

Beliefs, knowledge and attitudes towards Parkinson's disease among a Xhosa speaking black population in South Africa: A cross-sectional study

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Abstract

Introduction

Many patients with Parkinson's disease (PD) in sub-Saharan Africa (SSA) are thought to be undiagnosed and untreated, leading to poor health outcomes. Increasing rates of diagnosis and treatment, with consequent improvements in the quality of life of people with PD in SSA requires an understanding of the how PD is perceived and conceptualized within communities.

Methods

A cross-sectional survey was conducted among a group of Xhosa speaking black South Africans. The survey involved the administration of questionnaires on beliefs, knowledge and attitudes about PD to the public, people with PD (PwPD) and traditional healers (THs).

Results

18% of the participants were able to identify PD through its symptoms. Mental illness, other diseases, stress, expressing strong emotions, consumption of certain foods or drinks and witchcraft were identified as possible causes of PD. PwPD and THs had a greater knowledge of PD than the public and greater age was a significant predictor of greater knowledge. The public and THs had a greater degree of concern about a range of symptoms of PD compared to PwPD.

Conclusion

There is a striking lack of knowledge about PD amongst black South Africans. Almost half the members of the general public interviewed felt that PwPD should not live amongst their community, and a third considered that witchcraft could be a cause of PD. Finding ways to effectively educate members of a community about PD would make it easier for PwPD to adapt to their condition within their communities.

Introduction

Parkinson's disease

PD is a progressive neurodegenerative disorder characterized by tremor, rigidity, bradykinesia and postural instability [1]. It is classically defined as a motor disorder, however there are a range of non-motor symptoms that occur with advancing age and disease severity[2].

Parkinson's disease in sub-Saharan Africa

There are few prevalence and no incidence studies on PD in SSA. This is partly due to limited access to diagnosis, treatment, multidisciplinary care and poor survival rate of people with PD in this setting[3]. Many patients with PD in SSA are probably undiagnosed and untreated resulting in impaired quality of life and markedly increased mortality rates[4]. Clinical diagnosis is important in SSA, as there are limited resources for brain imaging to support decision-making. However, even clinical diagnosis is challenging since there are very few or even no neurologists in many countries in SSA and there is a general lack of awareness about PD among healthcare workers[4,5]. Allied to this, the majority of patients do not seek medical help for their symptoms, possibly due to confusing them with the ageing process or associating the illness with a curse or witchcraft, although they may present to THs[6].

Knowledge attitudes and beliefs towards PD

Improving efforts aimed at dealing with diagnosis and treatment disparities and the overall quality of life of people with PwPD in SSA requires an understanding of how PD is perceived and conceptualized within communities. Knowledge, beliefs and attitudes are important predictors of the psychological outcome in people with chronic illness and evidence suggests these could also be significant in furthering the understanding of psychological functioning in PwPD[7].

This study assessed knowledge, beliefs and attitudes towards PD among PwPD, the public and THs and is the first study in SSA that addresses the perspectives of PwPD and THs on this subject. Greater understanding of these issues will enable more informed public education campaigns about the nature of PD and potentially assist in the development of interventions that are aimed to improve lifestyle and coping strategies of those living with the illness[8].

Methods

Study design

A cross-sectional survey was carried out among a group of Xhosa speaking black South Africans, as they present a pure hitherto unexplored group. The Xhosa people are a group of black South Africans who traditionally live in the Eastern Cape region of South Africa; with increasing urbanization many Xhosa people now live in the Western Cape.

Questionnaires were administered to PwPD, the public (people without PD) and THs. 95% of the study participants were from the municipality of the city of Cape Town.

Recruitment

PwPD (n=25) were recruited from Tygerberg and Frere Hospitals, tertiary hospitals in the Western and Eastern Cape provinces respectively. PwPD, were diagnosed by Neurologists working in the above mentioned hospitals, using the UK PD Society Brain Bank criteria (UKPDSBBC). All PwPD who attended either hospital during the study period were approached and those who consented were enrolled. Nine patients declined participation.

The public (n=98) were people without PD seeking general healthcare services at a district clinic in a region in Cape Town which is virtually exclusively populated by people of Xhosa origin. Participants were selected using systematic random sampling at the pharmacy waiting area. Every 8th patient file at the pharmacy was selected and the patient was invited to participate. 15 people declined participation.

THs (n=31) were identified through an experienced TH who has worked previously with a movement disorder specialist (JC) at Tygerberg hospital. This TH had knowledge of local customs and traditions and had extensive networks with other THs in the Cape Town. THs were interviewed at their homes or places of work.

Study setting

The study was conducted from January to May 2016. Participants were interviewed using a questionnaire which was administered by the researcher (JM) and two research assistants, who were Xhosa speaking and served as interpreters. The research assistants received training on the use and administration of the questionnaire prior to interviewing. In addition, they had extensive knowledge of the community which was useful in the research process and in the recruitment of THs.

Research tool

A questionnaire was used as the data collection tool to assess knowledge, beliefs and attitudes about PD (Appendix 3). The items in this questionnaire were sourced from a study on beliefs and knowledge on PD that was carried out in Australia[8], with inputs from other similar studies relating to Epilepsy [6,9–11] and from a movement disorders expert (JC). The questionnaire was piloted on a group of 10 students for validation purposes.

The questionnaire was divided into four sub sections:

1. Demographics of participants;

Demographic items assessed included gender, age, marital status, education status, income, cultural background, and area of residence. Relationship to PD was separated into those diagnosed with PD, those who had met someone with PD, and those who had never met someone with PD. People included in the study were adults (18 years or older).

2. Belief systems;

In this section, participants were presented with a video of patient with PD, and asked what term they would use to describe the disease and what it meant to them. Perceived rarity of PD, perceived personal likelihood of contracting PD, perceived seriousness of the illness and usefulness of traditional healing methods (THM) in treating PD were assessed using a Likert- type scale. A range of items on the potential causes of PD was provided, from which a particular respondent could select multiple causes. Disease stigma was also assessed using yes/no items concerning the belief that people with PD may have been punished because they had previously done something bad, and whether they should be allowed to live in the community. The impact of PD on work, marriage and ability to have children was also assessed. A second video of a person with drug-induced dyskinesias was shown to the participants and they were asked if such a person should live in their community and if they would mind if someone with these symptoms were their neighbour.

3. Knowledge

Knowledge of PD was assessed through a 9-item yes/no assessment containing statements about PD, for example 'Is PD more common in the elderly?' and 'Does PD progress very rapidly?' Each statement was allocated a value of 1. Correctly answered statements were summed and multiplied by 100% to produce a knowledge score.

4. Attitudes, reflected by the level of concern about a range of symptoms of PD.

Attitudes were measured through a 15-item assessment. The items were a range of potential effects and consequences of PD, such as pain, physical disability and mental deterioration. Each item had 3 response categories of 1= not worried, 2= worried and 3= greatly worried, forming a Likert-type scale, in which survey participants were asked to select one category in each item. Items were summed to produce an attitudes score, whereby higher scores represented a greater degree of worry about PD. The maximum and minimum possible scores on this scale were 45 and 15 respectively.

Data analysis and statistical methods

The data were analysed using standard statistical software, Stata/IC 13, and summarised in terms of mean (continuous or parametric data), median (ordinal or non-parametric data) and frequency (nominal data). Spearman's correlation coefficient was used to assess association between variables that were measured at an ordinal or interval/ratio level. Differences between the three groups studied were compared using ANOVA, the Kruskal-Wallis test or the Chi-squared test as appropriate. The t-test and the Mann-Whitney test were used to compare two groups. Multiple linear regression modelling was used to adjust for confounders when assessing knowledge and attitudes. A backward selection was used with exit criteria set at $p < 0.05$. Two-tailed tests were used throughout and the threshold for statistical significance set at 5%.

Ethics approval

Ethical approval was obtained prior to data collection from the Health Research Ethics Committee of Stellenbosch University. All participants provided informed consent.

Results

1. Demographics of the study participants (n=154)

Table 1: Characteristics of subjects interviewed (n=154)

Variable	Person with PD (PwPD) n (%)	Public n (%)	Traditional Healers (THs) n (%)
	25 (100)	98 (100)	31 (100)
Relationship of interviewee to PD			
Person with PD	25 (100)	0 (0)	0 (0)
Has met person with PD		10 (10)	2 (6)
No relationship to PD		88 (90)	29 (94)

Gender			
Male	14 (56)	42 (43)	5 (16)
Female	11 (44)	56 (57)	26 (84)
Age in years			
18-40	0 (0)	48 (49)	8 (26)
41-60	10 (40)	42 (43)	18 (58)
61-80	13 (52)	8 (8)	5 (16)
81-100	2 (8)	0 (0)	0 (0)
Mean Age (SD)	66 (11)	40 (14)	49 (12)
Education level			
No schooling	3 (12)	1 (1)	1 (3)
Below Grade 7	10 (40)	17 (17)	1 (3)
Grade 8-12	10 (40)	37 (38)	14 (45)
Completed High school	0 (0)	27 (28)	13 (42)
Completed college/University	2 (10)	16 (16)	2 (6)
Monthly Income			
Disability grant	9 (36)	7 (7)	0 (0)
< 1000 Rand	7 (28)	26 (27)	0 (0)
1000-10000 Rand	8 (32)	62 (63)	28 (90)
10000-20000 Rand	1 (4)	3 (3)	3 (10)
Marital status			
Never married	7 (28)	50 (51)	12 (39)
Married	15 (60)	41 (42)	13 (42)
Widowed	0 (0)	7 (7)	5 (16)
Divorced	3 (12)	0 (0)	1 (3)

2. Belief system assessment

The level of knowledge in terms of defining and describing PD among the participants was found to be limited. After showing them a video of a person with symptoms of PD, and asking them what they would call the illness, only 18% (44% PwPD, 13% public and 13% THs) were able to identify the disease correctly. The following Xhosa words were used to describe the features of PD as seen on the video:

1. **Idumbe** [shaking or tremor disease/illness]
2. **Ukuqina kwe misipha/ Ukomelela** [muscle stiffness].
3. **Ngcangcazela** (shaking from being nervous).

Of the total group, 54% thought that PD was extremely rare or rare (80% PwPD, 46% public and 58% THs), 74% thought they were unlikely or extremely unlikely to ever develop PD (68% public and 94% THs) and 51% thought that PD was an extremely serious disease (52% PwPD, 61% public and 16% THs).

Table 2: Beliefs on the causes of PD, impact of PD on lives of PwPD and a measure of the stigma associated with PD

Beliefs on the causes of PD	PwPD, n (%)	Public, n (%)	THs, n (%)	Overall proportion
Underlying medical disorder	13 (52)	77 (79)	29 (94)	0.77
Mental problem	16 (64)	81 (83)	30 (97)	0.82
Stress	17 (74)	77 (87)	30 (97)	0.81
Strong emotions	15 (60)	71 (73)	30 (97)	0.75
Exposure to dangerous substance	10 (40)	70 (71)	30 (97)	0.71
Inheritance	2 (8)	63 (64)	28 (90)	0.60
Certain foods or drinks	6 (24)	57 (58)	30 (97)	0.60
Witchcraft	2 (8)	31 (32)	22 (71)	0.36
Infection	6 (24)	8 (8)	11 (35)	0.16
Impact of PD on the lives of people with PD	PwPD, n (%)	Public, n (%)	THs, n (%)	
People with PD cannot work	10 (48)	76 (68)	5 (16)	0.59
Chance of getting married is affected	10 (48)	82 (73)	6 (19)	0.64
Chance of having children is affected	7 (33)	80 (71)	5 (16)	0.60
Measure of stigma associated with PD	PwPD, n (%)	Public, n (%)	THs, n (%)	
People have PD as a punishment for something bad they did previously	6 (24)	14 (14)	4 (13)	0.16
People with PD should not live in community	2 (8)	17 (17)	1 (3)	0.13
People with PD with drug induced dyskinesia should not live in the community	9 (36)	44 (45)	6 (19)	0.38

Usefulness of Traditional Healing Methods (THM)

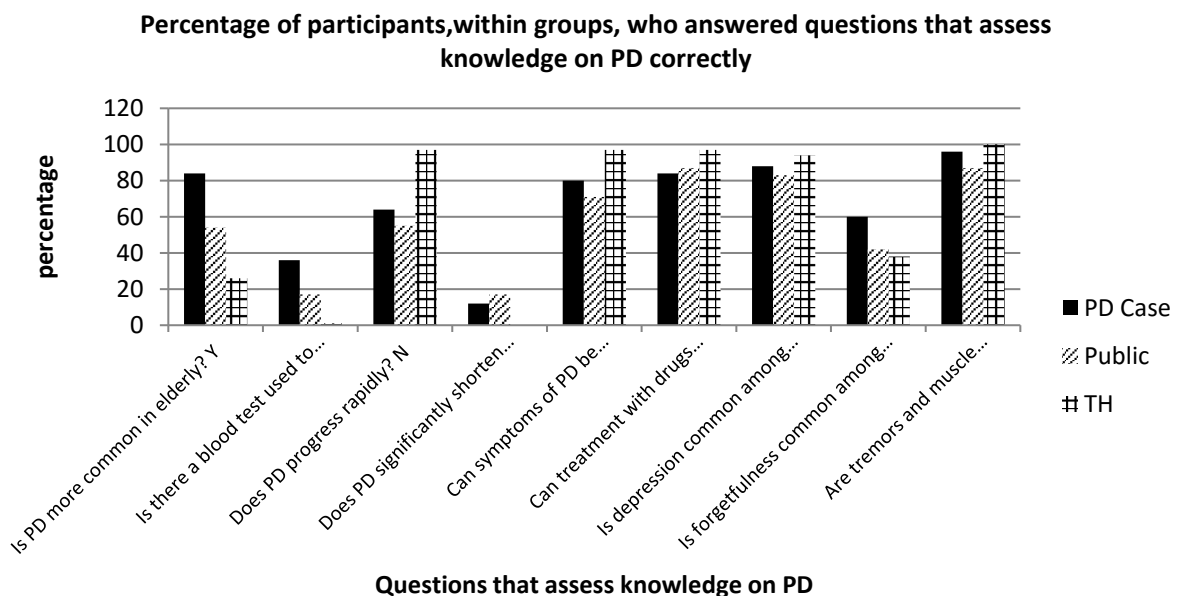
53% of the total participants were satisfied that PD could be treated by THM (44% PwPD, 42% public, and 97% THs).

Among the methods identified by THs that could be used in the management of PD were;

- The use of plants such as; aloe vera, large tinsel flower, ribbon bush plant, white milkwood, African potato and marijuana. These plants are ground into a powder and then smoked, put into a drink or placed into small incisions made on the skin (scarification). According to the TH, use of these plants provides a relaxing effect.
- Steaming: a purification process that involves exposing a person to steam from boiling water for a period of time.
- Removing the patient away from the community: this is done since the patient is viewed as being possessed by evil spirits.
- Offering some form of special prayers conducted by the TH where he/she communicates with the ancestral spirits, to make peace on behalf of the patient.

3. Knowledge assessment

Figure 1, which shows a comparison (by percentage) of PwPD, public and THs groups, with respect to their knowledge on PD.



The overall mean knowledge score of the sample was 63% (SD 15.6). The mean (SD) knowledge score among PwPD, the public and THs was 71.6% (11.6), 58.2% (16.8) and 68.1% (7.5) respectively. There were differences between the three groups with regard to knowledge score ($F=10.68$, $p<0.001$). Following Bonferroni adjustment, PwPD had higher knowledge scores compared to the public (mean difference= 13.1%, $p<0.001$, 95% CI 9.1% to 17%) as THs compared to the public (mean

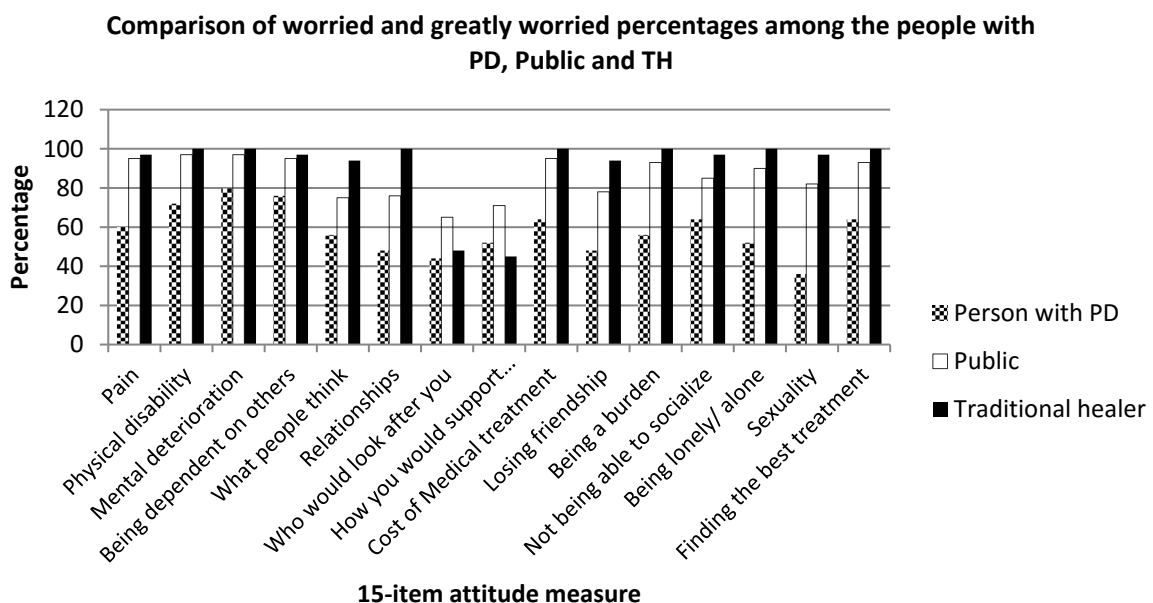
difference= 9.6%, $p < 0.005$, 95% CI 6.2% to 13%). There was no difference in knowledge between PwPD and THs.

Among the public, higher knowledge scores correlated moderately with greater age ($r = 0.407$, $p < 0.001$) and with lower education ($r = -0.305$, $p = 0.002$).

Using multivariable linear regression modeling, greater age ($\beta = 0.37$, $p = 0.001$, 95% CI 0.20 to 0.54) emerged as a significant predictor of greater knowledge whilst adjusting for group, ($F = 14.16$, $P < 0.001$, $r^2 = 0.22$, adjusted $r^2 = 0.20$). After adjusting for age, knowledge difference between PwPD and the public was only 3.27% ($p = 0.396$), therefore age was a confounder in the association between knowledge and group.

4. Attitudes.

Figure 2, displays a comparison percentage score of 'worried' and 'greatly worried' attitudes towards 15 different aspects of PD.



Apart from the attitudes expressed by the PD patients themselves, members of the public and THs were also asked to express their opinion as to how someone with the illness would feel. The mean (SD) attitude score amongst PwPD, the public and THs was 28.0 (9.0), 36.9 (6.0) and 37.6 (5.7) respectively (scale ranging from 15 to 45). The attitudes scale had a high internal consistency (Cronbach alpha 0.85).

There were differences between the three groups with regard to attitude score ($F = 20.07$, $p < 0.001$). Following Bonferroni adjustment, the public had higher attitude scores compared to PwPD (mean difference= 19.8, $p < 0.001$, 95% CI 16.8 to 22.9) as did THs compared to PwPD (mean difference= 21.2, $p < 0.001$, 95% CI 17.9 to 24.5). There was no difference in attitude score between the public and THs.

Among PwPD, greater worry over symptoms moderately correlated with lower PD knowledge score ($r=-0.429, p=0.033$).

Within the public cohort, greater worry over symptoms moderately correlated with higher PD knowledge score ($r = 0.302, p < 0.003$). High attitude score was associated with not having met someone with PD ($t = 3.72, p < 0.003$). There were no significant gender, age, income or education differences in attitudes.

Among THs, there was a moderate correlation between greater worry over symptoms and younger age ($r= -0.424, p= 0.018$). Females also had a higher attitude score compared to males ($t= 2.3, p=0.02$). Level of education and income did not affect the attitudes score.

In multivariable linear regression modeling, not having met someone with PD ($\beta= 8.07, p = 0.005, 95\% CI 2.5$ to 13.6) emerged as a significant predictor of greater worry over symptoms whilst adjusting for group ($F= 16.8, p<0.001, r^2=0.25, adjusted r^2 = 0.24$).

Discussion

This is the first study from SSA to examine the role of THs and PwPD, in addition to that of the public on knowledge, beliefs and attitudes towards PD. This study provides insights into how people in this population perceive PD. Information of this nature is useful for designing PD awareness programs and in addressing treatment campaigns in SSA.

Knowledge on PD was relatively high. However, there were important misconceptions, such as that a blood test could be used to diagnose PD, and that PD significantly shortens lifespan. This is similar to the findings of a study conducted in Australia where a considerable number of participants believed that the disease progresses rapidly, inevitably leads to dementia, and shortens life [8].

Consistent with other studies[6,12], knowledge on the cause of PD was limited and associated with stigmatizing misconceptions. More than half of the participants listed mental illness, other underlying medical disorders, stress, strong emotions and consumption of certain foods or drinks as being possible causes of PD. Also, 36% of the participants identified witchcraft as a cause of PD. Witchcraft is widely believed to cause variety of illnesses and misfortunes in SSA and therefore people with certain illnesses are perceived to be bewitched[13]. Often, certain movements which are a consequence of an illness such as dyskinesias or even seizures, that are not known or experienced by members of a community, are often attributed to witchcraft[11]. These beliefs result in negative community reactions towards people with these conditions, which in turn lower their self-esteem and negatively impact on their quality of life. As shown from the study, 38% of the participants believed that PwPD with drug induced dyskinesia should not live in the community.

Low levels of knowledge among the general public was striking, despite the higher education level in this group; with lower levels of knowledge about PD being associated with a younger age. Given that PD is associated with ageing, it is likely that young people might not view knowledge about PD as being important, especially if they have not come across a person with PD. Equally, older people might have the tendency to actively seek knowledge on risk factors and diseases associated with aging and could also learn by being exposed to peers or family members with such conditions. This situation could make it difficult for people with young onset PD to integrate into a community that perceives PD as an old age disease[8].

Among the public, greater worry about the symptoms of PD was associated with high levels of knowledge and not having met someone with PD. This is in contrast to PwPD where greater worry about symptoms was associated with lower levels of knowledge. This suggests that having information about a condition makes it easier to adjust and adapt to its symptoms when experiencing the disease either personally or through people close to you, as opposed to having no experience, which brings about anxiety and depression over the unknown future with the risk of disability, economic loss and becoming dependant. Understanding the disease process and ways to handle disease symptoms can be helpful in reducing anxiety towards the disease especially in the early stages for people diagnosed with PD. Although greater public knowledge about PD would help in demystifying the disease, finding ways to effectively educate the public without instilling anxiety would make it easier for people with PD to easily adapt to their condition within their communities.

From the study, 51% of the participants believed that THMs could be used in the management of PD, with 42% of PwPD having visited a TH for treatment. Many individuals within African communities seek treatment and health information from THs[9,14]. Given appropriate skills and means, they are well placed to play a larger role in combating Africa's major diseases[14]. The situation in SSA is that many countries have very limited neurological services and PwPD may be undiagnosed and untreated [4]. In such situations, it would be worth considering training of THs around PD as this would also increase awareness of the condition and hopefully lead to more patients being diagnosed and referred to specialists for treatment.

Strengths and limitations

Limitations of the study include relatively small PD and TH population. Furthermore, sampling of THs was not random, which could have possibly introduced selection bias, however we were not able to identify any additional THs. Reliance on closed-ended assessments may have limited the amount of information that was obtained. Despite these limitations, the findings of this study highlight the

need to develop community specific interventions and educational programs to improve the knowledge and awareness of the general public about PD.

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Conflict of Interest

The authors declare no conflict of interests.

Author's contributions

Jolynne Mokaya and Jonathan Carr designed the study. Jolynne Mokaya collected data. Jolynne Mokaya and Keith Gray performed data analyses. Jolynne Mokaya and Jonathan Carr wrote the paper. Jonathan Carr supervised the project and revised the paper for important intellectual content.

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References

- [1] J. Stochl ,A. Boomsma , E. Ruzicka ,H. Brozova , P.Blahus , On the structure of motor symptoms of Parkinson's disease, *Mov Disord.* 23 (2008) 1307–12.
- [2] P.Garcia-Ruiz ,K.R. Chaudhuri, P.Martinez-Martin , Non-motor symptoms of Parkinson's disease A review from the past, *J Neurol Sci.* 338 (2014) 30–3.
- [3] J.Blanckenberg, B. Glanzmann,N.U. Okubadejo ,J.A.Carr , S.Bardien, The prevalence and genetics of Parkinson's disease in sub-Saharan Africans, *J Neurol Sci.* 335 (2013) 1–2.
- [4] C. Dotchin,R. Walker, The management of Parkinson's disease in sub-Saharan Africa, *Expert Rev Neurother.* 12(2012) 661–6.
- [5] Bower, H.James,G. Zenebe. Neurologic services in the nations of Africa, *Neurology.* 64(2005) 412–5.
- [6] G. Mshana, C.L.Dotchin,R.W. Walker, "We call it the shaking illness": perceptions and experiences of Parkinson's disease in rural northern Tanzania,*BMC Public Health.* 11 (2011) 219.
- [7] J. Simpson, T. Crawford, G.Lekwuwa, Illness beliefs and psychological outcome in people with Parkinson's disease, *Chronic Illn.* 9(2013)165–76.
- [8] K.Moore,S. Simon, Beliefs and Knowledge about Parkinson's Disease, *E-JAP E-Journal Appl Psychol.* 2 (2006) 15–21.
- [9] A.S.Winkler,M. Mayer,M. Ombay,B. Mathias,E. Schmutzhard,L. Jilek-Aall, Attitudes towards African traditional medicine and Christian spiritual healing regarding treatment of epilepsy in

- a rural community of northern Tanzania, *Afr J Tradit Complement Altern Med.* 7 (2009) 162–70.
- [10] D.Mushi,E. Hunter,C. Mtuya, G.Mshana , E.Aris,R. Walker, Social–cultural aspects of epilepsy in Kilimanjaro Region, Tanzania: knowledge and experience among patients and carers, *Epilepsy Behav.*20(2011) 338–43.
- [11] A.S.Winkler, M.Mayer,S. Schnaitmann ,M. Ombay,B. Mathias,E. Schmutzhard , L. Jilek-Aall, Belief systems of epilepsy and attitudes toward people living with epilepsy in a rural community of northern Tanzania. *Epilepsy Behav*, 19(2010) 596–601. Available from: <http://dx.doi.org/10.1016/j.yebeh.2010.09.023>
- [12] M.Kaddumukasa,M.N. Kaddumukasa ,E. Ddumba,L. Mugenyi ,M. Sajatovic,E.Katabira,A. Kakooza, Knowledge and Attitudes of Parkinson’s Disease in Rural and Urban Mukono District, Uganda: A Cross-Sectional, Community-Based Study,*Parkinsons Dis.* 2015(2015).
- [13] H.L .Moore,T. Sanders, *Magical Interpretations, Material Realities: modernity, witchcraft and the occult in postcolonial Africa*, Routledge,2003.
- [14] I.Madamombe , Traditional healers boost primary health care, *Africa Renew.* 19(2006) 5.