



## “Old people problems”, uncertainty and legitimacy: Challenges with diagnosing Parkinson’s disease in Kenya

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### ABSTRACT

Very little is known about the experience of people living with Parkinson’s disease (PD) in low- and middle-income countries, such as those in sub-Saharan Africa. The number of specialists in the region is low and awareness is limited among the population and healthcare professionals. Drawing on ten months of ethnographic fieldwork in urban and rural Kenya with 55 people living with PD (PwP), 23 family members and 22 healthcare professionals from public and private clinics, we set out to understand the experience of diagnosis among PwP in Kenya. The diagnostic journeys of our study participants were typically long, convoluted and confusing. Lack of relevant information, combined with comorbidities and expectations about ‘normal’ ageing, often conspired to delay interactions with health services for many. There often followed an extended period of diagnostic uncertainty, misdiagnosis and even ‘undiagnosis’, where a diagnostic decision was reversed. Following diagnosis, patients continued to lack information about their condition and prognosis, making it difficult for friends, family members and others to understand what was happening to them. We suggest that awareness of PD and its symptoms needs to improve among the general population and healthcare professionals. However, diagnosis is only the first step, and needs to be accompanied by better access to information, affordable treatment and support.

### 1. Introduction

Parkinson’s disease (PD) is one of most common neurodegenerative diseases globally yet is almost entirely absent from “global health” policy discourse and research, especially in low- and middle-income countries (LMICs). PD is associated with motor symptoms, including tremor, muscular rigidity (stiffness), slowness of movement, loss of spontaneous voluntary movement and balance issues (DeMaagd and Philip, 2015). Non-motor complications (some of which may present several years before onset of motor symptoms) include depression, anxiety, apathy, cognitive dysfunction, pain, sleep disturbances, and incontinence, among others. PD is a progressive condition, so medication cannot alter the course of the disease. However, symptomatic drug therapy is effective in improving motor symptoms as well as quality and

length of life.

Several PD prevalence studies have been carried out globally yet, as Okubadejo et al. (2006) and Dekker et al. (2020) have noted, data on prevalence in sub-Saharan Africa remains extremely limited. Existing prevalence estimates range from 7 per 100,000 population in Ethiopia (Tekle-Haimanot, 1985) to 40 per 100,000 in Tanzania (age-standardised to the UK) (Dotchin et al., 2008). These estimates are generally lower than those in high-income countries (HICs), e.g. a prevalence of 667/100,000 in males over 45-years-old in the USA (Marras et al., 2018), but a lack of diagnostic capacity in LMICs (as we discuss below) means that these are almost certainly under-estimates. Moreover, as a condition associated with later life, the prevalence of PD is set to rise across SSA and other regions of the world as life expectancy continues to improve (United Nations, 2019). Dorsey and Bloem (2018) warn of an

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imminent “Parkinson Pandemic”, with the number of people living with PD globally projected to rise from 6.2 million currently to a conservative estimate of 12.9 million by 2040.

Sub-Saharan Africa, and other lower-income regions of the world, are ill-prepared to manage this situation, with diagnostic and treatment capacity lagging far behind most HICs (Dotchin et al., 2007; Dorsey and Bloem, 2018). Although prevalence is almost certainly rising, PD remains a largely unknown condition across Africa, and people experiencing symptoms associated with PD often face considerable social stigma and lack access to biomedical treatment due to misdiagnoses and financial barriers to healthcare (Mshana et al., 2011; Kaddumukasa et al., 2015; Mokaya et al., 2017; Walga, 2019).

A lack of specialist neurological services across the continent makes diagnosis challenging (Dotchin et al., 2007), while PD treatment is often unavailable or unaffordable (Mokaya et al., 2016; Okubadejo et al., 2019). Early diagnosis and effective treatment can delay onset of severe symptoms, thereby increasing both length and quality of life and reducing the burden of care on family members (Dotchin et al., 2014). In Tanzania, Mshana et al. (2011) found that barriers to diagnosis and treatment resulted in PwP experiencing emotional, psychological and physical difficulties, reducing their, and their caregivers, quality of life. Understanding the challenges that people with Parkinson’s disease (PwP), their families and healthcare professionals face in diagnosing and managing PD in resource-constrained settings is therefore crucial; however, we currently know very little about how PwP access, and interact with, healthcare services in LMIC settings or how they negotiate life with PD.

This paper focuses on the first pre-requisite to managing PD effectively: obtaining a timely and reliable diagnosis. We know from earlier studies (Okubadejo et al., 2006; Dotchin et al., 2007, 2008; Dotchin and Walker, 2012), that many – probably most – PwP in SSA are not diagnosed and, if they are, diagnosis is usually delayed. Delayed diagnosis is not exclusive to LMICs: in some HICs, PwP are reported to delay seeking care for some time after onset of symptoms (Schrage et al., 2018), and this may be particularly true for under-served sectors of the population (for example, African-American and Latino populations; see Dahodwala et al. (2009)). However, given the lack of specialist services, this is likely to be a very significant issue in Africa and other lower-income regions.

We report below on a qualitative, ethnographic study on the experiences of Parkinson’s disease in Kenya, an East African country with relatively good levels of healthcare provision compared with other countries in the region. The specific focus is on understanding how people negotiate what is typically a long and convoluted diagnostic process. More generally, this study also contributes to the small but growing literature on PD and ageing in Africa. Drawing on concepts and theories derived from studies on other chronic conditions in SSA, we situate the findings within ideas and expectations around ageing, “personhood” (Degnen, 2018) and “interdependence” in later life (McIntosh, 2017); chronic and existential “uncertainty” (Whyte, 2009); and the role of “biolegitimacy” (Fassin, 2009) in making sense of the condition. However, as we shall see, PD diverges in some important ways from some other, ‘higher-profile’ chronic conditions (HIV/AIDS and diabetes, for example), owing not least to its relative political invisibility and its inevitably progressive nature.

### 1.1. Research setting and background

This study was conducted across multiple sites in Kenya, a lower-middle-income country situated on Africa’s east coast. As of 2018, 34.4% of Kenyans were living in extreme poverty (World Bank, 2019). Although poverty rates are higher in rural Kenya (40%) compared to urban areas (29%) (Diwakar and Shepherd, 2018), 70% of residents in the capital city, Nairobi, live in slums and informal settlements (APHRC, 2014). Older people living in slums are becoming increasingly vulnerable because of weakening support networks, ill health, poor access to health facilities and lack of pension support (Wilunda et al., 2015;

Wairiuko et al., 2017). During the years 2017–2019, 11.3% of the working-age Kenyan population (aged 15–64) were actively contributing to a pension scheme (ILO, 2018).

### 1.2. Epidemiological profile

Kenya has seen significant improvements in life expectancy (66 years in 2017) since the turn of the century (51 years in 2000) (United Nations, 2019), associated with significant reductions in maternal and child mortality, and action on major infectious diseases (especially malaria, tuberculosis, HIV) in line with Millennium Development Goal targets (United Nations, 2008). However, as with many LMICs, an increasing ageing population coupled with significant ‘lifestyle shifts’ has been associated with a rising prevalence of non-communicable diseases (NCDs) and, often, multiple co-morbidities, placing significant new pressures on health services (Bigna and Noubiap, 2019). In 2018, NCDs accounted for 50% of inpatient admissions in Kenyan public facilities and 40% of hospital deaths (Onyango and Onyango, 2018).

### 1.3. Healthcare services and associated costs

PD cannot be ‘cured’, but effective management under neurologists and geriatricians (with specialisation in movement disorders) can slow progression and improve quality of life. However, clinical capacity in these areas is very limited across the African continent (Dotchin et al., 2013; Bower et al., 2014). Kenya is among the better served African countries in this respect, with numbers increasing in recent years, but it still has fewer than 20 neurologists, all of whom are located in three major cities (Fothergill-Misbah et al., 2020a).

Capacity in Kenya is particularly limited in the public sector (WHO, 2019). The main national referral hospital in Nairobi holds Kenya’s only public neurology clinic, yet it is chronically understaffed (The National Assembly, 2019); overwhelmed clinics mean that registrars with limited specialist training often run outpatient clinics with little or no supervision. Outside the capital city, there is no public-sector provision at all for PD. The private healthcare sector in Kenya is one of the most highly-developed in Africa (Barnes et al., 2010) yet, as noted above, treatment is only available in the three major cities. Even for those living within reach of a hospital offering appropriate treatment, user consultation costs can be prohibitive. As of 2019, public clinic fees were \$6 while private fees could reach \$300 – completely unaffordable for 90% of Kenyans (Prince, 2018). Mokaya et al. (2016) determined that, based on a monthly minimum wage in Kenya of 11,222Ksh (\$100), individuals have 7% of their net salary (or \$9) left for healthcare costs every month after basic living expenses. However, with the informal sector accounting for more than 80% of Kenya’s workforce (Okungu and McIntyre, 2019), most do not receive minimum wage.

This situation is compounded by low coverage of health insurance in Kenya (19% of the population) (Barasa et al., 2018), with flat-rate contributions and default penalties deterring informal workers from enrolling (Barasa et al., 2017). Consequently, out-of-pocket payments for healthcare drove 1.1 million individuals into poverty in 2018, with older people, those affected by chronic disease and people regularly accessing outpatient services disproportionately affected (Salari et al., 2019).

Against this background, we sought to understand how PwP in Kenya go about trying to obtain a diagnosis and what challenges they encounter along the way.

## 2. Methods

The data presented here come from a larger ethnographic study exploring the lived experience of PwP, and their families, in Kenya. The lead author conducted ten months of ethnographic fieldwork in Kenya (March 2018–December 2018 and May 2019), involving participant observation, in-depth semi-structured interviews and informal

conversations with PwP, family members and healthcare professionals. An ethnographic approach enabled a holistic and in-depth understanding of how PwP and their families lived with, and managed, PD in a resource-constrained setting characterised by uncertainty and improvisation.

### 2.1. Participants and study sites

The majority of fieldwork was conducted in two major cities, Nairobi and Mombasa, with shorter periods of study in rural settings (seven days in rural central Kenya and two days in Western Kenya) to understand what services outside of neurology were available. Fifty-five PwP were recruited from: two private neurology clinics (one in Nairobi (N = 9) and one in Mombasa (N = 16)); one public neurology clinic in Nairobi (N = 12); and a PD support group in Nairobi (N = 18). Of the 55, 39 PwP lived in urban areas, while 16 lived in rural Kenya and had travelled to Nairobi or Mombasa for diagnosis and follow-up. The sample is heavily skewed towards urban residents by necessity: neurology clinics and support groups are available only in the major cities and are unreachable for most rural Kenyans. The only rural residents in the sample were those with sufficient resources and connections to be able to travel to the city to seek diagnosis and/or care. This is a limitation of the study but one that is difficult to avoid, since the vast majority of rural Kenyans with PD, and those with lower social/financial capital, remain undiagnosed and thus ‘invisible’. For this reason, we avoid generalising about rural-urban contrasts; essentially, the act of diagnosis, as well as subsequent treatment and support, always happened in cities.

At each clinic, the researcher identified PwP through clinic files, with permission and help from the staff, and invited PwP to participate. At the support group meetings, the researcher described the project to attendees who then approached the researcher if they were interested. Most were eager to share their experiences, generating rich data. Healthcare professionals were also approached for interview at hospitals and clinics; interviews were conducted with three private neurologists, four neurologists who worked in private and public clinics, one palliative care specialist, two nurses from an urban public hospital, five registrars from an urban public hospital, five doctors from private rural hospitals and two doctors from public rural hospitals (Table 1).

### 2.2. Data collection

All interviews and observations were conducted by the first author who speaks English and Kiswahili. Participants were interviewed in either English or Kiswahili, according to their preference; the majority chose English. An additional interpreter was present for interviews conducted in Kiswahili to ensure accuracy of translation into English. All materials were translated into English prior to analysis, with a sample back translated, to check for consistency.

Formal interviews and informal conversations with PwP and family members took a biographical approach, drawing on participant’s experience of life before diagnosis through to the end of life, where relevant, lasting 30–135 min. Informal conversations with 55 PwP totalled 72.5 h. Formal in-depth follow-up interviews with nine PwP totalled 9.5 h. In-depth semi-structured interviews with 23 family members and caregivers totalled 21.5 h of material. No PwP were

present during interviews with family members, allowing them to discuss their experiences freely. In many cases, a family member was present with PwP during their interviews. Formal interviews and informal conversations with healthcare professionals drew on their own practise, knowledge of PD, experience of caring for PwP, and experience of private, public and alternative therapeutic landscapes, totalling 14.5 h. All formal interviews were audio-recorded (with consent). Informal conversations were not audio-recorded as this risked rapport, particularly with healthcare professionals who were generally busy during practice hours. Instead, detailed field notes were handwritten.

Observations (165 h in total) aimed to gain an empathetic understanding of participants’ emotions, feelings, behaviours, experiences and social interactions within a culturally specific setting. Thirty-six hours of observations took place in public neurology clinics, and 12 h in private neurology clinics. Observations offered insights into groups of PwP with fewer resources who accessed public care and those who accessed private Kenyan biomedical services – private neurologists charged a significantly higher fee. Ethnographic observations detailed how people manoeuvred the clinic and negotiated challenges, their actions and emotions, the ‘system’ of the clinics, routine of events, consultations, people’s interactions with neurologists and registrars, and interactions between patients, family members, friends and hospital staff.

### 2.3. Ethics

Ethical approval for the research was obtained from Kenya Medical Research Institute (KEMRI) and Newcastle University Research Ethics Committee. All participants provided written informed consent to participate after reading the study information sheet (in English or Kiswahili), or having it read to them; verbal consent was obtained for interviews to be audio recorded, where applicable. Oral consent for observations at support groups was an on-going process. However, informing everyone at the public clinic waiting room (typically over 200 people) was impossible and impractical (Murphy and Dingwall, 2001). Approval was sought from the chief nurse, information office staff, nurses and neurologists in the public clinic, and receptionists and neurologists in private clinics. The researcher took notes on a password-protected smartphone during clinics, making their presence less obvious and intrusive. 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 – a smartphone was not used during one-on-one conversations.

### 2.4. Analysis

Member-checking was used throughout fieldwork by returning analysed data to participants during support group meetings to improve the accuracy, validity and trustworthiness of common findings (Birt et al., 2016). Interview and observation data were analysed using Braun and Clarke’s (2006) six phases of inductive thematic analysis. This systematic, ‘bottom up’, reflexive approach allowed themes to be identified from the data, without trying to fit data into pre-existing categories or analytic preconceptions and maintaining the depth and individuality of participants’ stories. The majority of data coding and analysis was carried out by the first author, with 10% of interview material coded by a second experienced qualitative researcher who was not involved in the data collection. This independent analysis was done to ensure reliability of the coding and to check for subjectivity.

The coding and analytical procedures were as follows. While still in the field, the first author transcribed all interviews and field notes, and read them carefully to focus data collection (Phase 1). Analysis required constant reviewing of interview transcripts, fieldnotes and personal reflections, using triangulation to test the quality of information and accuracy of ethnographic material (Fetterman, 2019). After initial notes

**Table 1**  
Profile of study participants.

Participant	Urban	Rural	Total
PwP	39	16	55
Family member	19	4	23
Private healthcare professional	4	5	9
Private & public healthcare professional	4	0	4
Public healthcare professional	7	2	9
<b>Total recruited</b>	<b>73</b>	<b>27</b>	<b>100</b>

and comments were made, Phase 2 entailed data coding and collation of material. In Phase 3, conceptualised empirical and theoretical codes were collated into main and sub-themes after iterative reviewing and refining by the research team (Phase 4). Themes were defined and named in Phase 5 and detailed analyses written, telling the story of the data in the final report (Phase 6). Quotations used in this paper are representative of wider responses. Reflexivity throughout fieldwork allowed the researcher to reflect on ideas and experiences, ensuring integrity (Arber, 2006).

### 3. Results

The study included 32 male and 23 female PwP (Table 1) with very different financial and social resources and living situations. Ages ranged from 33 to 81 years old (median age 66.5 years). Time since diagnosis ranged from one month to 18 years, although onset of symptoms usually began many years before a diagnosis. Altogether, 34 respondents attended private neurology clinics in Nairobi (N = 22) and Mombasa (N = 12), 12 attended the public neurology clinic in Nairobi and nine did not attend any neurology clinic. For the reasons noted above, most study participants were living in urban areas; those based in rural settings had all travelled to cities for diagnosis/treatment and were thus not representative of rural Kenyans (with PD) in general.

Thematic analysis revealed three main themes in relation to PD diagnosis, explored in turn below: first, the range of initial symptoms experienced by PwP and how these sit within expectations around norms of ageing and associated comorbidities; second, the complexity and uncertainty surrounding diagnosis and experiences of misdiagnosis; and third, the importance of information provision and, specifically, knowing the name of the condition. This section is prefaced with an ethnographic account of one individual – Leah – whose experiences serve to illustrate each theme. Pseudonyms are used throughout.

#### 3.1. Leah's story

Leah was 78-years-old and lived in the house she and her husband had built many years ago in rural Kenya. One of her daughters, Pauline, lived nearby; she looked after her parents while also running her own business. Her other daughter, Esther, lived and worked in Nairobi. Esther explained that Leah began experiencing symptoms nine years ago, complaining of backache and other symptoms they assumed were “old people problems”. Over the years, Leah's symptoms deteriorated; she began to lose her voice and her pain worsened.

After six years, Esther brought Leah to Nairobi to have her back pain assessed and paid for her to see a private orthopaedic doctor who, after hearing her speak and seeing her walk, suggested that she consult a neurologist, mentioning the possibility of PD. Esther tried to take Leah to see a private neurologist but could not get an appointment: “it was like the work of the receptionist to turn people away”. Instead, they asked a family friend who happened to be a neurosurgeon. He confirmed that Leah probably had PD, sent her for an MRI and prescribed PD medication. However, Esther was puzzled by the fact Leah's memory was still good and she had no tremor at all.

Back in rural Kenya, Leah visited a heart specialist for hypertension in a local hospital. Leah told the specialist that she was taking medication for Parkinson's, which he questioned, noting that she “had no facial expression like Parkinson's”: she was able to smile and was not shaking. Leah's symptoms were being controlled by her medication, yet he ‘cancelled’ the medicines. After Leah was effectively “un-diagnosed”, Esther took her to see another private neurologist in Nairobi who requested an MRI on her back, prescribed painkillers and confirmed the “un-diagnosis”. Leah went back home, took the painkillers as prescribed and almost died as her blood pressure dropped drastically. She then “abandoned” the painkillers and continued taking her hypertension medication.

Two years later, Leah was unable to walk or speak; according to

Esther, she had “wasted away”. Esther returned with Leah to Nairobi to see another private neurologist who asked Leah to write her name, five or six times, observing the micrographia and slanting of the text (key features of PD). On this basis, he confirmed that Leah *did* in fact have Parkinson's and prescribed medication. However, they received no further information; as Esther suggested, “Five minutes in his office is too much” (i.e. the neurologist was unwilling to give them any more time). During follow-up appointments, she was cursorily examined, given a prescription and a date for an appointment in six months. Although Leah's condition improved after resuming medication, the family felt they had been left on their own. Esther struggled to reconcile the opposing diagnoses of various ‘specialists’.

At home, Leah continued to visit her local hospital for hypertension. The family had learnt to tell all the doctors they encountered about Leah's Parkinson's diagnosis. Esther said she had seen the staff ‘Googling’ the medication Leah was taking. Esther and Pauline began “educating” the hospital staff about PD from what they had learnt on the internet but felt there was nowhere to find out more about the condition, no one to relate to and no awareness about it in Kenya. Pauline said the staff were grateful for the knowledge. Esther joined a support group for PD in Nairobi; until then, she thought Leah was the “only Kenyan” with Parkinson's.

#### 3.2. Recognising symptoms

Leah's story illustrates how people may (mis-)interpret symptoms when there is little or no prior awareness or knowledge of PD in Kenya. Distinguishing backache and “old people problems” from PD is extremely challenging, particularly when knowledge among healthcare professionals is so limited, resulting in numerous misdiagnoses, even among specialists. The symptoms of PD are easy to confuse with those of better-known conditions, pre-existing comorbidities, or merely expected trajectories of ageing.

PwP often recalled their experience before diagnosis with phrases like: “I started feeling funny” or had “strange feelings” or “my body was not behaving well”. However, these aches, pains, fatigue, and slowness were often assumed to be part of ‘normal’ ageing, not requiring particular medical attention. The symptoms of PD could thus be disguised for years:

“She [PwP] thought it was something normal and didn't go to the doctor. She had slow movement, so thought she was just ageing” (Daughter of 67-year-old PwP)

Comorbidities could further confuse and disguise the symptoms of PD. Bouts of dizziness and weakness or falls were often attributed to pre-existing diagnosed high blood pressure or low blood sugar. Others attributed their symptoms to other, better-known conditions like arthritis or stroke, which mirror some symptoms of PD.

It was usually only when the ‘slowness’ and pain began impacting significantly on PwPs' daily lives and their ability to carry out basic tasks (such as eating *ugali* (maize meal), or working) that family members began to suspect that something else might be wrong (Mshana et al. (2011) reported similar findings among PwP in Tanzania). In some cases, it was non-family members – friends and sometimes even strangers – who noticed their “strange” symptoms and convinced them to seek help.

#### 3.3. The uncertainty and complexity of obtaining a PD diagnosis

Recognising the need to seek medical attention was, however, only the first part of what were almost always long, uncertain and convoluted journeys to diagnosis, often with several misdiagnoses along the way. For example, one participant had taken his mother to 16 different private doctors before she was eventually diagnosed with PD; she had pain, a tremor and had begun drooling.

“While we were seeing him [doctor], 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’” (Son of 78-year-old PwP)

This participant described his “relief” when his mother was finally diagnosed but also his “disappointment” that she had experienced so many misdiagnoses. Many others spent months, or years, in search of an accurate diagnosis. As the daughter of one 71-year-old PwP explained, her family were “fighting an unknown” while misdiagnoses “kept them in the dark” for several years. Similar cases of misdiagnosis, or lack of diagnosis, have been described in Ethiopia (Walga, 2019) and Tanzania (Mshana et al., 2011).

For our study participants in Kenya, obtaining a diagnosis required not only dogged persistence, but also having sufficient funds for multiple consultations, scans, examinations and tests, most of which were available only in private-sector facilities:

“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” (Son of 69-year-old PwP)

Even for those in better financial situations, the mounting costs often deterred them from pursuing a diagnosis until their symptoms worsened significantly. This is reminiscent of Prince’s (2018) description, also in Kenya, of the ‘back and forth’ that children with undiagnosed cancer experienced between health centres, hospitals and healers, only receiving a diagnosis after significant disease progression. Some PwP reported 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 PwP)

Both patients and neurologists pointed to the limited awareness among non-specialist doctors as being a significant obstacle to diagnosis or referral to a specialist. It was acknowledged that doctors were much more familiar with other conditions that could produce similar symptoms, such as stroke or epilepsy, which they saw on a regular basis. Moreover, as Leah’s case demonstrates, not everyone presents with ‘typical’ symptoms straightaway, leading sometimes to PD being ruled out as a diagnosis, even where there is some level of awareness of the condition. As a result of misdiagnoses, some PwP had reportedly been prescribed “unsuitable” treatment, resulting in worsening symptoms and/or severe medical scares. Others, who had received a PD diagnosis, remained uncertain and sought out second (and third) opinions from different specialists, withholding their previous PD diagnosis for fear that it may be wrong.

In the face of these obstacles, serendipity could play a key route to diagnosis. For example, Frank (aged 77) had begun shaking but thought he was “just getting old”. A friend at his church in Mombasa also noticed Frank’s hand shaking and insisted he see a doctor. Similarly, in Nairobi, Matthew (aged 62) had a tremor in his hand, his voice had lowered, and speech had slowed, but he had not thought these changes required attention. Again, someone at his church directed him to a neurologist. In one case, a hospital doctor in rural Kenya happened to have some knowledge of PD and spotted advanced symptoms in a handful of patients who had been admitted for other conditions. In most cases, though, doctors in under-staffed rural government hospitals, without specialist training, are unlikely to pick up cases, especially less advanced ones; most will go unrecognised unless patients or their families have the wherewithal to reach a major city to see a neurologist.

### 3.4. Knowledge, information and understanding of PD at diagnosis

Participants reportedly experienced multiple barriers to gaining knowledge at diagnosis. Most of those attending the public clinic were

not told the name of their condition, ‘Parkinson’s disease’. Many PwP described their frustration that PD had been “forgotten” while other diseases received more attention and publicity.

“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 PwP)

Several participants recalled feeling alone, “clueless” and receiving very little information (in both public and private facilities) during the diagnostic process. Some were not told that PD was progressive; the nephew of one PwP explained, “When we are given medicine, we just assume it is for curing”. Neurologists also admitted not providing explanations about prognosis. Few PwP reported being provided with any verbal information at diagnosis.

Informational resources for PwP and their families were extremely limited, and those that existed were only available in English. Consequently, some PwP were at a loss in how to understand and explain their condition, wondering whether it was their “brain getting rotten”, a result of working too hard, or a punishment from God or Satan. A few reported ‘Googling’ PD but not all had access to the internet. The limited information received at diagnosis has also been reported in some HICs (Parkinson’s Disease Society, 2008; Schrag et al., 2018). However, in Kenya, this was more extreme: nine of the 12 PwP recruited from the public clinic did not know they had PD, seriously limiting their opportunity to find out about their condition.

Neurologists who participated in the study were asked to reflect on why so little information was provided with diagnosis. They readily admitted that, in both private and public clinics, the time spent with patients was limited and they were under pressure to rush through appointments. In the public clinic, the main priority was “churning out numbers” as one neurologist put it. Some neurologists were apparently reluctant to disclose a specific diagnosis because they worried that patients would then ask lots of questions that they had no time to answer. Neurologists were more inclined to disclose a diagnosis in private clinics, although additional explanations were still limited. Although probably more extreme, this situation is not limited to LMICs; in Europe, Schrag et al. (2018) identified that only 38% of 1775 PwP felt they had been given enough time to ask questions at diagnosis.

Neurologists also pointed to the challenges of explaining things – especially in a short time-frame – to patients with lower levels of education and English proficiency; as a result, they tended to give more information to those they perceived to be more capable of understanding it. As reported by Andersen (2004) in Ghanaian hospitals, neurologists “categorised” patients according to perceived educational level. Some admitted to becoming “different doctors” when interacting with patients with (apparently) lower levels of education and/or fewer resources, offering less information or time for questions. In some cases, neurologists justified these actions by pointing to the longer amount of time required to take a proper history from patients or family members who were less able to explain; as one neurologist put it:

“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” (Neurologist B)

(See also Ferguson and Candib (2002); Van den Berg (2016) for other examples of challenges around (perceived) language proficiency and doctor-patient communications in Africa.)

Some neurologists also mentioned their reluctance to deliver bad news as a reason for withholding a definitive diagnosis. A PD diagnosis was not a “positive one” as one neurologist put it. Initial treatment for PD typically results in an initial, immediate improvement of symptoms and it was difficult, said some, to take away people’s hopes of recovering by labelling them with a progressive disease with no cure:

“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” (Neurologist A)

As a result, they would often use vaguer terms and explanations: “*something neurological*”, “*the shaking problem*”, “*the system is low*”, “*nerve issue*”, and suchlike, to avoid mentioning the name ‘Parkinson’s disease’. This phenomenon of physicians withholding ‘bad news’ from patients and their families has been described in relation to cancer care in Kenya by Mulemi (2008). Similar considerations led some family members in our study to collude in this practice in order to ‘protect’ the PwP from despair. However, as with Mulemi (2008) study, most of our participants with PD *wanted* to know what their symptoms meant. Several expressed the relief that came from receiving a diagnosis, which helped them to make sense of previously inexplicable symptoms and take some control of the situation, by beginning treatment, searching for information and perhaps joining a support group – although, of course, access to these were heavily contingent on social position, connections and affordability.

The consequences of *not* receiving a diagnostic label were manifold and had important consequences for PwP. It did not necessarily prevent them from receiving appropriate medication, if they could afford it; as one neurologist explained, it is quicker to write a prescription than to provide a detailed explanation. 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 (albeit that these were scarce and often unaffordable anyway). It also contributed to ongoing stigma associated with apparently inexplicable (and perhaps even supernaturally-acquired) symptoms. For example, Magnus (aged 66) had been told by doctors at the government clinic just to “*manage*” his unnamed condition. Alone in Nairobi, Magnus felt he could not return to his village where people would assume that he was the target of witchcraft; as a result, he had not seen his family in years. Similarly, Nzambi, aged 58, had been attending the government clinic for 17 years for his “*sickness*”, and had developed severe dyskinesia. In the absence of a plausible explanation for these symptoms, Nzambi’s wife had recently left him, taking their children with her. The same happened to two other younger male PwPs, whose families abandoned them, fearing that malevolent supernatural forces were at play.

#### 4. Discussion

Through the accounts presented above of PwP, their family members and neurologists, the reasons why so many PwP in Kenya (and probably other LMICs) go undiagnosed become clear. First, levels of awareness of PD are extremely low, even among healthcare professionals. As a result, symptoms are often dismissed as being a ‘normal’ part of ageing or associated with (diagnosed and undiagnosed) co-morbidities. Second, even when symptoms are identified as being problematic (usually only when they have become advanced), a lack of capacity and training in Kenya means that misdiagnosis (and even ‘un-diagnosis – reversal of a previous diagnosis) is common. And finally, whether because of time constraints, unfortunate stereotyping of certain ‘types’ of patients, or a well-meaning desire to protect patients from ‘bad news’, in many cases, neurologists fail to communicate the diagnosis to individuals and their family/caregivers. In a country like Kenya, where treatment for PD is scarce and expensive, obtaining a diagnosis is no guarantee of appropriate care. However, *without* a diagnosis, accessing information, care and maintaining the support of a family network become almost impossible.

As well as illuminating the empirical situation on the ground in Kenya, the data from this study also speak to wider theoretical concerns emerging from the rise of chronic conditions associated with ageing in Africa, which we elaborate below.

#### 4.1. Expectations around ageing

First, the initial step in diagnosis – recognition by the patient and/or those close to them that there may be ‘something wrong’ – is closely bound with expectations about the changes in capabilities and bodily functions associated with ageing. Becoming stooped, slowing down, being in pain and developing a slight tremor were widely regarded as being an inevitable and ‘normal’ part of ageing. This is not unique to Kenya; similar observations were made in the USA, by Solimeo (2009), who described how early symptoms of PD are often mistaken for “normal” ageing processes.

Among our study participants, bodily changes were thought to require attention only when they began to impact seriously on PwPs’ ability to carry out important daily activities and could no longer be dismissed as “*old people problems*”. These threats to “personhood” (Degnen, 2018) were often therefore defining moments. Luborsky (1994, p. 240) has suggested that socially legitimated, full personhood is “*earned by achieving and maintaining expected social roles and ideals*”. Those expected roles necessarily shift over the course of a lifetime. In East Africa, McIntosh (2017) and Whyte (2017) have suggested that a decline in old age is expected and that a relationship of “desired interdependence”, with elders being supported by their kin, is the ideal. However, as PwPs’ conditions deteriorated, they became increasingly dependent on others and less able to reciprocate in expected ways, precipitating a move to seek medical opinions/care.

With a growing ageing population in Africa, we urgently need to understand more about expectations of ageing and associated social and political contingencies (Powell and Hendricks, 2009). In particular, we need to understand *why* many people in SSA may expect to have some form of disability as they age (Sagner, 2002), and to what extent this is associated with the limited diagnosis and treatment of many chronic conditions (including PD).

#### 4.2. Uncertainty and agency

Uncertainty in the diagnostic journey for our study participants was multifaceted and took on different forms and depths: it was evident from the onset of symptoms, during initial consultations and even after diagnosis, when the lack of definitive clinical tests to confirm PD meant that diagnosis could later be questioned or even reversed. This contrasts with the “digital certainty” Whyte (2014) talks of regarding HIV testing in Uganda, as well as the apparent objectivity of “numbers” associated with diabetes and hypertension.

To some extent, diagnostic uncertainty thus results from characteristics of the disease itself (lack of specificity in symptoms and diagnostic tests) and of an underdeveloped and often unreliable biomedical health system. However, uncertainty is also *produced* whereby information is (sometimes deliberately) withheld from patients and caregivers, because of time constraints during consultations, assumptions on the part of clinicians about patients’ educational and social positions, or a desire to avoid communicating disheartening news about an incurable degenerative condition. Uncertainty thus does important *work*, potentially helping to maintain ‘hope’ in the face of a grim prognosis, but also serving perhaps to undermine the agency of patients to seek care, live well, gain legitimacy and form sociality around their condition.

While our study participants varied considerably in their reactions to diagnosis, for the most part, uncertainty and lack of information were associated with heightened fear rather than hope, echoing findings by Selman et al. (2009) on the needs of patients with incurable progressive diseases in Uganda and South Africa. However, the agency conferred by diagnostic certainty was nonetheless still limited by the lack of available treatment options for PwP living in Kenya.

#### 4.3. Naming and legitimacy

One important consequence of not knowing the name of their

condition was the social stigma associated with uncanny symptoms that were not legitimised with a diagnostic label. Naming symptoms as a diagnosis has been described as crucial in the social construct of disease (Fleischman, 1999), enabling those affected to be socially “normalised” (Jutel, 2011) and enjoy a form of “biogitimacy” (Fassin, 2009, p. 52). Writing about HIV/AIDS in South Africa, Fassin proposed that acquiring a diagnostic label opens up possibilities for making claims to treatment and care through forms of “biological citizenship” or “therapeutic citizenship” (Rose and Novas, 2007; Nguyen et al., 2010; Marsland, 2012).

Subsequent work on therapeutic citizenship in sub-Saharan Africa has also focussed predominantly on HIV/AIDS and access to life-saving anti-retroviral therapy (ART) which, especially in the early days, was available largely through trials and non-governmental organisations. Crucially, access to treatment, which was highly politicised, depended absolutely not just on *getting* a diagnosis but on being able to *use* that diagnosis to make claims for medication in the context of a highly-fragmented and contingent treatment landscape (Nguyen et al., 2010; Whyte, 2012).

By contrast, PD has remained politically and socially invisible in Kenya and indeed across the African continent. Unlike HIV/AIDS, receiving a diagnostic label for PD does not offer a clear pathway to making ‘citizen-like’ claims to treatment for the vast majority of Kenyans who cannot afford fees for expensive private clinics and medication and who lack the necessary social connections (what Whyte (2014) called ‘technical know-who’) to access services (see also Marsland (2012)). However, it could, in some cases, enable participants to access (albeit limited) information and support, plan for their future, and have their suffering legitimised, for themselves and others. Since the end of fieldwork, a new material benefit has also emerged: PwP in Kenya can now register with the National Council for Persons with Disabilities, entitling members to tax exemptions, state allowances and tax-free disability aids (Republic Of Kenya, 2019), although the take-up and impact of this initiative has yet to be seen.

## 5. Conclusion

This research has contributed to the very limited understanding about the experience of Parkinson’s disease in sub-Saharan Africa, through exploring PwPs’ diagnostic journeys in Kenya. Participants acknowledged their symptoms as ‘abnormal’ through a threat to personhood and desired interdependence, while constantly negotiating the deep and multifaceted uncertainty surrounding PD, and the limits of biogitimacy. PD, in the context of Kenya and likely other low-resource settings, differs from conditions which have been the object of political organisation (for example, HIV). Knowing the name ‘Parkinson’s disease’ does not automatically provide access to claims, services, or treatment; however, giving a name to symptoms and suffering had important social implications and allowed PwP to justify their illness to themselves, family, friends, and society. Diagnostic labels can help to increase the social and political visibility of a condition like PD that remains largely off-radar in terms of government and donor support.

Improving PD awareness would not only assist with ensuring early recognition of symptoms, timely diagnosis, and – if available – the commencement of appropriate treatment; it would also reduce the substantial costs associated with referrals and misdiagnoses, while challenging stigmatising perceptions within communities. However, with the low number of neurologists, largely unaffordable private consultations, and overwhelmed public clinics, access to effective treatment remains very limited for most Kenyans, particularly perhaps for rural populations without urban networks and the resources required to travel to the city. In other words, reliable and timely diagnosis is just the starting point; it is a *necessary* but not a *sufficient* condition for effective treatment. This next step is beyond the scope of the current paper, but there has been some promising work around developing low-cost PD treatment in Africa using *Mucuna pruriens*, a levodopa-containing leguminous plant that has demonstrated encouraging results in on-going

trials (Cilia et al., 2018; Fothergill-Misbah et al., 2020b). However, technological innovation will need to be accompanied by significant, joined-up healthcare investment and increased prioritising of geriatric care to achieve tangible results at a larger scale.

## Credit author statement

Natasha Fothergill-Misbah: Conceptualization, Formal analysis, Funding acquisition, Investigation, Methodology, Writing – original draft preparation. Richard Walker: Conceptualization, Writing – review & editing, Supervision. Juzar Hooker: Writing – review & editing. Judith Kwasa: Writing – review & editing. Kate Hampshire: Conceptualization, Formal analysis, Methodology, Writing – review & editing, Supervision

## Ethical approvals

Ethical approval to conduct this study was obtained from Newcastle University Research Ethics Committee (Application No.: 1293/14933/2017), Kenya Medical Research Institute (KEMRI) Scientific Ethics Review Unit (SERU) (Reference: NON-KEMRI 609), Kenyatta National Hospital-University of Nairobi (KNH-UoN) Ethics & Research Committee (P451/06/2018) and Aga Khan University Hospital Nairobi Institutional Ethics Review Committee (2018/REC-57).

## Declaration of competing interest

None.

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