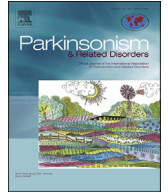




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# Beliefs, knowledge and attitudes towards Parkinson's disease among a Xhosa speaking black population in South Africa: A cross-sectional study

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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 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 could 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.

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## 1. Introduction

### 1.1. 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].

### 1.2. 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, multi-disciplinary 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

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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].

### 1.3. 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].

## 2. Methods

### 2.1. 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.

### 2.2. Recruitment

PwPD 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. All PwPD who attended either hospital during the study period were approached and those who consented were enrolled.

The public cohort 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.

THs 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.

### 2.3. 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.

### 2.4. Research tool

A questionnaire was used as the data collection tool to assess knowledge, beliefs and attitudes about PD (Appendix 1). 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:

#### 2.4.1. 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).

#### 2.4.2. 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.

#### 2.4.3. 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.

#### 2.4.4. 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.

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