and the (lack of) support available to them also merits further study.

Finally, pilot studies developing PD support groups across SSA are required to assess the benefits and applicability to other countries. This would of course require in-country support and access to PD populations as well as support from international PD organisations for materials. Furthermore, intervention studies could assess the possibilities of collaborations with international organisations and the benefits of developing information packs and resources to improve PWPD and their families' understanding regarding PD management.

8.6 Conclusion

This study set out to understand the lived experiences of people living with Parkinson's disease in Kenya using an ethnographic approach. Empirical findings have shown, in more detail than previous studies, how people live with and manage PD, particularly concerning issues around diagnosis, therapeutic management, care in the home and at the end of life. Key theoretical findings identified were the crucial role of sociality in treatment, the obligation of families to care for older PWPD and consequences for interdependence in later life, the improvisation required to manage disease from diagnosis through to the end of life (albeit limited), and the importance of hope, faith and legitimacy throughout the PD journey. This thesis has raised important practical and policy implications concerning the diagnosis, and management, of PD, support groups as actors within the wider therapeutic landscape, the unaffordable costs of medication, and the poor coverage of pension and insurance schemes. 'Large-scale' implications, recognising the societal changes occurring in Kenya and aligning with the country's quest for universal health coverage, are also acknowledged.

If PWPD are to manage their condition well, the awareness about PD in Kenya needs to improve, while basic, essential medication needs to be made available and affordable. This will have far-reaching consequences for families who currently risk financial devastation trying to keep PWPD alive and prevent substantial suffering. The needs of older people with long term health conditions must also be acknowledged as a global public health challenge, while questioning outdated policy and development models; this could have significant benefits across society. The study's findings, and use of ethnographic methods, could help spur others to conduct similar work in low-resource settings to understand the experiences, and needs, of people living with PD globally.

Appendices

Appendix A: Information sheet and consent form for PWPD participating in questionnaire survey (English)

Information sheet and consent form for participation of PWPD in questionnaire

Part I: Information sheet

Introduction

My name is Natasha and I am a PhD student studying at Newcastle University in the United Kingdom. I am interested in finding out what living with Parkinson's disease is like for adults in Kenya. I am going to give you some information and invite you to be part of this research. You don't need to decide today about whether you want to participate in this research, and you can talk to someone about this before you decide. If there are parts of this information sheet that you do not understand, please let me know and I will take the time to explain this fully to you. If you have any questions later, I will provide my contact details and you can ask me about anything you are concerned about.

Purpose of the research

I want to learn about what it is like living with Parkinson's disease and what support there is available to you and your family.

What will you be asked to do?

If you would like to take part in this study, you will be asked a number of questions about your health and living situation and I will put your answers on a form. At the end of the questionnaire, I will ask you whether you'd be happy to be invited to participate in an interview at a later date, which you can say yes or no to.

Participant selection

You have been invited to take part in this research because we believe your experience of living with Parkinson's disease can contribute to our understanding of the disease, knowledge of the treatment options available to you and your experience of ageing.

Do you understand what the study is about?

Voluntary participation

Your participation in this research is entirely voluntary. It is your choice whether you participate or not. If you choose not to participate, all the services you receive will continue and nothing will change.

Do you understand that you do not have to participate in this research study if you don't want to?

Procedures

A. We are asking you to help us learn more about Parkinson's disease in your community. We are inviting you to take part in this research project. If you accept you will be asked to sign the consent form and we will ask you to complete a questionnaire.

B. I will ask you questions from the questionnaire and you can tell me the answer which I will write down or circle from the options. If you don't want to answer any of the questions in the questionnaire you can skip them and ask me to move on to the next question. The information being collected is confidential and your name will not be included in the forms, only a number will identify you.

C. If you decide after the questionnaire that you no longer want to be included in the study, I will delete all your information.

Duration

The questionnaire will take approximately 1 hour to complete.

Risks

We are asking you to share some personal and confidential information, and you may feel uncomfortable answering some of the questions. You don't have to answer any question if you don't want to and that is fine. You don't have to give a reason for not responding to any question. I understand that it can be emotional talking about this topic, and you can ask me to skip any questions you are not comfortable answering.

Benefits

There will be no direct benefit to you, except a better understanding of Parkinson's disease if you'd like to ask me any questions. Your participation is likely to help us find out more about how to treat Parkinson's disease in your community. The data from this study will help to inform policy in the future in order to improve services for Parkinson's disease.

Confidentiality

The questionnaires will be administered either in the hospital or in a place you feel comfortable. If the questionnaire is being done in your home, it may draw attention from other people in the community. I will not be sharing any information about you to anyone outside of the research team. The information collected from this study will be kept private. Any information about you will have a number on it instead of your name. Only the researchers will know what your number is, and we will lock that information up and keep it protected. It will not be shared with anyone except my supervisors who will help me understand the interviews.

Do you understand that the answers you provide will be kept confidential?

Sharing the results

Nothing that you tell me today will be shared with anybody outside the research team and nothing will be attributed to your name. Any results that come from this research will be made available to you if you wish. The results will be published so that other researchers and people interested in the research area may learn from this study.

Right to refuse or withdraw

You do not have to take part in this research if you do not wish to and choosing to participate will not affect your current treatment in any way. You may stop participating in the questionnaire at any time. I will give you an opportunity at the end of the questionnaire to check your responses and you can ask to modify parts if you find you did not understand the question correctly or I didn't understand your response.

This study was approved by the Faculty of Medical Sciences Research Ethics Committee, part of Newcastle University's Research Ethics Committee. This committee contains members who are internal to the Faculty, as well as one external member. This study was reviewed by members of the committee, who must provide impartial advice and avoid significant conflicts of interests.

Who to contact?

If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact any of the following:

Natasha Fothergill Misbah

+254…

n.fothergill-misbah@ncl.ac.uk

KEMRI/ERC:

The Secretary, Tel 020-2722541 or 0717719477

You can ask me any more questions about any part of the research study, if you wish to.

Do you have any questions?

Thank you for your cooperation.

Part II: Certificate of Consent

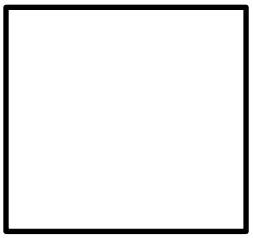
I have been invited to participate in research about Parkinson's disease in Kenya. This research will involve me completing a questionnaire. I have been given and read the information, or the information has been read to me. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study.

_____ _____

Name of participant Date

_____

Signature of participant



Thumb print

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands the details of the study. I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily. A copy of this Information and Consent Form has been provided to the participant.

_____ _____

Name of researcher Date

_____

Signature of researcher

I have read the information sheet and confirm that the confidentiality of the participant will be ensured at all times. I confirm that the information I translate today will not be shared with anyone and the participant will not be made identifiable.

_____ _____

Name of interpreter Date

_____

Signature of interpreter

Appendix B: Information sheet and consent form for PWPD participating in questionnaire survey (Kiswahili)

Fomu ya habari na idhini ya kushiriki kwa watu wanaougua ugonjwa wa kutetemeka katika Hojaji

Sehemu ya kwanza: Fomu ya habari

Utangulizi

Jina langu ni Natasha na mimi ni mwanafunzi wa Uzamifu katika Chuo kikuu cha Newcastle, Uingereza. Ningependa kujua jinsi kuishi na ugonjwa wa Kutetemeka kulivyo kwa watu wazima nchini Kenya. Nitakupa taarifa fulani kisha nikualike ushiriki kwenye utafiti huu. Sio lazima uamue leo kama unataka kushiriki kwenye utafiti huu na unaweza kuzungumza na mtu kuihusu kabla ya kuamua. Ikiwa kuna sehemu ya karatasi hii ya taarifa ambayo huielewi, tafadhali nifahamishe na nitachukua muda kukufafanulia zaidi. Ikiwa utakuwa na maswali yoyote baadaye, nitakupa taarifa kuhusu jinsi unavyoweza kuwasiliana nami na unaweza kuniuliza chochote ambacho huna uhakika nacho.

Lengo la utafiti

Ningependa kupata maelezo zaidi kuhusu hali ilivyo ya kuishi na ugonjwa wa kutetemeka na maoni yako kuhusiana na usaidizi unaopatikana kwako na familia yako.

Utahitajika kufanya nini

Ikiwa ungependa kushiriki katika utafiti huu, utaulizwa maswali mengi kuhusu afya yako na hali yako ya maisha na nitaandika majibu yako katika fomu. Mwishoni mwa hojaji hii, nitakuuliza iwapo utafurahia kualikwa kushiriki katika mahojiano ya tarehe ya baadaye, ambapo unaweza kukubali au kukataa.

Kuteuliwa kushiriki

Umealikwa kushiriki kwenye utafiti huu kwa sababu tunaamini kwamba uzoefu wako wa kuishi na ugonjwa wa kutetemeka unaweza kuchangia katika kuelewa kwetu kwa ugonjwa huu, maarifa ya chaguo za tiba zinazopatikana kwako na mambo unayoyashuhudia unapozeeka.

Je unaelewa utafiti huu unahusu nini?

Kushiriki kwa hiari

Kushiriki kwako katika utafiti huu ni kwa hiari kabisa. Ni chaguo lako kushiriki au kutoshiriki. Ukichagua kutoshiriki, utaendelea kupokea huduma zote ambazo ulikuwa unapokea na hakuna kitu kitakachobadilika.

Je, unaelewa kwamba si lazima ushiriki katika utafiti huu ikiwa hutaki kufanya hivyo?

Hatua

A. Tunakuomba utusaidie kujua zaidi kuhusu ugonjwa wa kutetemeka katika jamii yako. Tunakualika kushiriki katika mradi huu wa kiutafiti. Ukikubali utaulizwa utie sahihi kwenye fomu ya idhini na tutakuomba ujaze hojaji.
B. Nitakuuliza maswali kutoka kwa hojaji na unaweza kuniambia jibu ambalo nitanukuu au nitavingira katika chaguo. Ikiwa hutaki kujibu swali lolote katika hojaji, tunaweza kulipita na kuniambia niende kwa swali linalofuata. Habari inayokusanywa ni ya siri na jina lako halitawekwa katika hizo fomu, nambari tu ndiyo itakutambulisha.
C. Ukiamua baada ya hojaji kwamba hutaki kujumuishwa kwenye utafiti, nitafuta habari zako zote.

Muda

Kujaza hojaji hii kutakuchukua takriban saa 1.

Hatari

Tunakuomba ushiriki baadhi ya habari ambazo ni za kibinafsi na za siri, na unaweza kufadhaika kujibu maswali mengine. Hutahitajika kujibu swali lolote ikiwa hutaki kufanya hivyo na hiyo ni sawa. Hutahitajika kutoa sababu ya kutojibu swali lolote. Ninaelewa kwamba kuzungumzia mada hii kunaweza kusababisha hisia sana, na unaweza kuniambia niruke swali lolote ambalo huna uwezo wa kulijibu.

Manufaa

Hakutakuwa na manufaa ya moja kwa moja kwako, isipokuwa kwamba utaelewa zaidi kuhusu ugonjwa wa kutetemeka ikiwa ungependa kuniuliza maswali. Kushiriki kwako kunaweza kutusaidia kujua zaidi kuhusu jinsi ya kutibu ugonjwa wa kutetemeka katika jamii yako. Data itakayotokana na utafiti huu itatumiwa kuchangia uwekaji wa sera siku za usoni ili kuboresha huduma za ugonjwa wa kutetemeka.

Siri

Hojaji zitatolewa ama kwa hospitali au katika pahali unapojihisi sawa napo. Ikiwa hojaji inaendeshwa nyumbani kwako, inaweza kuvutia umakini wa watu wengine wa jamii. Sitashiriki habari zozote zinazokuhusu na mtu yeyote nje ya timu ya utafiti. Habari zitakazokusanywa kutoka kwa utafiti huu zitakuwa siri. Habari zozote utakazotoa zitakuwa na nambari badala ya jina lako. Watafiti pekee ndio watakaojua nambari yako na tutafungia taarifa hiyo na tuiweke salama. Haitashirikiwa na mtu yeyote isipokuwa wasimamizi wangu watakaonisaidia kuelewa mahojiano.

Je, unaelewa kuwa majibu utakayotoa yatabaki kuwa siri?

Kushiriki matokeo

Hakuna chochote utakachoniambia leo kitakachoshirikiwa na mtu yeyote nje ya timu ya utafiti na hakuna kitu kitakachorejelewa kwa jina lako. Matokeo yoyote yatakayotokana na utafiti huu yatatolewa kwako ikiwa utayahitaji. Matokeo yatachapishwa ili watafiti na watu wengine wanaojishughulisha na aina hii ya utafiti wanufaike na utafiti huu.

Haki ya kukataa au kujiondoa

Sio lazima ushiriki katika huu utafiti ikiwa hupendelei kushiriki, na kuchagua kushiriki hakutaathiri matibabu yako ya sasa kwa njia yoyote. Unaweza kuacha kushiriki kwenye hojaji wakati wowote. Nitakupatia fursa mwishoni mwa hojaji kupitia majibu yako na unaweza kuuliza kurekebisha baadhi ya sehemu ukipata kuwa hukufahamu swali vyema au hukulielewa jibu lako.

Utafiti huu uliidhinishwa na Kamati ya Maadili ya Kiutafiti ya Kitivo cha Sayansi za Kimatibabu, ambayo ni sehemu ya Kamati ya Maadili ya Kiutafiti ya Chuo Kikuu cha Newcastle. Kamati hii ina wanachama ambao wanatoka ndani ya Idara, pamoja na mmoja kutoka nje. Utafiti huu ulipitiwa na wanachama wa kamati, ambao ni lazima watoe ushauri usioegemea upande wowote na waepuke kujali maslahi ya kibinafsi tu.

Mtu wa kuwasiliana naye

Ikiwa una maswali yoyote,unaweza kuyauliza sasa au baadaye. Ukitaka kuuliza maswali baadaye, unaweza kuwasiliana na yeyote kati ya hawa:

Natasha Fothergill Misbah
+254…
n.fothergill-misbah@ncl.ac.uk

KEMRI/ERC:
The Secretary, Tel 020-2722541 or 0717719477

Ikiwa unataka, unaweza kuniuliza maswali yoyote zaidi kuhusu sehemu yoyote ya utafiti huu.

Je, una maswali yoyote?

Ahsante kwa ushirikiano wako.

Sehemu ya Pili: Cheti cha idhini

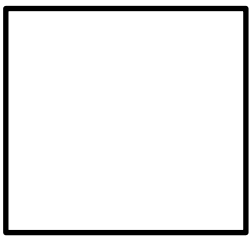
Nimealikwa kushiriki katika utafiti unaohusu ugonjwa wa kutetemeka nchini Kenya. Utafiti huu utahusisha mimi kushiriki katika mahojiano. Nimepewa taarifa na kuzisoma, au nimesomewa taarifa hizo. Nilikuwa na nafasi ya kuuliza maswali kuhusu utafiti na maswali yote niliyoyauliza yalijibiwa na nikaridhika. Ninakubali kwa hiari kuwa mshiriki katika utafiti huu.

_____ _____

Jina la mshiriki Tarehe

_____

Sahihi ya mshiriki



Kidole

Nimemsomea mshiriki mtarajiwa karatasi ya taarifa vizuri, na nikahakikisha kadri ninavyoweza kwamba mshiriki ameelewa masuala ya utafiti. Ninathibitisha kuwa mshiriki alipewa nafasi ya kuuliza maswali kuhusu utafiti, na maswali yote yaliyoulizwa na mshiriki yamejibiwa kwa usahihi na kadri ya uwezo wangu. Ninathibitisha kuwa mtu huyo hakulazimishwa kutoa idhini, na kwamba alitoa idhini akiwa huru na kwa hiari. Mshiriki allipewa nakala ya taarifa hii pamoja na fomu ya idhini.

_____ _____

Jina la mtafiti Tarehe

_____

Sahihi ya mtafiti

Nimesoma karatasi ya taarifa na ninathibitisha kuwa siri za mshiriki zitadumishwa wakati wote. Ninathibitisha kuwa taarifa ninazotafsiri leo hazitashirikiwa na mtu yeyote na mshiriki hatatambulishwa.

_____ _____

Jina la mkalimani Tarehe

_____

Sahihi ya mkalimani

Appendix C: Information sheet and consent form for PWPD participating in formal interview (English)

Information sheet and consent form for participation of PWPD in formal interview

Part I: Information sheet

Introduction

My name is Natasha and I am a PhD student studying at Newcastle University in the United Kingdom. I am interested in finding out what living with Parkinson's disease is like for adults in Kenya. I am going to give you some information and invite you to be part of this research. You don't need to decide today about whether you want to participate in this research and you can talk to someone about this before you decide. If there are parts of this information sheet that you do not understand, please let me know and I will take the time to explain this fully to you. If you have any questions later, I will provide my contact details and you can ask me about anything you are concerned about.

Purpose of the research

I want to learn more about what it is like living with Parkinson's disease and what your perceptions of available treatment are. I would also like to understand your experiences of ageing, the care you receive and your family or community relationships.

What will you be asked to do?

You are being contacted about this study as you have previously said that you would be happy to take part in an in-depth interview. If you would like to take part in this study, you will be taking part in a face-to-face interview with me. You may have a family member or carer present during the interview if you'd like but I will be addressing the questions to you.

Participation selection

You have been invited to take part in this research because we believe your experience of living with Parkinson's disease can contribute to our understanding of the disease, knowledge of treatment options available to you and your experience of ageing.

Do you understand what the study is about?

Voluntary participation

Your participation in this research is entirely voluntary. It is your choice whether you participate or not. If you choose not to participate, all the services you receive will continue and nothing will change.

Do you understand that you do not have to participate in this research study if you don't want to?

Procedures

A. We are asking you to help us learn more about Parkinson's disease in your community. We are inviting you to take part in this research project. If you accept you will be asked to sign the consent form and we will ask you to take part in an interview.

B. If you choose to participate in an interview, I will sit down with you in a comfortable place at the hospital or if it's better for you, at your family home. The interview will not be formal, I want to hear your views and opinions on the topic and hear about your experiences. There is no right or wrong answer, so you would just need to be as honest as you can. If you don't want to answer any of the questions, then we can skip them and move on to the next question. The interview will be audio recorded with your consent; however, you will not be identifiable on the recording. Recording the interview allows us to analyse the data from the interviews. I will be assisted by an interpreter to help with the interviews, who will also ensure your confidentiality.

C. If you decide after the interview that you no longer want to be included in the study, I will delete all your information and the interview.

Duration

The interview will last approximately 1.5 hours, however, if you'd like to stop it before then that is absolutely fine.

Risks

We are asking you to share some personal and confidential information, and you may feel uncomfortable talking about some of the topics. You don't have to answer any question if you don't want to and that is fine. You don't have to give a reason for not responding to any question. I understand that it can be emotional talking about this topic, and you can ask me to skip any questions you are not comfortable answering.

Benefits

There will be no direct benefit to you, except a better understanding of Parkinson's disease if you'd like to ask me any questions. Your participation is likely to help us find out more about how to treat Parkinson's disease in your community. The data from this study will help to inform policy in the future in order to improve services for Parkinson's disease.

Confidentiality

The interviews will be conducted either in the hospital in a quiet, private room or in a location you feel comfortable, such as your home. If the interview is taking place in your home, it may draw attention from other people in the community. I will not be sharing any

information about you to anyone outside of the research team. The information collected from this study will be kept private. Any information about you will have a number on it instead of your name. Only the researchers will know what your number is and we will lock that information up and keep it protected. It will not be shared with anyone except my supervisors who will help me understand the interviews.

Do you understand that the answers you provide will be kept confidential?

Sharing the results

Nothing that you tell me today will be shared with anybody outside the research team and nothing will be attributed to your name. Any results that come from this research will be made available to you if you wish. The results will be published so that other researchers and people interested in the research area may learn from this study.

Right to refuse or withdraw

You do not have to take part in this research if you do not wish to and choosing to participate will not affect your current treatment in any way. You may stop participating in the interview at any time. If you decide at the end of the interview that you don't want the information you have provided to be used in this study, I will delete the recording.

This study was approved by the Faculty of Medical Sciences Research Ethics Committee, part of Newcastle University's Research Ethics Committee. This committee contains members who are internal to the Faculty, as well as one external member. This study was reviewed by members of the committee, who must provide impartial advice and avoid significant conflicts of interests.

Who to contact?

If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact any of the following:

Natasha Fothergill Misbah
+254…
n.fothergill-misbah@ncl.ac.uk

KEMRI/ERC:
The Secretary, Tel 020-2722541 or 0717719477

You can ask me any more questions about any part of the research study, if you wish to.

Do you have any questions?

Thank you for your cooperation.

Part II: Certificate of Consent

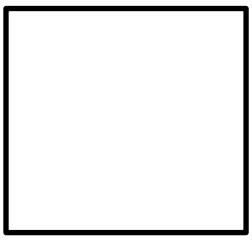
I have been invited to participate in research about Parkinson's disease in Kenya. This research will involve me participating in an interview. I have been given and read the information, or the information has been read to me. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study.

_____ _____

Name of participant Date

_____

Signature of participant



Thumb print

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands the details of the study. I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily. A copy of this Information and Consent Form has been provided to the participant.

_____ _____

Name of researcher Date

_____

Signature of researcher

I have read the information sheet and confirm that the confidentiality of the participant will be ensured at all times. I confirm that the information I translate today will not be shared with anyone and the participant will not be made identifiable.

_____ _____

Name of interpreter Date

_____

Signature of interpreter

Appendix D: Information sheet and consent form for PWPD participating in formal interview (Kiswahili)

Fomu ya habari na idhini ya kushiriki kwa mtu anayeugua ugonjwa wa Kutetemeka katika mahojiano

Sehemu ya kwanza: Fomu ya habari

Utangulizi

Jina langu ni Natasha na mimi ni mwanafunzi wa Uzamifu katika Chuo kikuu cha Newcastle, Uingereza. Ningependa kujua jinsi kuishi na ugonjwa wa Kutetemeka kulivyo kwa watu wazima nchini Kenya. Nitakupa taarifa fulani kisha nikualike ushiriki kwenye utafiti huu. Sio lazima uamue leo kama unataka kushiriki kwenye utafiti huu na unaweza kuzungumza na mtu kuihusu kabla ya kuamua. Ikiwa kuna sehemu ya karatasi hii ya taarifa ambayo huielewi, tafadhali nifahamishe na nitachukua muda kukufafanulia zaidi. Ikiwa utakuwa na maswali yoyote baadaye, nitakupa taarifa kuhusu jinsi unavyoweza kuwasiliana nami na unaweza kuniuliza chochote ambacho huna uhakika nacho.

Lengo la utafiti

Ningependa kupata maelezo zaidi kuhusu hali ilivyo ya kuishi na ugonjwa wa kutetemeka na maoni yako kuhusiana na tiba inayopatikana. Pia ningependa kuelewa kuhusu mambo uliyoyashuhudia kuhusiana na uzee, utunzaji unaopokea na uhusiano wako na familia yako au jamii.

Utahitajika kufanya nini

Unahusishwa katika utafiti huu kwa sababu hapo awali umesema kuwa ungefurahia kushiriki katika mahojiano ya kina. Ikiwa ungependa kushiriki katika utafiti huu, utakuwa ukishiriki kwenye mahojiano ya ana kwa ana na mimi. Ikiwa utapenda, mwanafamilia au mtunzaji wako anaweza kuwepo wakati wa mahojiano lakini nitakuwa nikiyaelekeza maswali kwako.

Kuteuliwa kushiriki

Umealikwa kushiriki kwenye utafiti huu kwa sababu tunaamini kwamba uzoefu wako wa kuishi na ugonjwa wa kutetemeka unaweza kuchangia katika kuelewa kwetu kwa ugonjwa huu, maarifa ya chaguo za tiba zinazopatikana kwako na mambo unayoyashuhudia unapozeeka.

Je unaelewa utafiti huu unahusu nini?

Kushiriki kwa hiari

Kushiriki kwako katika utafiti huu ni kwa hiari kabisa. Ni chaguo lako kushiriki au kutoshiriki. Ukichagua kutoshiriki, utaendelea kupokea huduma zote ambazo ulikuwa unapokea na hakuna kitu kitakachobadilika.

Je, unaelewa kwamba si lazima ushiriki katika utafiti huu ikiwa hutaki kufanya hivyo?

Hatua

A. Tunakuomba utusaidie kujua zaidi kuhusu ugonjwa wa kutetemeka katika jamii yako. Tunakualika kushiriki katika mradi huu wa kiutafiti. Ukikubali utaulizwa utie sahihi kwenye fomu ya idhini na tutakuomba ushiriki katika mahojiano.
B. Ukichagua kushiriki katika mahojiano, nitakaa chini nawe mahali pazuri hospitalini au nyumbani kwa familia yako kama utapendelea hivyo. Mahojiano yatakuwa rasmi, ningependa kuyasikia maoni yako kuhusu mada hii na kuhusu mambo uliyoyapitia. Hakuna jibu sahihi au lisilo sahihi, kwa hivyo utahitajika tu kuwa mwaminifu kadri unavyoweza. Ikiwa hutaki kujibu swali lolote, tunaweza kulipita na kuendelea hadi kwa swali linalofuata. Mahojiano yatarekodiwa kwa idhini yako, hata hivyo, hutatambulishwa kwenye rekodi hiyo. Kurekodi mahojiano hutuhusu kuchanganua data inayotokana na mahojiano. Nitasaidiwa na mkalimani kwenye mahojiano, ambaye pia atahakikisha kuwa siri imedumishwa.
C. Ukiamua baada ya mahojiano kwamba hutaki kujumuishwa kwenye utafiti, nitafuta habari zote ulizotoa pamoja na mahojiano.

Muda

Mahojiano yatachukua kama saa 1.5, hata hivyo, ukitaka kuyakomesha kabla ya muda huo kuisha basi hiyo ni sawa kabisa.

Hatari

Tunakuomba ushiriki baadhi ya habari ambazo ni za kibinafsi na za siri, na unaweza kufadhaika kuzungumzia mada zingine. Hutahitajika kujibu swali lolote ikiwa hutaki kufanya hivyo na hiyo ni sawa. Hutahitajika kutoa sababu ya kutojibu swali lolote. Ninaelewa kwamba kuzungumzia mada hii kunaweza kusababisha hisia sana, na unaweza kuniambia niruke swali lolote ambalo huna uwezo wa kulijibu.

Manufaa

Hakutakuwa na manufaa ya moja kwa moja kwako, isipokuwa kwamba utaelewa zaidi kuhusu ugonjwa wa kutetemeka ikiwa ungependa kuniuliza maswali. Kushiriki kwako kunaweza kutusaidia kujua zaidi kuhusu jinsi ya kutibu ugonjwa wa kutetemeka katika jamii yako. Data itakayotokana na utafiti huu itatumiwa kuchangia uwekaji wa sera siku za usoni ili kuboresha huduma za ugonjwa wa kutetemeka.

Siri:

Mahojiano yataendeshwa ama hospitalini mahali faraghani pasipo na kelele au mahali utakapopendelea wewe, kama vile nyumbani kwako. Ikiwa mahojiano yanaendeshwa nyumbani kwako, yanaweza kuvutia umakini wa watu wengine wa jamii. Sitashiriki habari zozote zinazokuhusu na mtu yeyote nje ya timu ya utafiti. Habari zitakazokusanywa kutoka kwa utafiti huu zitakuwa siri. Habari zozote utakazotoa zitakuwa na nambari badala ya jina lako. Watafiti pekee ndio watakaojua nambari yako na tutafungia taarifa hiyo na tuiweke salama. Haitashirikiwa na mtu yeyote isipokuwa wasimamizi wangu watakaonisaidia kuelewa mahojiano.

Je, unaelewa kuwa majibu utakayotoa yatabaki kuwa siri?

Kushiriki matokeo

Hakuna chochote utakachoniambia leo kitakachoshirikiwa na mtu yeyote nje ya timu ya utafiti na hakuna kitu kitakachorejelewa kwa jina lako. Matokeo yoyote yatakayotokana na utafiti huu yatatolewa kwako ikiwa utayahitaji. Matokeo yatachapishwa ili watafiti na watu wengine wanaojishughulisha na aina hii ya utafiti wanufaike na utafiti huu.

Haki ya kukataa au kujiondoa

Sio lazima ushiriki katika huu utafiti ikiwa hupendelei kushiriki, na kuchagua kushiriki hakutaathiri matibabu yako ya sasa kwa njia yoyote. Unaweza kuacha kushiriki kwenye mahojiano wakati wowote. Ikiwa mwishoni mwa mahojiano utaamua kwamba hutaki taarifa ulizotoa zitumiwe katika utafiti huu, nitafuta yale yaliyorekodiwa.

Utafiti huu uliidhinishwa na Kamati ya Maadili ya Kiutafiti ya Kitivo cha Sayansi za Kimatibabu, ambayo ni sehemu ya Kamati ya Maadili ya Kiutafiti ya Chuo Kikuu cha Newcastle. Kamati hii ina wanachama ambao wanatoka ndani ya Idara, pamoja na mmoja kutoka nje. Utafiti huu ulipitiwa na wanachama wa kamati, ambao ni lazima watoe ushauri usioegemea upande wowote na waepuke kujali maslahi ya kibinafsi tu.

Mtu wa kuwasiliana naye

Ikiwa una maswali yoyote,unaweza kuyauliza sasa au baadaye. Ukitaka kuuliza maswali baadaye, unaweza kuwasiliana na yeyote kati ya hawa:

Natasha Fothergill Misbah
+254…
n.fothergill-misbah@ncl.ac.uk

KEMRI/ERC:
The Secretary, Tel 020-2722541 or 0717719477

Ikiwa unataka, unaweza kuniuliza maswali yoyote zaidi kuhusu sehemu yoyote ya utafiti huu.

Je, una maswali yoyote?

Ahsante kwa ushirikiano wako.

Sehemu ya Pili: Cheti cha idhini

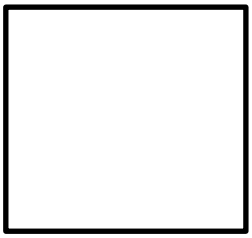
Nimealikwa kushiriki katika utafiti unaohusu ugonjwa wa kutetemeka nchini Kenya. Utafiti huu utahusisha mimi kushiriki katika mahojiano. Nimepewa taarifa na kuzisoma, au nimesomewa taarifa hizo. Nilikuwa na nafasi ya kuuliza maswali kuhusu utafiti na maswali yote niliyoyauliza yalijibiwa na nikaridhika. Ninakubali kwa hiari kuwa mshiriki katika utafiti huu.

_____ _____

Jina la mshiriki Tarehe

_____

Sahihi ya mshiriki



Kidole

Nimemsomea mshiriki mtarajiwa karatasi ya taarifa vizuri, na nikahakikisha kadri ninavyoweza kwamba mshiriki ameelewa masuala ya utafiti. Ninathibitisha kuwa mshiriki alipewa nafasi ya kuuliza maswali kuhusu utafiti, na maswali yote yaliyoulizwa na mshiriki yamejibiwa kwa usahihi na kadri ya uwezo wangu. Ninathibitisha kuwa mtu huyo hakulazimishwa kutoa idhini, na kwamba alitoa idhini akiwa huru na kwa hiari. Mshiriki allipewa nakala ya taarifa hii pamoja na fomu ya idhini.

_____ _____

Jina la mtafiti Tarehe

_____

Sahihi ya mtafiti

Nimesoma karatasi ya taarifa na ninathibitisha kuwa siri za mshiriki zitadumishwa wakati wote. Ninathibitisha kuwa taarifa ninazotafsiri leo hazitashirikiwa na mtu yeyote na mshiriki hatatambulishwa.

_____ _____

Jina la mkalimani Tarehe

_____

Sahihi ya mkalimani

Appendix E: Interview schedule for formal interviews with PWPD

Topic guide for semi-structured interviews with person with Parkinson's disease

Participant number: _____

Date and place of interview: _____

Time start: _____

Time end: _____

Voice recorded? Yes No

Introduction

Thank you so much for agreeing to take part in this interview. I'm Natasha and I'm from Newcastle University in the UK. I am conducting this study to understand adults' experiences of living with Parkinson's disease in Nairobi. I want to hear your views and opinions and listen to your experience of Parkinson's disease, treatment and services available to you and your experience of ageing. There are no right or wrong answers and I won't judge your views and opinions. Everything you say will be anonymous, even from my research team, so be as honest as you can. The interview should last about an hour and a half, but if you'd like to stop it before then that is fine. If I ask anything that you are not comfortable answering please let me know and we can move on to a different question or stop the interview if you'd like. With your permission I will be recording the interview and you won't be identifiable on the recording. This is to allow me to transcribe the interview so I can analyse it later. An interpreter is present to help me translate the questions to you and translate your responses as well.

Is there anything you'd like to ask me before we start the interview?

Interview

Firstly, could you tell me about your life before you had PD?

Examples to probe around:

- What kind of work did you do?
- Can you tell me about when you first noticed symptoms of PD?
- How did your condition change?

Can you tell me about what it is like living with PD now?

Examples to probe around:

- How do you manage day to day? How has it affected your work?

- How has your condition changed over the years?
- Has it changed your ability to carry out daily tasks? If so, how?

Can you tell me about the treatment you have had for PD?

Examples to probe around:

- How do you feel about the medication you've received? For example, any side effects, the cost, availability?
- You mentioned you stopped taking medication (if appropriate), could you tell me why?
- You mentioned you had seen a traditional healer/faith healer, can you tell me about this? (if appropriate)
- How do you think the traditional/faith healer helped you? (if appropriate)
- How do you feel about the PD services available to you, for example at the hospital, any support groups you attend?

Can you tell me about your family?

Examples to probe around:

- You told me you lived with [relations], could you tell me about your relationships with them?
- You identified [relation] as your main caregiver, can you tell me about your relationship? How do they support you?
- What is your relationship like with your [children/grandchildren] (if don't live with them)?
- Could you tell me about your role within your family?

End

Thank you so much for giving up your time to take part in this research and for revealing some 'emotional' information (appropriate word depending on what has been said in interview).

Is there anything else you'd like to talk about that you think is important that we haven't covered?

Thank you again, this recording will be kept safe and will be transcribed over the next few weeks and made anonymous.

Appendix F: Information sheet and consent form for family member participating in formal interview (English)

Information sheet and consent form for participation of family member in formal interview

Part I: Information sheet

Introduction

My name is Natasha and I am a PhD student studying at Newcastle University in the United Kingdom. I am interested in finding out what living with Parkinson's disease is like for adults in Kenya, as well as what it is like caring for someone with Parkinson's disease. I am going to give you some information and invite you to be part of this research. You don't need to decide today about whether you want to participate in this research, and you can talk to someone about this before you decide. If there are parts of this information sheet that you do not understand, please let me know and I will take the time to explain this fully to you. If you have any questions later, I will provide my contact details and you can ask me about anything you are concerned about.

Purpose of the research

I want to learn more about what it is like caring for someone with Parkinson's disease and what your perceptions of available treatment are. I would also like to understand your experiences of the services available to you and your family.

What will you be asked to do?

If you would like to take part in this study, you will be taking part in a face-to-face interview with me. You may have a family member present during the interview if you'd like but I will be addressing the questions to you.

Participation selection

You have been invited to take part in this research because we believe your experience of caring for someone with Parkinson's disease can contribute to our understanding of the disease and knowledge of treatment options and services available.

Do you understand what the study is about?

Voluntary participation

Your participation in this research is entirely voluntary. It is your choice whether you participate or not. If you choose not to participate, all the services your relative receives will continue and nothing will change.

Do you understand that you do not have to participate in this research study if you don't want to?

Procedures

A. We are asking you to help us learn more about Parkinson's disease in your community. We are inviting you to take part in this research project. If you accept you will be asked to sign the consent form and we will ask you to take part in an interview.

B. If you choose to participate in an interview, I will sit down with you in a comfortable place at the hospital or if it's better for you, at your family home. The interview will not be formal, I want to hear your views and opinions on the topic and hear about your experiences. There is no right or wrong answer, so you would just need to be as honest as you can. If you don't want to answer any of the questions, then we can skip them and move on to the next question. The interview will be audio recorded with your consent; however, you will not be identifiable on the recording. Recording the interview allows us to analyse the data from the interviews. I will be assisted by an interpreter to help with the interviews, who will also ensure your confidentiality.

C. If you decide after the interview that you no longer want to be included in the study, I will delete all your information and the interview.

Duration

The interview will last approximately 1 hour, however, if you'd like to stop it before then that is absolutely fine.

Risks

We are asking you to share some personal and confidential information, and you may feel uncomfortable talking about some of the topics. You don't have to answer any question if you don't want to and that is fine. You don't have to give a reason for not responding to any question. I understand that it can be emotional talking about this topic, and you can ask me to skip any questions you are not comfortable answering.

Benefits

There will be no direct benefit to you, except a better understanding of Parkinson's disease if you'd like to ask me any questions. Your participation is likely to help us find out more about how to treat Parkinson's disease in your community. The data from this study will help to inform policy in the future in order to improve services for Parkinson's disease.

Confidentiality

The interviews will be conducted either in the hospital in a quiet, private room or in a location you feel comfortable, such as your home. If the interview is taking place in your home, it may draw attention from other people in the community. I will not be sharing any

information about you to anyone outside of the research team. The information collected from this study will be kept private. Any information about you will have a number on it instead of your name. Only the researchers will know what your number is and we will lock that information up and keep it protected. It will not be shared with anyone except my supervisors who will help me understand the interviews.

Do you understand that the answers you provide will be kept confidential?

Sharing the results

Nothing that you tell me today will be shared with anybody outside the research team and nothing will be attributed to your name. Any results that come from this research will be made available to you if you wish. The results will be published so that other researchers and people interested in the research area may learn from this study.

Right to refuse or withdraw

You do not have to take part in this research if you do not wish to and choosing to participate will not affect your relative's current treatment in any way. You may stop participating in the interview at any time. If you decide at the end of the interview that you don't want the information you have provided to be used in this study, I will delete the recording.

This study was approved by the Faculty of Medical Sciences Research Ethics Committee, part of Newcastle University's Research Ethics Committee. This committee contains members who are internal to the Faculty, as well as one external member. This study was reviewed by members of the committee, who must provide impartial advice and avoid significant conflicts of interests.

Who to contact?

If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact any of the following:

Natasha Fothergill Misbah
+254…
n.fothergill-misbah@ncl.ac.uk

KEMRI/ERC:

The Secretary, Tel 020-2722541 or 0717719477

You can ask me any more questions about any part of the research study, if you wish to.

Do you have any questions?

Thank you for your cooperation.

Part II: Certificate of Consent

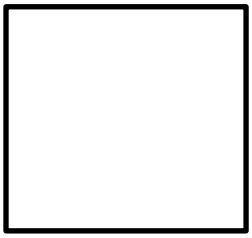
I have been invited to participate in research about Parkinson's disease in Kenya. This research will involve me participating in an interview. I have been given and read the information, or the information has been read to me. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study.

_____ _____

Name of participant Date

_____

Signature of participant



Thumb print

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the details of the study. I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily. A copy of this Information and Consent Form has been provided to the participant.

_____ _____

Name of researcher Date

_____

Signature of researcher

I have read the information sheet and confirm that the confidentiality of the participant will be ensured at all times. I confirm that the information I translate today will not be shared with anyone and the participant will not be made identifiable.

_____ _____

Name of interpreter Date

_____

Signature of interpreter

Appendix G: Information sheet and consent form for family member participating in formal interview (Kiswahili)

Fomu ya habari na idhini ya kushiriki kwa mwanafamilia katika mahojiano

Sehemu ya kwanza: Fomu ya habari

Utangulizi

Jina langu ni Natasha na mimi ni mwanafunzi wa Uzamifu katika Chuo kikuu cha Newcastle, Uingereza. Ningependa kujua jinsi kuishi na ugonjwa wa kutetemeka kulivyo kwa watu wazima nchini Kenya, na vile vile ilivyo kumtunza mtu anayeugua ugonjwa wa kutetemeka. Nitakupa taarifa fulani kisha nikualike ushiriki kwenye utafiti huu. Sio lazima uamue leo kama unataka kushiriki kwenye utafiti huu na unaweza kuzungumza na mtu kuihusu kabla ya kuamua. Ikiwa kuna sehemu ya karatasi hii ya taarifa ambayo huielewi, tafadhali nifahamishe na nitachukua muda kukufafanulia zaidi. Ikiwa utakuwa na maswali yoyote baadaye, nitakupa taarifa kuhusu jinsi unavyoweza kuwasiliana nami na unaweza kuniuliza chochote ambacho huna uhakika nacho.

Lengo la utafiti

Ningependa kupata maelezo zaidi kuhusu hali ya kumtunza mtu anayeugua ugonjwa wa kutetemeka ilivyo na maoni yako kuhusiana na tiba inayopatikana. Pia ningependa kuelewa kuhusu mambo uliyoyashuhudia kuhusiana na huduma zinazopatikana kwako na kwa familia yako.

Utahitajika kufanya nini

Unahusishwa katika utafiti huu kwa sababu hapo awali umesema kuwa ungefurahia kushiriki katika mahojiano ya kina. Ikiwa ungependa kushiriki katika utafiti huu, utakuwa ukishiriki kwenye mahojiano ya ana kwa ana na mimi. Ikiwa utapenda, mwanafamilia au mtunzaji wako anaweza kuwepo wakati wa mahojiano lakini nitakuwa nikiyaelekeza maswali kwako.

Kuteuliwa kushiriki

Umealikwa kushiriki kwenye utafiti huu kwa sababu tunaamini kwamba uzoefu wako wa kumtunza mtu anayeugua ugonjwa wa kutetemeka unaweza kuchangia katika kuelewa kwetu kwa ugonjwa huu na maarifa ya chaguo za tiba na huduma zilizopo.

Je unaelewa utafiti huu unahusu nini?

Kushiriki kwa hiari

Kushiriki kwako katika utafiti huu ni kwa hiari kabisa. Ni chaguo lako kushiriki au kutoshiriki. Ukichagua kutoshiriki, jamaa yako ataendelea kupokea huduma zote ambazo alikuwa akipata na hakuna kitu kitakachobadilika.

Je, unaelewa kwamba si lazima ushiriki katika utafiti huu ikiwa hutaki kufanya hivyo?

Hatua

A. Tunakuomba utusaidie kujua zaidi kuhusu ugonjwa wa kutetemeka katika jamii yako. Tunakualika kushiriki katika mradi huu wa kiutafiti. Ukikubali utaulizwa utie sahihi kwenye fomu ya idhini na tutakuomba ushiriki katika mahojiano.
B. Ukichagua kushiriki katika mahojiano, nitakaa chini nawe mahali pazuri hospitalini au nyumbani kwa familia yako kama utapendelea hivyo. Mahojiano yatakuwa rasmi, ningependa kuyasikia maoni yako kuhusu mada hii na kuhusu mambo uliyoyapitia. Hakuna jibu sahihi au lisilo sahihi, kwa hivyo utahitajika tu kuwa mwaminifu kadri unavyoweza. Ikiwa hutaki kujibu swali lolote, tunaweza kulipita na kuendelea hadi kwa swali linalofuata. Mahojiano yatarekodiwa kwa idhini yako, hata hivyo, hutatambulishwa kwenye rekodi hiyo. Kurekodi mahojiano huturuhusu kuchanganua data inayotokana na mahojiano. Nitasaidiwa na mkalimani kwenye mahojiano, ambaye pia atahakikisha kuwa siri imedumishwa.
C. Ukiamua baada ya mahojiano kwamba hutaki kujumuishwa kwenye utafiti, nitafuta habari zote ulizotoa pamoja na mahojiano.

Muda

Mahojiano yatachukua kama saa 1.5, hata hivyo, ukitaka kuyakomesha kabla ya muda huo kuisha basi hiyo ni sawa kabisa.

Hatari

Tunakuomba ushiriki baadhi ya habari ambazo ni za kibinafsi na za siri, na unaweza kufadhaika kuzungumzia mada zingine. Hutahitajika kujibu swali lolote ikiwa hutaki kufanya hivyo na hiyo ni sawa. Hutahitajika kutoa sababu ya kutojibu swali lolote. Ninaelewa kwamba kuzungumzia mada hii kunaweza kusababisha hisia sana, na unaweza kuniambia niruke swali lolote ambalo huna uwezo wa kulijibu.

Manufaa

Hakutakuwa na manufaa ya moja kwa moja kwako, isipokuwa kwamba utaelewa zaidi kuhusu ugonjwa wa kutetemeka ikiwa ungependa kuniuliza maswali. Kushiriki kwako kunaweza kutusaidia kujua zaidi kuhusu jinsi ya kutibu ugonjwa wa kutetemeka katika jamii yako. Data itakayotokana na utafiti huu itatumiwa kuchangia uwekaji wa sera siku za usoni ili kuboresha huduma za ugonjwa wa kutetemeka.

Siri

Mahojiano yataendeshwa ama hospitalini mahali faraghani pasipo na kelele au mahali utakapopendelea wewe, kama vile nyumbani kwako. Ikiwa mahojiano yanaendeshwa nyumbani kwako, yanaweza kuvutia umakini wa watu wengine wa jamii. Sitashiriki habari zozote zinazokuhusu na mtu yeyote nje ya timu ya utafiti. Habari zitakazokusanywa kutoka kwa utafiti huu zitakuwa siri. Habari zozote utakazotoa zitakuwa na nambari badala ya jina lako. Watafiti pekee ndio watakaojua nambari yako na tutafungia taarifa hiyo na tuiweke salama. Haitashirikiwa na mtu yeyote isipokuwa wasimamizi wangu watakaonisaidia kuelewa mahojiano.

Je, unaelewa kuwa majibu utakayotoa yatabaki kuwa siri?

Kushiriki matokeo

Hakuna chochote utakachoniambia leo kitakachoshirikiwa na mtu yeyote nje ya timu ya utafiti na hakuna kitu kitakachorejelewa kwa jina lako. Matokeo yoyote yatakayotokana na utafiti huu yatatolewa kwako ikiwa utayahitaji. Matokeo yatachapishwa ili watafiti na watu wengine wanaojishughulisha na aina hii ya utafiti wanufaike na utafiti huu.

Haki ya kukataa au kujiondoa

Sio lazima ushiriki katika utafiti huu ikiwa hupendelei kushiriki, na kuchagua kushiriki hakutaathiri matibabu ya sasa ya jamaa yako kwa njia yoyote. Unaweza kuacha kushiriki kwenye mahojiano wakati wowote. Ikiwa mwishoni mwa mahojiano utaamua kwamba hutaki taarifa ulizotoa zitumiwe katika utafiti huu, nitafuta yale yaliyorekodiwa.

Utafiti huu uliidhinishwa na Kamati ya Maadili ya Kiutafiti ya Kitivo cha Sayansi za Kimatibabu, ambayo ni sehemu ya Kamati ya Maadili ya Kiutafiti ya Chuo Kikuu cha Newcastle. Kamati hii ina wanachama ambao wanatoka ndani ya Idara, pamoja na mmoja kutoka nje. Utafiti huu ulipitiwa na wanachama wa kamati, ambao ni lazima watoe ushauri usioegemea upande wowote na waepuke kujali maslahi ya kibinafsi tu.

Mtu wa kuwasiliana naye

Ikiwa una maswali yoyote,unaweza kuyauliza sasa au baadaye. Ukitaka kuuliza maswali baadaye, unaweza kuwasiliana na yeyote kati ya hawa:

Natasha Fothergill Misbah
+254…
n.fothergill-misbah@ncl.ac.uk

KEMRI/ERC:
The Secretary, Tel 020-2722541 or 0717719477

Ikiwa unataka, unaweza kuniuliza maswali yoyote zaidi kuhusu sehemu yoyote ya utafiti huu.

Je, una maswali yoyote?

Ahsante kwa ushirikiano wako.

Sehemu ya Pili: Cheti cha idhini

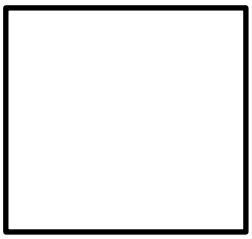
Nimealikwa kushiriki katika utafiti unaohusu ugonjwa wa kutetemeka nchini Kenya. Utafiti huu utahusisha mimi kushiriki katika mahojiano. Nimepewa taarifa na kuzisoma, au nimesomewa taarifa hizo. Nilikuwa na nafasi ya kuuliza maswali kuhusu utafiti na maswali yote niliyoyauliza yalijibiwa na nikaridhika. Ninakubali kwa hiari kuwa mshiriki katika utafiti huu.

_____ _____

Jina la mshiriki Tarehe

_____

Sahihi ya mshiriki



Kidole

Nimemsomea mshiriki mtarajiwa karatasi ya taarifa vizuri, na nikahakikisha kadri ninavyoweza kwamba mshiriki ameelewa masuala ya utafiti. Ninathibitisha kuwa mshiriki alipewa nafasi ya kuuliza maswali kuhusu utafiti, na maswali yote yaliyoulizwa na mshiriki yamejibiwa kwa usahihi na kadri ya uwezo wangu. Ninathibitisha kuwa mtu huyo hakulazimishwa kutoa idhini, na kwamba alitoa idhini akiwa huru na kwa hiari. Mshiriki allipewa nakala ya taarifa hii pamoja na fomu ya idhini.

_____ _____

Jina la mtafiti Tarehe

_____

Sahihi ya mtafiti

Nimesoma karatasi ya taarifa na ninathibitisha kuwa siri za mshiriki zitadumishwa wakati wote. Ninathibitisha kuwa taarifa ninazotafsiri leo hazitashirikiwa na mtu yeyote na mshiriki hatatambulishwa.

_____ _____

Jina la mkalimani Tarehe

_____

Sahihi ya mkalimani

Appendix H: Interview schedule for formal interviews with family members

Topic guide for semi-structured interviews with family member

Participant number: _____

Date and place of interview: _____

Time start: _____

Time end: _____

Voice recorded? Yes No

Introduction

Thank you so much for agreeing to take part in this interview. I'm Natasha and I'm from Newcastle University in the UK. I am conducting this study to understand adults' experiences of living with Parkinson's disease in Nairobi, but also carers' experiences of caring for someone with PD. I want to hear your views and opinions and listen to your experience of living with and caring for someone with Parkinson's disease. There are no right or wrong answers and I won't judge your views and opinions. Everything you say will be anonymous, even from my research team, so be as honest as you can. The interview should last about an hour but if you'd like to stop it before then that is fine. If I ask anything that you are not comfortable answering please let me know and we can move on to a different question or stop the interview if you'd like. With your permission I will be recording the interview and you won't be identifiable on the recording. This is to allow me to transcribe the interview so I can analyse it later. An interpreter is present to help me translate the questions to you and translate your responses as well.

Is there anything you'd like to ask me before we start the interview?

Interview

Firstly, can you tell me about your life before you started caring for [person with PD]?

Examples to probe around:

- What kind of work did you do?
- Did you have to start caring for them as soon as their symptoms began? What kind of tasks did you have to do?
- How did this change over time?

Can you tell me about what it is like now caring for someone with PD?

Examples to probe around:

- How has it affected your work?
- How do you manage to live your own life? Has it affected your social life?
- What kind of tasks do you have to do? For example, providing treatment, cooking, feeding, and helping to walk?

Can you tell me about your family?

Examples to probe around:

- Do you have your own family [if not spouse], could you tell me about them?
- You told me you live with [relations], could you tell me about your relationships with them?
- What is your relationship with [person with PD] like? Has this changed?
- How does your family support you?

Could you tell me about the services [person with PD] attends?

Examples to probe around:

- What do you think of the self-help group/outpatient clinic/physiotherapy? (if appropriate)
- What did you think about the traditional/faith healer? (if appropriate)
- Do you think [person with PD] and yourself would benefit from extra help from professional services? In what way?

End

Thank you so much for giving up your time to take part in this research and for revealing some 'emotional' information (appropriate word depending on what has been said in interview).

Is there anything else you'd like to talk about that you think is important that we haven't covered?

Thank you again, this recording will be kept safe and will be transcribed over the next few weeks and made anonymous.

Appendix I: Information sheet and consent form for healthcare professional participating in formal interview

Information sheet and consent form for participation of healthcare professional in formal interview

Part I: Information sheet

Introduction

My name is Natasha and I am a PhD student studying at Newcastle University in the United Kingdom. I am interested in finding out what living with Parkinson's disease is like for adults in Kenya, as well as what it is like caring for someone with Parkinson's disease. I am going to give you some information and invite you to be part of this research. You don't need to decide today about whether you want to participate in this research, and you can talk to someone about this before you decide. If there are parts of this information sheet that you do not understand, please let me know and I will take the time to explain this fully to you. If you have any questions later, I will provide my contact details and you can ask me about anything you are concerned about.

Purpose of the research

I want to learn more about what it is like managing Parkinson's disease and what treatment is available in private and public facilities in Kenya.

What will you be asked to do?

If you would like to take part in this study, you will be taking part in a face-to-face interview with me.

Participation selection

You have been invited to take part in this research because we believe your experience of managing Parkinson's disease can contribute to our understanding of the disease and knowledge of treatment options and services available.

Do you understand what the study is about?

Voluntary participation

Your participation in this research is entirely voluntary. It is your choice whether you participate or not.

Do you understand that you do not have to participate in this research study if you don't want to?

Procedures

A. We are asking you to help us learn more about Parkinson's disease in your community. We are inviting you to take part in this research project. If you accept you will be asked to sign the consent form and we will ask you to take part in an interview.

B. If you choose to participate in an interview, I will sit down with you in a comfortable place. The interview will not be formal, I want to hear your views and opinions on the topic and hear about your experiences. There is no right or wrong answer, so you would just need to be as honest as you can. If you don't want to answer any of the questions, then we can skip them and move on to the next question. The interview will be audio recorded with your consent; however, you will not be identifiable on the recording. Recording the interview allows us to analyse the data from the interviews.

C. If you decide after the interview that you no longer want to be included in the study, I will delete all your information and the interview.

Duration

The interview will last approximately 1 hour, however, if you'd like to stop it before then that is absolutely fine.

Risks

We are asking you to share some personal and confidential information. You don't have to answer any question if you don't want to and that is fine. You don't have to give a reason for not responding to any question. You can ask me to skip any questions you are not comfortable answering.

Benefits

There will be no direct benefit to you. Your participation is likely to help us find out more about how to treat Parkinson's disease in your community. The data from this study will help to inform policy in the future in order to improve services for Parkinson's disease.

Confidentiality

The interviews will be conducted either in the hospital in a quiet, private room or in a location you feel comfortable. The information collected from this study will be kept private. Any information about you will have a number on it instead of your name. Only the researchers will know what your number is, and we will lock that information up and keep it protected. It will not be shared with anyone except my supervisors who will help me understand the interviews.

Do you understand that the answers you provide will be kept confidential?

Sharing the results

Nothing that you tell me today will be shared with anybody outside the research team and nothing will be attributed to your name. Any results that come from this research will be made available to you if you wish. The results will be published so that other researchers and people interested in the research area may learn from this study.

Right to refuse or withdraw

You do not have to take part in this research if you do not wish to. You may stop participating in the interview at any time. If you decide at the end of the interview that you don't want the information you have provided to be used in this study, I will delete the recording.

This study was approved by the Faculty of Medical Sciences Research Ethics Committee, part of Newcastle University's Research Ethics Committee. This committee contains members who are internal to the Faculty, as well as one external member. This study was reviewed by members of the committee, who must provide impartial advice and avoid significant conflicts of interests.

Who to contact?

If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact any of the following:

Natasha Fothergill Misbah
+254724840760
n.fothergill-misbah@ncl.ac.uk

KEMRI/ERC:
The Secretary, Tel 020-2722541 or 0717719477

You can ask me any more questions about any part of the research study, if you wish to.
Do you have any questions?

Thank you for your cooperation.

Part II: Certificate of Consent

I have been invited to participate in research about Parkinson's disease in Kenya. This research will involve me participating in an interview. I have been given and read the information, or the information has been read to me. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study.

_____ _____

Name of participant Date

_____

Signature of participant

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the details of the study. I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily. A copy of this Information and Consent Form has been provided to the participant.

_____ _____

Name of researcher Date

_____

Signature of researcher

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