

OCCASIONAL PAPER

The challenge of Parkinson's disease management in Africa

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Abstract

Parkinson's disease (PD) is said to be less common in Africa than elsewhere in the world, but previous studies have been based on small numbers. Also, the differences may be due to the diagnostic criteria used, case finding methods and different population age structures. Developing countries have few facilities for chronic disease management and non-communicable diseases, although on the increase, tend to play second fiddle to malaria and HIV/AIDS. Previous reports suggest that, at least from anecdotal information, under-diagnosis of PD is common and long-term availability of medication, follow-up, patient education and multidisciplinary input is lacking. Published literature is scarce and there is a lack of recent information. We are currently conducting a door-to-door prevalence study in northern Tanzania in a population of 161,162. We have reviewed previous literature on PD in Africa and illustrate our personal experience of PD and its management in Africa with three cases.

Keywords: *Parkinson's disease, management, developing countries, elderly*

Introduction

It has been suggested that Parkinson's disease (PD) is seen less frequently in populations of African origin [1]. Worldwide crude prevalence rates have varied from 7 [2] (in Ethiopia) to 405 [3] (in Uruguay) per 100,000 of the population. Whether there is a true difference in susceptibility of these populations would be of great importance epidemiologically, in terms of investigating the cause(s) of PD. However, this difference could be accounted for by several factors: under-diagnosis of PD in these communities, differences in case finding methods, differences in diagnostic criteria used and early mortality owing to other causes in these populations.

Previous studies in sub-Saharan Africa (SSA) have been performed using differing methods, making them difficult to compare with each other and other studies elsewhere in the world: door-to-door studies carried out by Osuntokun *et al.* (Nigeria) [4] and Tekle-Haimanot *et al.* [2] (Ethiopia); case finding from neurological clinics and neurological admissions by Harries *et al.* [5] (Kenya) and Bower *et al.* (Ethiopia) [6]; retrospective review of hospital admissions by Lombard and Gelfand [1] (Zimbabwe); and using data on levodopa (L-dopa) usage by Cosnett *et al.* (South Africa) [7]. Most of the

studies have been on small population sizes and most are now over 20 years old. As there are few studies, papers describing both idiopathic PD and Parkinsonism are included. Within each section, we have tried to make it clear exactly who was included in the study. Unless stated, the African studies are all on the basis of black African populations.

Door-to-door studies in Africa

In 1986, a door-to-door study was performed by Osuntokun *et al.* [4] in a Nigerian town, Igbo-Ora, with a population of 20,000. They looked at all neurological disorders, not specifically PD. They used a two-step procedure, with a screening questionnaire carried out by non-medically trained administrators, followed by an expert history and examination if they answered positively to the questionnaire. Nearly 95% of the population took part in the study. Only 11% of the population were over 50 years (compared with over 33% in the United Kingdom). No diagnostic criteria for PD are described. Their results showed a point prevalence rate for PD of 10 per 100,000, i.e. only two cases were identified. The age and sex of these cases is not reported.

A second door-to-door survey was carried out by Tekle-Haimanot [2] in rural Ethiopia between 1986 and 1988.

Again, this study, which included a population of 60,820, looked at all neurological disorders, and not just PD. Participation rates were between 95 and 100%. The median age of this population was 14.5 years with 59% of the population being <20 years old. They found four cases of PD (all male), giving a crude prevalence rate of 7 per 100,000. No diagnostic criteria for PD were documented. The authors state that the reason for the difference in the prevalence of PD among white populations is due to the difference in population age structure. However, age standardised rates were not calculated.

Studies using retrospective review of hospital admissions

Lombard and Gelfand [1] looked at notes from admissions of black Africans to Harare Hospital between 1973 and 1976 and compared this to admissions to a nearby hospital covering a white African population (the Andrew Fleming Hospital) in 1974–76. There were 17 admissions of cases of PD (nine female and eight male) in the black population over that time period compared with 33 in the white population. However, the total number of admissions in the former hospital was 82,453 from a population of 430,000 compared with 34,952 of the total white admissions from a population of 126,000. To try and correct for the difference in population sizes, they multiplied the number of cases in the white population by 3, showing a big discrepancy between the two races (17 in the black population versus 99 in the white population). Of course, as this is a hospital-based study, cases in the community would not have been taken into account. No diagnostic criteria for PD are mentioned, although they do report that none of the cases had a prior history of encephalitis and carbon monoxide or manganese poisoning was thought to be unlikely. However, one patient was on a neuroleptic drug (chlorpromazine) and vascular Parkinsonism was suspected in a few patients. Therefore, it is unlikely that this entire group had idiopathic PD.

Studies of neurological outpatient consultations

Using retrospective records from the neurological consultations and data on the usage of L-dopa, Cosnett and Bill [7] reviewed the presentation of black patients in Natal, South Africa and compared this to local Indian and white African populations. Over a 7-year period (1979–85 inclusive), 1,984 black patients were reviewed by a neurologist and only three cases of idiopathic PD were noted (age and sex not reported). PD diagnosis was based on 'the grounds of bradykinesia, rigidity, resting tremor and postural instability'. Ten patients were felt to have a diagnosis of 'secondary' Parkinsonism, which the authors classify as being due to drugs, hypoxia, encephalitis or typhoid fever. Within the black population, 22.8% were over the age of 50, 9.4% over the age of 60 and 1.8% over the age of 70. In the same

population of white patients attending neurological clinics, 47.8% of the population were over 50 years. The authors also looked at the frequency of L-dopa prescription. In the black population, there was approximately nine times less L-dopa prescribed than in the white populations. They propose that one reason so few cases were seen, was an early selective mortality in the black population. It was suggested that the elderly blacks were less likely to seek medical attention than other races. However, similar numbers of black and white patients with motor neurone disease were seen.

A recent paper (2005) reported a review of consultations at a university hospital neurology clinic in Ethiopia [6]. One hundred and nine patients with movement disorders were seen at the clinic in 2003–04. This accounted for over 15% of all referrals. Of the 720 patients 52 had Parkinsonism, of whom 46 were diagnosed with idiopathic PD. The diagnostic criteria used are not mentioned. There was a male predominance. Interestingly, and in contrast to other reports, 90% of patients were treated with L-dopa, but, in contrast to the UK practice, 82% were also taking an anticholinergic medication. Fourteen of the patients on L-dopa had financial concerns regarding their medication, compared with only two taking the anticholinergic medications. The authors comment that they are unaware of the prevalence of PD in their community, and so do not know how many have not sought, or cannot afford, help.

Use of L-dopa in Africa

Harries [5] looked at the use of L-dopa for Parkinsonism in African patients in 1972. All patients were said to have idiopathic PD, although no diagnostic criteria are documented. He begins his article by saying that PD is not uncommon in Africans, and indeed he had noticed 30 cases in the previous 5 years in his outpatient clinic in Nairobi, Kenya. He chronicles the use of L-dopa in seven patients (six male and one female) aged 43–65 years. It is not clarified whether these are black or white Africans; however, they were reported to converse in Kiswahili, making it seem likely that they were black African patients. All except one patient made an improvement as defined by the Webster rating scale and all patients reported increased well being on the treatment. Side effects were noted in five of seven cases: constipation, hallucinations (thought to have been related to benzhexol introduction and not the L-dopa alone), dyspepsia and dystonia.

Clinical presentation

Haimanot [8] looked prospectively at 70 cases of PD in Ethiopia who attended his private neurology outpatient clinic at a teaching hospital between 1980 and 1984. Diagnosis was based upon the presence of bradykinesia, rigidity and tremor, although it is conceded that patients with Parkinsonism owing to other causes (e.g. vascular disease) may have been included. Additional factors that helped strengthen the

diagnosis were facial masking, abnormal postural reflexes, typical gait disturbance, speech disturbance and autonomic dysfunction. Data on age at onset of disease, current age, sex, initial symptoms of PD, history of head injury, use of neuroleptic drugs, syphilis infection and previous encephalitis were recorded. He also checked various blood tests and skull X-rays were requested in 63 patients. During this period of the study, only two patients were actually admitted to hospital, and the others were managed on an outpatient basis. This confirms that using the number of hospital admissions to estimate the impact of PD misses the majority of cases. During the same period of study, four patients died of pneumonia and one from a malignancy. PD was seen more frequently in males (7:3) and the commonest decade was 61–70 (25 cases). Four of the cases identified were under 40 years. The mean age at onset of symptoms was 54.6 years. The most common presenting symptom was tremor (90%) followed by bradykinesia (86%) and stiffness (71%). In 70% of patients their symptoms had been unilateral at onset, but progressed to involve the opposite side. Twenty-one patients had previously suffered a significant head injury (one of whom had a depressed skull fracture on X-ray), six patients had a positive venereal disease research laboratory test (but only one had features suggestive of neurosyphilis) and, interestingly, one patient gave a family history of PD (his father had died at the age of 68 and never received any treatment for his symptoms). Most patients did not present themselves to a doctor until they had had symptoms for 2–5 years and at presentation, only 22.9% had Hoehn and Yahr stage I (early) disease, and 10% had stage V (late) disease. Again, lack of continuous availability of medication was a problem and most were treated with benzhexol, with only a few receiving L-dopa. Haimanot concludes that black races are relatively protected against PD.

Lombard and Gelfand [1] also discuss the presentation of PD in their cases. They reported tremor as being the main feature in nine patients, and tremor and rigidity in two patients. Only one case is reported as having bradykinesia, a prerequisite for the diagnosis of PD in the UK PD brain bank criteria.

Perception of PD in Africa

Perception of PD in Africa is likely to be different from other areas. Often, patients with neurological disease such as epilepsy or leprosy are seen as ‘cursed’ and as a result are often cast out of society [8]. The cultural norm tends to be to visit traditional healers before seeking medical help and as a result patients tend to present later than those in developed countries, if at all. Haimanot [8] also noted that several Parkinsonian patients had ended up as beggars, as their visual appearance aroused sympathy in the public. This may well have an impact on whether the patients present to western medical care or to a traditional healer. It may also mean that patients with these symptoms would try to conceal them. Both these factors will have an impact on how frequently PD is seen in hospitals

and by medical practitioners, meaning they are important considerations in any report on the prevalence of PD in Africa.

Autonomic symptoms in African patients with PD

Autonomic dysfunction is well recognised in PD, particularly as the disease progresses. Okubadejo *et al.* [9] studied the frequency of autonomic dysfunction in 33 patients with PD in Nigeria and age-matched controls. Autonomic function tests utilised included heart rate variability to deep breathing, standing and the Valsalva manoeuvre and blood pressure response to standing. They found that autonomic dysfunction was common in Africans with PD, especially those over the age of 65. Among the patients with PD, 51.5% had abnormal parasympathetic function, which was significantly higher than controls, although many of these patients (41.2%) had no symptoms associated with it.

Services available in Africa to support patients with PD

The WHO Neurology Atlas [10] compares neurology services by continent, based on a questionnaire sent out to 106 member states including 16 countries in the African region. The African responders reported 0.03 inpatient neurology beds per 10,000 of the population. On average, there were only 0.03 consultant neurologists per 100,000 of the population, and all African populations reported <1 consultant neurologist per 100,000 of the population. Drugs for PD in Africa were available to only 12.5% of those who needed them, compared to 79.1% in Europe. As nearly 60% of the population live off less than \$2 US per day [11], it is unlikely that they will ever be able to afford treatment, be it pharmaceutical, expert medical or informal help with care.

Background information about Tanzania

Tanzania lies in East Africa and has a population of 37.9 million. It covers an area of 364,900 square miles. Life expectancy is 44 years for men and 45 years for women. By 2025, the population is expected to rise to 52.1 million. Forty-four per cent of the population are <15 years and 4% are >65 years. The infant mortality rate is 68/1000. Six and a half per cent of the population aged 15–49 years have HIV/AIDS [12]. In Tanzania, in 2002 it was estimated that 36% of the population were living below the poverty line [13], but on a more recent website this had been revised to 50% [14].

The Hai district of Tanzania [15] is in the northeast of the country on the slopes of Mount Kilimanjaro, the highest mountain in Africa. The predominant tribe is the Chagga, and most people are subsistence farmers, growing maize or bananas on ‘shambas’ (smallholdings). Most of the population are Christian, but there are some Muslim and other denominations too. Most of these people are

born, brought up and live their entire life in the same community. The local major hospital is the Kilimanjaro Christian Medical Centre in the town of Moshi. It provides tertiary services for a population of 11 million people and has 450 inpatient beds. The nearest consultant neurologist works in Dar-es-Salaam, an 8 h drive away, and there are only two consultant neurologists serving the whole country (both in Dar-es-Salaam), and one geriatrician (in Moshi) that we are aware of.

PD in Tanzania

After searching through Medline, we have not found any studies looking specifically at PD prevalence in Tanzania. The only quote relating to Tanzania that we have come across is from 1965, when Haddock [16] reported that Parkinsonism was seen less frequently in Tanzania than in the United Kingdom. Anecdotal information from physicians and neurologists who have previously worked in the country suggest that there are cases of PD, but most that come to attention of these services have been previously undiagnosed and are not on any treatment. Little is known about the condition in the general population and therefore most people would not seek help from medical services and would first visit a traditional healer or 'medicine man'.

While conducting our work in Tanzania, we came across specific problems faced by people with PD, which are illustrated by the following three case histories.

Case vignette (1)

A 55-year-old man was reviewed regarding PD medication. He is a retired pharmacy assistant, married to a paediatric ward sister. He had been diagnosed by a visiting neurologist 5 years previously, when he had presented with 6 months of tremor in his right (dominant) hand. He was taking co-careldopa of 125 mg once daily (mornings). The neurologist had prescribed co-careldopa TDS, but he could not afford this.

The visiting neurologist has now left Tanzania, so the patient attends only a medical clinic where he is followed-up for hypertension. He visits a different physician every time. Since diagnosis, he has taken several different medications in different doses. Local pharmacies cannot continually stock co-careldopa, and rely upon infrequent charitable donations, which sometimes include the drug, varying in dose and preparation. If unavailable, benzhexol is supplied instead. Co-careldopa is relatively expensive (one tablet costing 500 Tanzanian shillings (Tsh) (approx 25p), compared to 10 Tsh for bendroflumethiazide), so he often 'rations it'—i.e. judging whenever he needs a dose, and not 'wasting it' by taking it regularly. The control of his disease is poor. At times he is stiff, unable to walk and very slow in talking and at other times, he hallucinates on benzhexol or feels nauseated from co-careldopa. He does not have dyskinesia.

He has never visited a physiotherapist, but has been referred to occupational therapy. He is the only PD patient

attending the OT department, so their experience is limited. There is very little provision of speech and language therapy in Tanzania (there is only one therapist that we are aware of), and he has had no input. He has no written information about PD and no long-term specialist follow-up.

Case vignette (2)

An 82-year-old man who presented with a tremor in his left hand for 6 months was seen at a hospital in Arusha, the nearest large town. He was diagnosed as having PD and given a two-month prescription of co-careldopa. He found good improvement in his symptoms, but was unable to afford any further medication. Since the discontinuation of his medication, unsurprisingly, his symptoms have worsened and he has gradually deteriorated. He has now been without medication for over a year. He has no follow-up appointment, and has had no multidisciplinary input whatsoever. He is unlikely to have the amount of money required again for a two-month prescription.

Case vignette (3)

The third case was seen, and diagnosed, 10 years ago by RW, when investigating stroke in the Hai district. At that stage, he was 30 years old and displayed clear signs of Parkinsonism. He had been unable to afford to visit anyone regarding his condition and as a result had become increasingly slow and his mobility had deteriorated markedly. He has left-sided tremor predominant PD. This has led him to give up work in his 'shamba', his only source of income, exacerbating the cruel cycle. CD visited him again at the end of 2005. Now, he is 40 years and is limited to mobilising around his house and in the small area of yard outside it. He has tried various treatments from the village traditional healer who had diagnosed 'evil spirits'. These have included oral medication, topical treatment, inhalations and tattoos, but none of them had benefit. He relies upon help and financial support from his nephews.

Discussion

These cases demonstrate the problems faced by those 'fortunate' enough to have their PD diagnosed. Owing to the cost, the treatment is intermittent or non-existent. Services available for therapy and monitoring are very limited. People often resort to local traditional treatments.

At present, there are likely to be many patients in SSA with undiagnosed and untreated PD. Even if the patient has been lucky enough to be visited by the medical services and diagnosed with PD, it is likely that he will face ongoing problems sourcing medication and, even if available locally, he will probably not be able to afford a continuous supply. Multidisciplinary input for patients is scarce, and most staff in these departments will have little, if any, prior knowledge of PD.

The perception of the disease within the population is very different from that seen in developed countries. The

symptoms are not recognisable to the general population as being a particular illness; often, people think it is part of the inevitable consequences of ageing, or in some areas local beliefs lead people to believe that they have been 'bewitched'. As a result, seeking the help of the local traditional healer is most likely to be the first port of call, and not western medical treatment. It also leads to stigma for those affected, and can have a devastating social impact.

In the United Kingdom and other developed countries, we take for granted that once diagnosed, PD symptoms can then be relatively easily treated, but in SSA, even if diagnosed, it is by no means certain that the PD patient will have a smooth clinical course. It seems that there is still a huge mountain to be climbed, as not only will there be difficulties in finding medication, maintaining a constant supply and having enough money to buy this, but also, often there is no one to monitor or follow-up treatment. Patients do not have access to education or nurse specialists as they do in the United Kingdom, and written information is not available in local languages and even then in the older age groups many patients have never been to school and would be unable to read this anyway.

The big question remains—how can we even begin to help? It seems that insurmountable problems exist and the fundamental problem is a lack of funding underpinning the whole system. Any solutions brought in from abroad tend to come across the problem of sustainability. At the end of the day, unless locally acceptable, affordable and maintainable solutions are found, these issues will never be solved. Following the G8 summit and Live 8 in 2005, problems in the developing world are more topical than ever before, and a feeling that they are our problems too, and that we have a duty to do something about them, seems to be widespread. HIV/AIDS, malaria and other infectious diseases are still undoubtedly the major issues, but they tend to eclipse non-communicable diseases, which are present and, to a large part, ignored. Raising the profile of such conditions is the only way that funding will be secured [17]. This recent article states that the WHO are producing a report on the public health challenges of neurological disorders in SSA, which in some part should address this issue. However, without data with respect to the burden of these diseases in the community, it is hard to know how big the problem is. Further studies, not just for PD, are necessary to address this issue.

PD is only one example. Many other chronic conditions receive little recognition in the developing world. With the population ageing, even in SSA, and available treatments for infectious diseases improving, such conditions are on the increase.

Key points

- Parkinson's disease is present in SSA and even those who are lucky enough to be diagnosed and afford treatment have a difficult clinical course.

- Drug treatment is difficult to find and rarely available, or affordable, continuously.
- No major improvements have been made in the past 20 years.
- Most people with PD remain undiagnosed and untreated in the community.
- Patient education and information are severely lacking. Generally, no written information or long-term follow-up is available.
- Only fledgling services are available for patients with PD in the developing world in comparison with those available and taken for granted in the developed world.

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