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The role of support groups in the management of Parkinson's disease in Kenya: Sociality, information and legitimacy

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ABSTRACT

Parkinson's disease (PD) is the second most common neurodegenerative disease globally. It is a progressive neurological disorder which can lead to a decline in wellbeing and quality of life for people living with PD (PwP) and their families/caregivers. However, little is known about the experience of PwP in low- and middle-income countries. In high-income countries, the benefits of support groups in providing social support, preventing social isolation and normalising the PD experience have been established. As part of a wider ethnographic study over 10 months, we explored the role of support groups in the management of PD in Kenya, sub-Saharan Africa. Fifty-five PwP and 23 informal family caregivers took part, and observations took place over ten support group meetings. Both positives and drawbacks were identified. The groups played a role in filling in gaps in information and services that the healing landscape in Kenya was unable to provide, while acting as an important source of care and support for PwP and caregivers, enabling 'sociality' and legitimacy. Drawbacks included limited reach and accessibility, 'social comparisons', and seeing the severity of progressed PD in others. Findings suggest PD support groups could become important components within resource-constrained healthcare settings.

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Introduction

Parkinson's disease (PD) is a neurodegenerative movement disorder that increases in prevalence with age. There are estimated to be 6.2 million people worldwide living with PD (Dorsey et al., 2018; Feigin et al., 2019) and this number is predicted to rise to 12.9 million by 2040 – described as the 'Parkinson Pandemic' (Dorsey & Bloem, 2018). This is largely due to an increase in total world population, increased longevity, population ageing and somewhat to declining smoking rates. Low- and middle-income countries (LMICs), such as those in sub-Saharan Africa (SSA), are not exempt from this 'pandemic', yet still very little is known about the experience of PD in resource-constrained settings.

PD is associated with a host of motor and non-motor symptoms (Connolly & Lang, 2014) that can lead to a decline in wellbeing and quality of life for both people living with PD (PwP) and family members/caregivers. Motor symptoms include tremor, muscular rigidity, balance issues and loss of spontaneous voluntary movements (DeMaagd & Philip, 2015). Non-motor symptoms can include

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depression, anxiety, cognitive dysfunction, sleep disturbances, constipation, and loss of sense of smell, among others. Symptomatic treatment is available and can significantly improve quality of life, but cannot alter the course of disease (NICE, 2017).

There has been very little research on PD in SSA, but available work suggests that treatment is typically unavailable or too expensive (Fothergill-Misbah et al., 2020; Mokaya et al., 2016; Okubadejo et al., 2019), which makes managing PD more difficult. The WHO Neurology Atlas (WHO, 2004) reported that PD medication is available to only 12.5% of PwP in SSA (perhaps fewer considering those who remain undiagnosed) compared to 79.1% of PwP in Europe. Kenya, like other SSA countries (Bower & Zenebe, 2005), also has very few PD specialists; approximately 20 neurologists in three major cities (Fothergill-Misbah et al., 2021). Knowledge about PD in SSA is very limited among the general population, resulting in associations with witchcraft, stigma towards PwP and the perception that PD is 'normal' with old age (Kaddumukasa et al., 2015; Mokaya et al., 2017; Mshana et al., 2011). Knowledge is also very limited among non-specialist healthcare professionals, resulting in misdiagnoses and PwP receiving very little information about their condition (see Fothergill-Misbah et al. (2021)). If PwP are diagnosed, 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). It is against this backdrop of the low number of specialists, limited access to, and affordability of, medication and services, and poor awareness about PD, that this study was conducted.

In a systematic review (with most data coming from high-income countries), Soundy et al. (2014) noted the difficulties people have adjusting to life with PD, the importance of maintaining individual identities, and the impact of social support on wellbeing. For example, in Tanzania, Mshana et al. (2011) found that PwP expressed a sense of 'loss of self' (Charmaz, 1983). Family members can play a crucial role in enabling PwP to maintain their social identity, and remain independent and self-sufficient (Roger & Medved, 2010). In Iran, Soleimani et al. (2014) found that PwP experienced disrupted social connectedness (relationships with others that underpin a sense of belonging and social identity (Cohen, 2004)) as a result of progressive physical disability, reduction in social activities and increasing isolation. Among PwP, social isolation has been associated with greater symptom severity and a lower reported quality of life (Subramanian, 2020). Social isolation can be exacerbated by what Scambler (2004) has described as 'enacted' stigma (discrimination by others towards someone because of their condition, for instance, the visible symptoms of PD), and 'felt' stigma, which is often associated with shame and embarrassment, resulting from self-perceived dependency (Nijhof, 1995) or shaking and drooling (Hermanns, 2013), for example. In many parts of the world, PwP also experience additional stigmatising perceptions resulting from associations of PD with witchcraft and curses (Kaddumukasa et al., 2015; Mokaya et al., 2017; Mshana et al., 2011).

It is thought that people who enjoy a higher degree of social support and community interaction have better health outcomes, including physical and mental health and wellbeing (Uchino, 2006; Uchino et al., 1996). In higher-income country contexts, the importance of PwP being able to maintain social relations and relate to others through support groups has been widely reported (Soundy et al., 2014). Support groups can provide a space where people feel accepted and experience camaraderie (Solimeo, 2009), offer a way to gain information, can enable continued engagement with society and provide social connection and support (Subramanian, 2020). 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*'. PD support groups in high-income countries are also increasingly using virtual communication methods and online forums to combat social isolation and provide alternative sources of social support, the uptake of which accelerated during global Covid-19 pandemic 'lockdowns' (Subramanian et al., 2020). Online support groups could also enable virtual knowledge sharing to LMICs. However, many populations may not be able to benefit from these initiatives due to digital exclusion resulting from the digital divide, with many unable to access, or afford, devices or internet data (Giansanti & Veltro, 2021).

In SSA, the potential benefits of support groups have been documented for people living with HIV, specifically in Kenya (Gillett & Parr, 2010; Prince, 2012), Uganda (Whyte, 2014), Tanzania

(Marsland, 2012), Burkina Faso and Cote d'Ivoire (Nguyen et al., 2010), where people have been encouraged to 'live positively' with HIV, forming identity around their diagnosis. Support groups for PD currently exist in Kenya, Ethiopia, Uganda, South Africa, Cameroon, Ghana and Nigeria. However, the benefits, and drawbacks, of these groups for PwP and their families have not been explored in a LMIC setting, and literature on the experiences of PD groups is lacking.

This paper reports on the role of PD support groups within the Kenyan healthcare landscape. Data from interviews and ethnographic observations, conducted as part of a wider study on the lived experiences of PwP in Kenya, are used to describe how the support groups were established, the reported benefits for PwP and caregivers, and the challenges of groups for a degenerative condition like PD. We provide some reflections on the potential role that support groups could play in promoting the health and wellbeing of PwP, and their families, in SSA and other low-income and lower-middle-income countries.

Materials and methods

Setting

The study took place over ten months (March–December 2018 and May 2019) across urban and rural Kenya. Support groups were located in Nairobi and Mombasa, the two largest cities in Kenya, with estimated populations of 4.4 and 1.9 million people respectively (KNBS, 2019). Kenya is urbanising by 4.3% every year (World Bank, 2016), with much of this increase happening in informal settlements; in Nairobi, for example, 2.5 million people live in one of the city's 200 slums and informal settlements (APHRC, 2014). As of 2018, 34.4% of Kenya's population lived in extreme poverty (World Bank, 2019).

Data collection

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 specific social and cultural setting. Data were collected using ethnographic methods, including participant observation, in-depth semi-structured interviews and informal conversations. Observations took place at a PD support group in Nairobi from March 2018 and at another in Mombasa after its establishment in October 2018. Both groups operated outside of the state and were run on a voluntary basis.

The Nairobi group was established in 2012 by a group of people who had been directly affected by PD and had struggled to obtain relevant information, initially meeting in the home of one member. After working closely with a PD non-governmental organisation (NGO) (also established in 2012) with the aim of improving the awareness about PD in Kenya, the group grew through advertisements in newspapers and through the NGO's website. The Nairobi group gained more members and began meeting in a local church classroom once a month. The group now has over 100 members; usually, 20–45 people attended meetings.

Drawing on the success of the Nairobi group, and in collaboration with a private neurology clinic, the first author established a new PD support group in Mombasa during the fieldwork period to help address an important information gap identified among PwP and their caregivers. Monthly meetings were held in the waiting room of a private neurology clinic, at a time that suited the participants; they were also open to those not accessing the clinic. The founder of the PD NGO ran the first meeting where attendees had the opportunity to introduce themselves, meet other members, and discuss future topics. Ensuring the group was led by attendees and clinic staff enabled the group to continue functioning after the researcher's departure. The group grew to almost 50 members with 10–20 attending each meeting. Both the Mombasa and Nairobi groups communicated through active WhatsApp groups, with members sharing articles and information, and answering queries about medication, symptoms or specialists.

Forty-two hours of observations took place during meetings (30 hours in Nairobi and 12 hours in Mombasa), with the goal of understanding life as an ‘insider’ while remaining an ‘outsider’, being as unobtrusive as possible (Mack et al., 2005). Particular attention was paid to understanding the benefits and drawbacks of the groups, how members interacted and engaged, and the role the groups played within the wider healthcare landscape. Handwritten field notes provided detailed and nuanced descriptions of the space, discussion topics, interactions between members, and participants’ actions and emotions, noting changes over the months. All notes were typed up fully the same day.

Across the whole study, a series of informal interviews and conversations were carried out with 55 PwP, of which 18 attended the Nairobi support group. Nine PwP were followed up with formal in-depth, semi-structured interviews at a later date (9.5 hours of interview material). Twenty-one PwP were living in Nairobi but did not attend the support group at the time of interviews (either because they did not know about it, because of transport/access difficulties, or because they chose not to participate), providing an important comparison; following interviews, six more PwP joined the group. In Mombasa, interviews with PwP ($N = 16$) took place before the establishment of the group, so data on the Mombasa group are limited to observations during the meetings. In addition, formal in-depth semi-structured interviews (21.5 hours) were carried out with 23 informal family caregivers of PwP, 14 of whom attended the Nairobi PD support group. Interviews were conducted by the researcher in either English or Kiswahili, according to each interviewee’s preference.

Ethical considerations

Ethical approval for the study was granted by Kenya Medical Research Institute (KEMRI) Scientific Ethics Review Unit and Newcastle University Research Ethics Committee. Ethical Guidelines of the Association of Social Anthropologists of the UK and Commonwealth were followed. Interview participants were given information sheets to read (English or Kiswahili), provided written consent and explicit consent for interviews to be audio-recorded. For ethnographic observations, participants were made aware of the position of the researcher. Consent was an on-going process, not a one-off event, and required negotiation over time. All participants were made aware throughout the study that they did not have to answer questions if they did not wish and could withdraw from the study at any point.

Analysis

Data were analysed using inductive thematic analysis, allowing themes to be identified from the data while maintaining the depth of individual stories and experiences (Braun & Clarke, 2006). Audio-recorded interviews were transcribed by the researcher enabling immersion in the data. Transcribed interviews and detailed field notes were read and re-read during fieldwork to focus data collection. Analysis was iterative, reflexive, and required constant reviewing of transcripts, field notes and personal reflections. Initial notes and comments were made on transcripts and field notes. Quotes and themes were coded and empirical and theoretical codes and supporting data were collated into main and sub-themes after reviewing and refining.

Results

This paper explores the experiences of PwP, and family members, who accessed support groups, the reasons why some did not utilise the groups and the experiences of very few who were deterred from attending meetings. Participants came from diverse social, environmental, educational and financial backgrounds. Overall, they reported largely positive experiences; however, the progressive nature of PD also posed challenges for some participants in their interaction with others in the group.

Nzambi's story

The following extract is from the researcher's field notes. Nzambi's experiences illustrate some of 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.

Nzambi, aged 58, had been living with PD for 18 years and attended the government neurology clinic. After meeting Nzambi, I mentioned the support group for PwP in Nairobi that he could access. He found it difficult to believe that there was anyone else in Kenya with the same condition, but he came to the next group meeting, a dance therapy session. I partnered with Nzambi; 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 as he put more and more weight on me until I felt as though I was holding him up. He sat down to rest.

Exactly one month after I first met Nzambi, we met again at the government neurology clinic. He had enjoyed the support group: *'It's good, because I made a friend and we exchanged ideas'*. Nzambi's new PD friend had walked him to the bus stop after the meeting; he had told Nzambi to think of happy things instead of his sickness. Nzambi said he had continued dancing at home, practicing the moves he had learnt. He was excited for the next one. At the next meeting, Nzambi had a long conversation with the visiting occupational therapist over tea; explaining that he lived alone but wanted to learn about exercises to help manage his condition.

Reported benefits of the groups

Group members appeared to gain several benefits from their participation. First, the groups provided an important source of information about PD that was otherwise lacking – this information came from various sources and in different formats. Even wealthier participants often struggled with the constraints of service availability, medication affordability and limited disease information, which resulted in PwP, caregivers and neurologists having to make use of what was available to them, rather than what was optimal. For those who were less well-off, access to information and treatment was typically minimal. The committee of the Nairobi group (made up of family members of a higher socioeconomic status) often invited speakers, some of whom were healthcare professionals, on a voluntary basis. Speakers, such as occupational therapists, provided members with information, advice and exercises to manage their condition at home; crucially, this advice was free. In this way, the groups took on certain roles the state was unable to provide, or people could not access.

So, that's where I learnt things like before they [PwP] take the medicine you have to control the protein, no one tells you such things, no one tells you. (Daughter of 78-year-old PwP)

Another source of information and advice came from members' own experiences of living with, and caring for, someone with, PD, as well as tips on negotiating the Kenyan healthcare landscape.

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 PwP)

A final source of information was through leaflets from PD foundations in high-income countries and advice on specialists and further resources. Although this information was often not tailored to the Kenyan context (for example, many specialists were not available), it still provided useful information regarding symptoms. In this way, the groups provided access to information rarely offered by neurologists because of time constraints in clinics, communication challenges, a reluctance to deliver bad news and barriers to additional information, services, and resources for PD in Kenya (see Fothergill-Misbah et al. (2021)). Many neurologists in Nairobi were also unaware of the groups' existence.

The second reported benefit of the groups was access to practical activities. The Nairobi group hosted dance, art and yoga sessions. During an art therapy session, attendees were encouraged to paint, regardless of how ‘good’ or ‘bad’ they thought they were. People seemed unsure at first but grew in confidence. At the end of the session, many were clearly proud of what they had produced and seemed happy with their work; several asked to take their artwork home to share with family. The art was photographed and made into postcards to sell and raise money for the group.

Thirdly, the groups provided important social support and relationships that were highly valued by PwP and family members. The daughter of one 79-year-old PwP described how the Nairobi group was a ‘lifesaver’, adding that she did not know what she would have done without it. PwP also described seeing that they were not alone:

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 PwP)

Some described feeling ‘at home’ among others who understood their frustrations and did not ‘judge’ them. As one caregiver explained, it was a ‘safe space’. Others believed that the group had helped them come to terms with having (or caring for someone with) PD. Seeing symptoms in others confirmed that the condition did really exist, legitimising PwPs’ own symptoms and diagnosis.

I went and I was just like, ‘Well, mum doesn’t accept it’. And then she [PwP] 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. (Daughter of 66-year-old PwP)

Many had never seen anyone else with PD before. For some, seeing other members worse off than themselves spurred them on to attend meetings and learn how to better manage their condition.

A final benefit was the provision of ‘PD alert cards’ from an international charity which read ‘I have Parkinson’s’. In addition to their intended purpose – to provide crucial information to doctors and emergency services – the cards fulfilled other important functions. They helped impart a form of identity and legitimacy for PwP, and they could be used to ‘educate’ others who might comment unfavourably on their appearance and behaviour. One PwP (aged 33) had fallen out of a bus and been declared ‘drunk’ before he acquired the card, underlining the case for recognition and legitimacy that the cards might facilitate.

Perceived drawbacks of the groups

Despite the generally positive experiences of the groups, there were also drawbacks. Firstly, and most importantly, they were only accessible to those who knew about them and had the means to reach them. The vast majority of Kenyans with PD (those living further away and in rural areas, those with limited resources for transport and/or without the necessary family support) were effectively excluded. Most attendees discovered the group through the website or Facebook page; media not available to many. The cost of travelling to meetings also deterred many from attending, particularly if using public transport was difficult. Group discussions, particularly in Nairobi, were usually conducted in English (some of the group committees who led the meetings did not speak Kiswahili), which many PwP could not speak confidently. Furthermore, much of the advice given to attendees about how to manage their conditions was not feasible because of limited resources and the lack of available, and affordable, services.

Second, some PwP were reluctant to attend meetings because it affirmed that they were ill; something that they would prefer to avoid having to confront. Others described how attending meetings was disheartening as they would see the progression of the disease in those at more advanced stages: as one daughter described ‘it freaked her mother out’. Others were concerned about hearing of the

'horrendous' symptoms they might experience in the future. Several PwP were wheelchair bound, could not talk, or could not feed themselves, which could be upsetting to see. Some family members were also deterred from asking about more advanced symptoms for fear of scaring others.

In contrast, some other PwP were deterred from attending meetings because they would see people less disabled than themselves and get 'jealous' or 'mad' that their PD was 'worse' than others.

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 PwP)

Family members of advanced PwP also described feeling disheartened by seeing others who could still walk. The spouse of one PwP did not attend 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. Some of the groups' activities (painting, dancing, etc.) could also be a painful reminder of things they could no longer do.

Discussion

Despite the drawbacks noted above, PD support groups clearly provided some PwP and their family caregivers with much-needed support, particularly in view of the serious constraints on access to other forms of support. Support groups provided people with access to specialist information that was otherwise unavailable, inaccessible, or unaffordable through government and private facilities; they enabled attendees to share knowledge, learn, and carry out group activities and exercises; and, crucially, they acted as an extended form of social support for PwP and those doing care work.

One of the most important aspects of the groups was the social networks attendees developed and the sociality formed around PD. The concept of 'biosociality' was coined by Rabinow (1996), who believed that the existence of new biotechnologies could lead to revised perceptions of biology, and in doing so could create new socialities around biological conditions. Biosociality has been used to understand the social relations that emerge from biotechnological advances, however, Marsland (2012) argues that, in Tanzania, a nuanced understanding of biosociality is required where 'sociality' is taken as seriously as 'bio', taking into account pre-existing social relations and family networks, such as seen in Kenya around PD. Literature around biosociality has been largely positive, highlighting the opportunities for people to form new relationships and identities around 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 Kenya, Prince (2012) described how people formed identities around their HIV status, while striving to normalise the disease in society. Prince also described the visibility of HIV support groups to organisations and potential funders; this contrasts with PD, which, as a condition largely associated with ageing, has not received the same levels of social and political attention. However, this study has illustrated the crucial role of sociality in the management of PD, particularly the biosociality (Rabinow, 1996) fostered through the support groups.

For many participants, attending the support group and seeing others with PD enabled a legitimacy that was not possible at the individual level. 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 'PD alert cards' enabled a way to externalise the legitimacy that a label conferred to others outside of PwPs' family and the groups. Legitimising their symptoms and suffering had important social implications and allowed PwP to justify their illness to themselves, family, friends, and society. This was an important step in moving towards an acceptance of the condition. Without the validity a diagnostic label ensures, PD will remain 'invisible' to government and donor support.

However, several PwP who attended the groups reported undertaking what Festinger (1954) described as a 'social comparison' of others. These comparisons could be a double-edged sword

in terms of impacts on wellbeing and self-esteem. What Festinger (1954) has proposed as ‘downward comparisons’ (with those with more advanced disease) sometimes helped people to appreciate what they had, but they could also serve as a painful reminder of the eventuality of progression and what was to come. ‘Upwards comparisons’ with those apparently doing better encouraged some to try to improve their condition through exercise or diet; but they could also provoke feelings of jealousy and heighten a sense of loss, deterring some from returning to the group.

These negative experiences illustrate a form of what might be called ‘bio-antisociality’ where participants 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 within a group setting that did not appeal). The progressive nature of PD partly explained this reluctance: medication can only serve to provide temporary alleviation of some symptoms, it cannot halt the progress, and this is only too evident to group members who observe each other’s inexorable decline. This is in marked contrast to other chronic conditions like HIV or diabetes, where lifestyle changes combined with medication can halt and even reverse the illness. The nature and role of biosociality around PD, and possibly other progressive, degenerative diseases, may require more nuanced consideration. 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.

Although literature on the negative effects of support groups in LMICs is lacking, similar challenges have been observed around PD in England (Williamson et al., 2008), USA (Solimeo, 2009) and Australia (Hudson et al., 2006). A potential strategy for tackling the negative impact of seeing advanced PwP could be to provide separate groups for those at different stages of the disease. However, there are questions about feasibility of doing this in SSA, where even maintaining a single group is challenging; consideration also needs to be given to impacts of differentiation of this kind for PwP and caregivers around stigmatising perceptions towards those with more advanced disease and reduced potential for support in smaller groups.

Finally, attendees described learning at every meeting, however, many recommendations came from countries with more advanced and better-resourced healthcare systems and are perhaps of 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. Again, ‘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. However, the groups did act as valuable sources of information about how to manage symptoms, an aspect of care they could not access elsewhere.

In the context of Kenya where formal social support is lacking and information is largely inaccessible, support groups become important components within the healthcare landscape, providing those who accessed the groups with information, support, sociality and legitimacy.

Conclusion

For almost all our research participants, PD care happened through social connections that could be strengthened and solidified through participation in support groups, through a form of biosociality. However, the study has shown that, although biosociality is a useful concept for understanding some of the positive experiences of participation in the groups, we cannot extrapolate straightforwardly from other chronic conditions prevalent in Africa, such as HIV (or diabetes) where the concept has been most widely deployed. The information, sociality and legitimacy the groups provided may be seen elsewhere in low-resource contexts for conditions with poor ‘visibility’ and for which access to government services and support is non-existent. However, the sociality of the groups could not fully make up for the inaccessibility of symptomatic therapy for a degenerative condition like PD.

This study has demonstrated the practicalities and possibilities of establishing support groups in Kenya and benefits for PwP and caregivers (albeit, a limited number), notwithstanding their limitations. It will be interesting to see whether, and how, the Mombasa group is sustained long-term, especially with the Covid-19 pandemic that struck not long after the researcher's departure. If PD awareness were to improve, the groups could play an important role across the African continent in providing people with aspects of care that scarce and already over-burdened neurological services might not be able to deliver. The support provided could considerably improve with backing from local government. Ideally, the capacity of specialist, neurological services would also increase, although this would require re-prioritisations of health budgets and resources within already overwhelmed healthcare systems.

Pilot studies developing support groups could assess the benefits and applicability to other countries, as well as the potential role of virtual groups. The Kenyan PD support groups began hosting biweekly virtual meetings during the Covid-19 pandemic, which proved popular and successful, demonstrating the possibilities of continuing to offer sociality and support through virtual methods across SSA, as has been seen in high-income countries. However, digital exclusion across the continent could prevent many families from accessing this valuable support. Furthermore, intervention studies could assess the possibilities of collaborations with international organisations and the benefits of developing context-specific resources. This would improve PwP and families' understanding regarding management and, crucially, improve awareness among the population and healthcare professionals in Kenya, and globally, to ensure PwP are diagnosed before their condition progresses significantly.

Despite the limitations of the groups, including reach, accessibility and the risks of bio-antisociality, this study has identified the important role support groups could play in the management of PD in Kenya, and possibly other LMICs, where awareness and the availability of information is limited, stigmatising perceptions are rife, basic medication and services are unaffordable and unavailable, and the number of specialist neurologists is very low. Support groups could play a role in combatting disrupted social connectedness, while also improving awareness about PD and tackling stigmatising perceptions.

Ethical approvals

Ethical approval to conduct this study was obtained from Newcastle University Research Ethics Committee (Application No.: 1293/14933/2017) and Kenya Medical Research Institute (KEMRI) Scientific Ethics Review Unit (SERU) (Reference: NON-KEMRI 609).

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