FELLOWSHIP OF THE GHANA COLLEGE OF PHYSICIANS

FACULTY OF INTERNAL MEDICINE

QUALITY OF LIFE OF PATIENTS WITH PARKINSON'S DISEASE IN THE CENTRAL BELT OF GHANA

A DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE AWARD OF THE FELLOWSHIP OF THE GHANA COLLEGE OF PHYSICIANS (FACULTY OF INTERNAL MEDICINE)

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DECLARATION

I, Vida Obese, declare that, apart from other references to other publications that have been duly acknowledged, this dissertation is my original work and has been authored based from findings from my own research at the Neurology Clinic, Komfo Anokye Teaching Hospital, Kumasi, Ghana. This dissertation has not been presented either in whole or in part elsewhere for the award of another qualification or for publication.

03/01/2023

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CERTIFICATION BY SUPERVISORS

We hereby certify that the study in this dissertation for the Fellowship of the Ghana College of Physicians, Faculty of Internal Medicine, subspecialty Neurology titled "QUALITY OF LIFE OF PATIENTS WITH PARKINSON'S DISEASE IN THE CENTRAL BELT OF GHANA" was done by the candidate Dr Vida Obese under our supervision.

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DEDICATION

I dedicate this project to my late dad and my phenomenal mum, who inspired and supported me at every step of my academic journey.

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No man is an island. This holds true, even more so, in research. The following people have been instrumental in the planning and execution of this dissertation:

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SUMMARY

Rationale/objectives of the study: The complications of Parkinson's Disease (PD) have been found to impact on the patients' Quality of life (QoL). There is a paucity of studies assessing QoL in developing countries such as Ghana. This study principally sought to examine the factors associated with the QoL in patients with idiopathic PD in the neurology clinic of Komfo Anokye Teaching Hospital (KATH) in Ghana. It assessed the associations between QoL and the extent of motor and non-motor complications, stigma, depression, and cognitive impairment among patients with Parkinson's disease.

Materials and methods: A cross-sectional study was conducted with a consecutive sample of 161 PD patients receiving treatment from the neurology clinic at KATH. Structured questionnaires were used for data collection. Parkinson's disease Questionnaire (PDQ-39) was used, motor and non-motor symptoms assessed using the MDS-UPDRS and Beck depression inventory (BDI) for assessment of depression. Global cognitive performance was assessed using the Montreal Cognitive Assessment Scale (MoCA) and stigma evaluated withthe 24-item stigma scale for chronic illness (SSCI)**.** Ethical clearance was obtained from the Kwame Nkrumah University of Science and Technology Institutional Review Board. The consent of patients was sought, and data gathered was password protected.

The data were organized under the research objectives for analysis. ANOVA and independent sampled t-test was used to analyse differences in QoL among patients with different socio-demographic characteristics. Stepwise multiple regression analysis was used to determine the factors that best account for variance in QoL scores. Multivariate linear regression model analysis was used to assess the effects of motor and non-motor variables on the QoL of PD patients.

Results: There were 161 participants in this study with an average age of men (n = 114) and women (n = 47) being 65.2 ± 4.96 and 65.5 ± 5.01 respectively. The mean (± SD) non-motor severity score was 41.8 ± 21.6 and that for the motor severity score was 37.1± 20.5 On the Hoehn and Yahr scale, nearly a third (31.7%) of participants were in stage 3. Overall, the mean PDQ-39 Summary Index (PD8-39 SI) was 37.2 ± 17.1 The mean score of the items on the stigma scale was 62.36±14.49. Majority (65.8%) of the study participants had mild cognitive impairment and almost half (44.1%) were moderately depressed. Multivariate linear regression analysis showed

that participant's cognition (β= -0.65, p-value= 0.031), depression(β = 0.52, p-value =0.013) and stigma status (β= 0.51, p-value <0.0001) were independently associated with overall QoL.

Conclusions: This study has identified stigma, depression and cognitive performance as independent factors significantly associated with overall health related QoL of individuals living with idiopathic PD in the central belt of Ghana. While non-motor complications were associated with QoL in limited multivariate linear regression models conducted in our study, their associations were lost in the fully adjusted regression models. Screening for depression, stigma and cognitive impairment should be done routinely at neurology clinics and integration of psychosocial support into the care of PD.

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LIST OF ABBREVIATIONS

ANOVA	**ANALYSIS OF VARIANCE**
ADL	**ACTIVITIES OF DAILY LIVING**
BOD	**BODILY DISCOMFORT**
BDI	Beck depression inventory
CES-D	Centre for Epidemiologic Studies Depression Scale
COMT	Catechol-O-MethylTrasnsferase
CSDD	Cornell Scale for the Assessment of Depression in Dementia
COG	Cognition
COM	Communication
DSM	Diagnostic and Statistical Manual of Mental Disorders
EMO	Emotional Well Being
GDS	Geriatric Depression Scale
HADS	Hospital Anxiety and Depression Scale
HAMS	Hamilton Depression Scale
HRQOL	Health-related quality of life
KATH	Komfo Anokye Teaching Hospital
MADRS	Montgomery-As- berg Depression Rating Scale
MAO-B	Monoamine Oxidase B
MDS-UPDRS	MDS-Unified Parkinson's Disease Rating Scale
M.EDL	Mean motor score
MOCA	Montreal Cognitive Assessment Scale
MOB	Mobility
NM.EDL	Mean non motor score

PD	Parkinson’s disease
PDQ39	Parkinson's Disease Questionnaire - 39
QOL	Quality of life
SOC	Social support
STI	Stigma
SDS	Self-Rating Depression Scale
SF-36	Short Form 36
SSCI	Stigma scale for chronic illness
UPDRS	Unified Parkinson's Disease Rating Scale
UPP	Ubiquitin–proteasome pathway

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CHAPTER ONE

1.0 INTRODUCTION

1.1. BACKGROUND

Parkinson's disease (PD) is an age-related chronic degenerative disease of the central nervous system that evolves slowly and progressively and is characterized by bradykinesia, muscle rigidity and resting tremor among other motor signs and symptoms [1]. PD can cause a variety of symptoms. The first symptoms of PD appear when the remaining production of dopamine has fallen below 20% of its original production or when 50% of the cells of the substantia nigra have been destroyed [2]. Gallagher *et al.* [3] posited that there are four main clinical symptoms of the disease: tremor, rigidity, slowness and problems with walking and posture. The important physical symptoms of PD are also a blank stare (the so-called "Parkinson's mask") and troubles with manual dexterity. Non-motor symptoms of the disease may include depression, sleep disorders, hallucinations and delirium, some of which may be related to treatment by dopaminergic drugs [4].

Early in the course of the disease, the most obvious symptoms are movement-related, including shaking, rigidity, slowness of movement and difficulty with walking and gait. Later, cognitive, and behavioural problems may arise, with dementia commonly occurring in the advanced stages of the disease. Other symptoms include sleep and emotional problems, depression, difficulties in coordination and speech, severe fatigue, problems with balance and pain [5].

According to Jankovic [6], the treatment of PD is primarily aimed at improving motor function. However, especially in advanced stages, PD is often complicated by additional problems such as treatment-related complications and falls, which may have a much greater impact on the patients' quality of life (QoL) than the cardinal features of PD [1].

Opara *et al.* [7] defined QoL as an individual's perception of his or her position in life in the context of the culture and value systems in which he or she lives, and in relation to his or her goals, expectations, standards, and concerns. QoL is increasingly recognised as an important measure in healthcare as it incorporates the patients' own perspective of their health [8]. According to Opara *et al.* [7], QoL is a comprehensive state

consisting of not only one's physical and mental status (or level of independence), which could easily be affected by PD symptoms but also several other factors such as emotional and social functioning. This implies that treating only the physical function and independence of patients with degenerative chronic conditions such as PD is less sufficient and requires a comprehensive assessment and management or treatment of various life domains to ensure total QoL.

According to Yousefi *et al.* [9], QoL measures are suitable as well for an outcome measure of a new treatment such as rehabilitation in PD patients. Subjective factors in QoL in PD patients include perception of symptoms, level of fitness, self-image, satisfaction with family life, work, economic situation, interaction with other people, social support, and life in general. The objective factors, on the other hand, include the clinical picture of disease, social status, social and living conditions and the number and intensity of social contacts [10].

Most studies on QoL for PD patients have been conducted in advanced countries, where proper structures and systems have been established to provide treatment and support for patients. Accordingly, the findings on PD patients from western countries are used to generalise for patients in developing countries like Ghana. Such research findings influence the kind of treatment and support to be provided for PD patients. Nonetheless, the differences in support structures and culture between a developing country like Ghana and the western countries could have varied implications on the QoL of PD patients [11].

Thus, formal structures and systems for proper care and support for PD patients are absent. PD patients are mostly cared for by immediate family members, including spouses, children, and siblings [12]. The low level of awareness about the disease coupled with the traditional nature of Ghanaian society could cause PD patients to experience high social stigma. Thus, spiritual, and superstitious factors are mostly advanced to explain the causes of the disease. As a result, PD patients mostly do not receive early proper treatment and care to prolong the development of some of the other symptoms such as cognitions and bodily discomfort [13]. These have critical implications on the QoL of PD patients.

1.2. PROBLEM STATEMENT

QoL is a multi-dimensional construct, which consists of at least three broad domains: physical, mental, and social. In the field of medicine, researchers and physicians have often used health-related quality of life concept, which specifically focuses on the impact of an illness and/or treatment on patients' perception of their status of health and subjective well-being or satisfaction with life [14]. QoL is defined as a general sense of well-being which is determined by multidimensional factors related to the individual, social interactions, and the environment in the context of a given culture and value system [7]. It also relates to the individual's perception of their position in life in relation to their goals, expectations, and concerns, and therefore, should be truly judged by the individuals themselves [7].

The definition of QoL stressed on environmental and cultural value systems which varies across regions. This suggests that the determination of QoL of PD patients should be context-specific and incorporate the socio-cultural and value systems of patients into the process. Nonetheless, studies on the QoL of PD patients had largely focused on the advanced countries whose socio-cultural and value systems might differ from resource-limited countries. Using findings from such studies to guide the treatment or analysis of the QoL of patients in a developing country like Ghana, with a different socio-cultural and value system may be misrepresentative. Thus, a clearer understanding of the factors associated with QoL of individuals living with PD in a low-income country such as Ghana is warranted to better guide clinicians in our setting to improve care using local research data.

1.3. JUSTIFICATION/ RATIONALE

The study is essential to situate QoL studies of PD patients in Ghana. The findings of the study are expected to help provide measures that are responsive to the peculiar socio-cultural needs of PD patients in Ghana. This study will serve as a point of comparison with studies from other African and foreign countries, identifying differences in regional disease trends. The results of this study will likely lead to improved awareness among PD patients, their caregivers, healthcare workers, advocacy, and support groups (in Ghana and West Africa) of the need to screen for and treat motor and non-motor complications of PD. This will lead to improvement in health-related quality of life for PD patients. This study will add to the existing body

of knowledge concerning Parkinson's disease in our subregion. The study is expected to help inform policies and structures to enhance the support and care for PD patients in Ghana for improved QoL.

Rationale for the Study

According to Martinez-Martin *et al.* [14], improvement in medicine has contributed significantly to increase life expectancy across the globe. This suggests that the number of the aged population will continue to increase as research and medical practices continue to evolve. The basic attribute of PD as a degenerative disease of the central nervous system associated with the aged, therefore, implies that the number of people to develop the PD will increase. As a result, any study that seeks to assess the motor and non-motor functions of PD patients and their QoL is a step in the right direction to inform policies that could help improve the QoL PD patients.

In addition, the complications associated with PD such as falls, depression, and dementia make patients more dependent on the active working age cohorts which also have negative economic implications on both micro and macro levels [15]. Accordingly, a study that focuses on all the three critical dimensions of QoL, physical, mental, and social, is considered as necessary to develop structures and systems that would enable PD patients fit more into the society.

Lastly, most of the studies on PD which are used to inform treatment and policy directives are done in advanced settings [16]. Studies from a developing setting like Ghana are therefore needed to have a balanced view about QoL associated with PD patients and the programmes that need to be implemented to enhance the QoL of PD patients. In other words, incorporating the findings from a developing setting with different social-cultural and economic setting into the policies and programmes for the treatment of PD will help present comprehensive strategies and activities that will be more responsive to the QoL needs of PD patients in developing countries. Hence, the study of QoL of PD patients in the central belt of Ghana is apt for the discourse and treatment processes of PD in the field of neurological studies.

1.4. RESEARCH QUESTIONS

1.What is the extent of motor and non-motor complications and their association with QoL among PD patients?

2.What is the level of stigma among PD patients and what is its association with QoL?
3.What is the extent of depression and cognitive impairment in PD patients and their association with QoL?

1.5. GENERAL & SPECIFIC OBJECTIVES

1.5.1. Aim (General Objective)

The overall aim of the study is to identify the factors that are associated with the QoL in patients with idiopathic PD detected in the neurology clinic of KATH.

1.5.2. Specific Objectives

The specific research objectives are outlined as follows:

1. To assess the extent of motor and non-motor complications and association with QoL,
2. To quantify severity of stigma among PD patients and its association with QoL, and
3. To assess the extent of depression and cognitive impairment, and their association with QoL.

1.6. HYPOTHESES

Hypotheses 1.
Motor and non-motor complications in Parkinson's Disease are not associated with the quality of life of patients.
Alternative Hypotheses
There is an association between motor and non-motor complications in Parkinson's Disease and overall quality of life of patients.
Hypotheses 2.
There is no association between quality of life and the severity of stigma of PD patients.
Alternate Hypotheses
The quality of life is associated with the severity of stigma among PD patients.

Hypotheses 3.

Depression and cognitive impairment are not associated with the quality of life of PD patients.

Alternate hypotheses

There is an association between depression and cognitive impairments in Parkinson's Disease and quality of life of patients.

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 OVERVIEW OF PARKINSON'S DISEASE

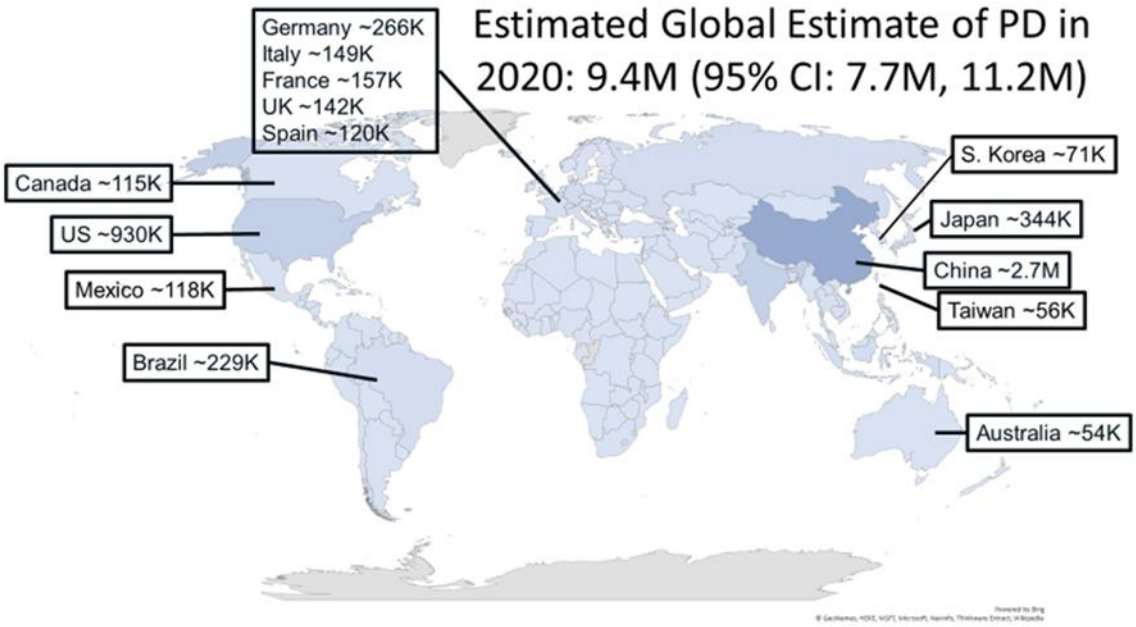
PD is the second most common neurodegenerative disorder and is characterized by the classical motor symptoms (resting tremor, bradykinesia, rigidity, postural instability) and non-motor symptoms, some of which may precede clinical diagnosis by several years [17]. Non-motor symptoms include autonomic dysfunction (constipation, urinary), cognitive decline (memory and attention), psychiatric disorders (depression, anxiety), sleep disturbances (vivid dreams, REM behaviour disorder) and fatigue, among others [18]. According to Yamanishi *et al.* [19], Health-Related QoL (HRQoL) in PD is determined by motor and non-motor symptoms and by the effects of treatment as well (efficacy and side effects).

Opara [20] postulated that early in the course of the disease, the most obvious symptoms are movement-related, including shaking, rigidity, slowness of movement and difficulty with walking and gait which affect the functionality of an individual. Later, cognitive, and behavioural problems may arise, with dementia commonly occurring in the advanced stages of the disease. Other symptoms including sleep and emotional problems, depression, difficulties in coordination and speech, severe fatigue, problems with balance and pain will have an impact on the patient`s QoL. We must also take into account complications caused by treatment with levodopa, like dyskinesias, dystonias, and fluctuations.

As the disease progresses, patients with PD are particularly prone to deterioration of HRQoL as a result of both increased motor disability and the burden of non-motor symptoms [16]. Among motor symptoms, the main determinants are disease severity, motor complications of treatment, postural instability, and gait disturbances [21]. Among non-motor symptoms, Barone *et al.* [22] posited that depression has been recognized as the main HRQoL determinant but other symptoms such as anxiety, cognitive impairment, fatigue, sleep disorders, pain and dysautonomia are also major contributors to low HRQoL in PD.

PD is estimated to have a high prevalence rate of 1-3% of the elderly population (above 60 years of age) [6]. Connolly and Lang [23] posited that the increasing rate of PD across

the globe is due to the increase in life expectancy resulting from improved pharmacology and medical processes. The implication is that medical practitioners and researchers have to deal with the conditions of PD for some time, considering the fact that treatment is focused on managing the symptoms. The treatment of PD is primarily aimed at improving motor function. However, especially in advanced stages, PD is often complicated by additional problems such as treatment related complications, falls, depression, and dementia, which may have much greater impact on the patients' QoL than the cardinal features of PD [24].



N. Maserejian, L. Vinikoor-Imler, A. Dilley. Estimation of the 2020 Global Population of Parkinson's Disease (PD) [abstract]. Mov Disord. 2020; 35 (suppl 1). https://www.mdsabstracts.org/abstract/estimation-of-the-2020-global-population-of-parkinsons-disease-pd/. Accessed February 18, 2023

Figure 2.1: Global Epidemiology of PD

2.2 HOSPITAL-BASED PREVALENCE OF PD IN NEUROLOGY CLINICS IN WEST AFRICA

The Komfo Anokye Teaching Hospital adult neurology clinic is located in Kumasi, Ghana and serves as a referral centre for the diagnosis, management, and follow-up of several patients with Parkinson's Disease (PD). Several of these patients are referred from peripheral medical centres and clinics. The clinic thus caters for a variety of

patients in different stages of PD in Kumasi and beyond. Sarfo *et al.* [25] showed that in Komfo Anokye Teaching Hospital in Kumasi, Ghana, 102 cases of PD were diagnosed out of 1,836 OPD attendants between 2011 and 2013 (5.6%). A study by Cilia *et al.* [26] indicated a crude prevalence of patients with a diagnosis of either PD or secondary parkinsonism presenting to the Korle Bu Teaching Hospital, another major referral centre between 2004 and 2009 as approximately 12%. A more recent study published in 2021 by Akpalu *et al.* [27] evaluated 7,950 out-patient adult neurological consultations between January 2003 and December 2019 at the same clinic. They found that Idiopathic PD accounted for 6.7% of cases, while other causes of Parkinsonism, such as vascular, drug-induced and Parkinson plus syndromes, accounted for 0.93%. In Lagos University Teaching Hospital, Nigeria, 20 out of 1,360 (1.47%) neurology clinic attendees were being diagnosed with PD between January 2005 to December 2006 [16].

2.3 PATHOPHYSIOLOGY OF PD

Physiologically, the symptoms associated with PD are the result of the loss of a number of neurotransmitters, most notably dopamine. Dopamine, like other neurotransmitters, transmits chemical messages from one nerve cell to another across the synapse, a space between the presynaptic cell and the postsynaptic receptor [28]. Dopamine is secreted into the synapse from membrane storage vesicles in the presynaptic membrane. It crosses the synapse and binds to the postsynaptic membrane, where it activates dopamine receptors. The cause of dopamine loss in the pathophysiology of PD is largely idiopathic but mostly attributed to some genetic factors, and the interactions between host susceptibility and environmental factors [29]. Damage to critical neuronal systems such as dorsal motor nucleus of the vagus nerve and the olfactory bulbs and nucleus, locus coeruleus, susbtantia nigra, and eventually the cortical areas of the brain account for the multi-faceted pathophysiologic changes that cause impairments not just to the motor system but also to the cognitive and neuropsychological systems [30].

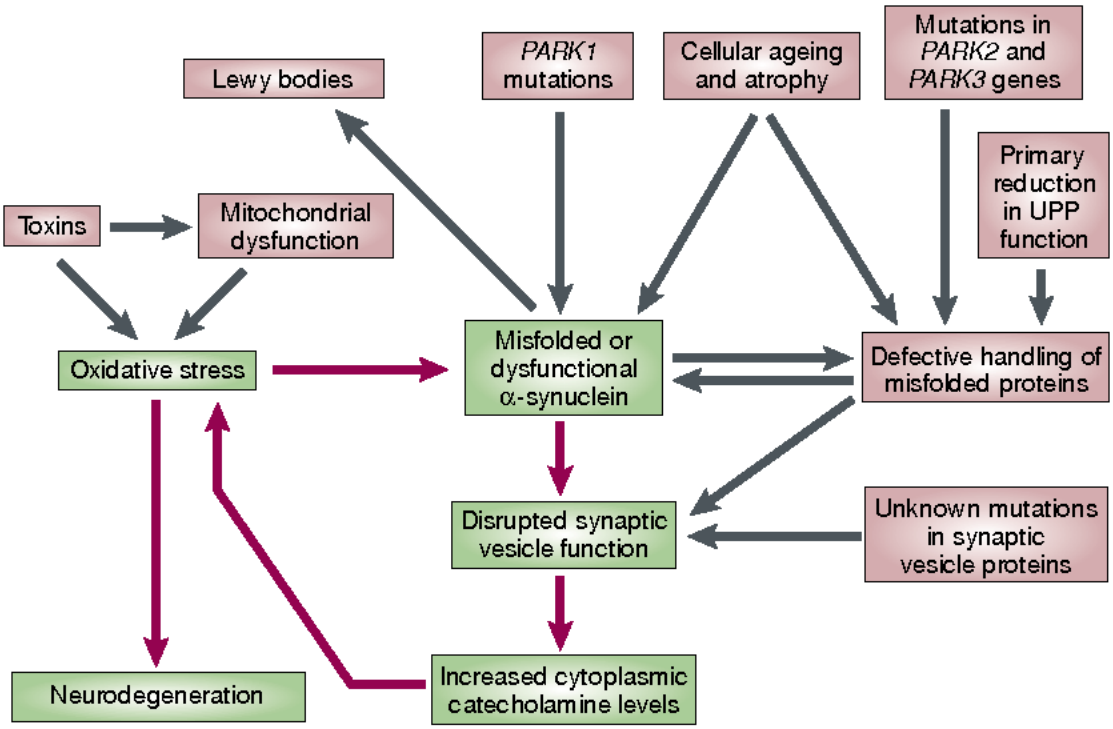


Figure 3 | **Increased levels of cytoplasmic dopamine: a final common pathway leading**

Figure 2. 21: Increased levels of cytoplasmic dopamine.

According to Lotharius and Brundin [31], the terms highlighted in green represent deleterious processes that are part of a vicious cycle leading to cell death (purple arrows). Even though different aetiological triggers might underlie sporadic and familial forms of Parkinson's disease, including those linked to mutations in the genes for α-synuclein (PARK1), parkin (PARK2) and ubiquitin carboxy-terminal hydrolase L1 (PARK5), and to defects in the ubiquitin–proteasome pathway (UPP), these different pathways might all result in the accumulation of dopamine in the cytoplasm. Given the high propensity of this and other catecholamines to oxidize when not stored in synaptic vesicles, elevations in cytoplasmic dopamine could lead to enhanced oxidative stress and neurodegeneration.

2.4 TREATMENT AND HEALTHCARE SERVICES FOR PD PATIENTS

Although, over the past three decades, cell-based therapies, based on replacement of the lost dopamine neurons by transplantation, are developing, PD is still considered as an illness that cannot be cured [32]. There are several approaches to its treatment, from a "wait and see" policy to starting with drug treatment immediately after identifying the diagnosis, but so far neurologists have not reached consensus regarding treatment. However, although curing PD is not yet possible, symptomatic treatment has improved

in recent years. The most used symptomatic therapy for PD is levodopa and carbidopa, introduced more than forty years ago, which efficacy is evident mostly in the beginning of the treatment [33]. Levodopa works by being converted to dopamine in the brain, while carbidopa works by preventing levodopa from being broken down before it reaches the brain [34]. This allows for a lower dose of levodopa, which causes less nausea and vomiting. However, after long using the levodopa the levodopa-induced side effects could appear: dyskinesias, motor fluctuations or neuropsychiatric disorders [29].

Another possibility, which has been used for treating PD symptoms since the 1970s, are the dopamine agonists, which are associated with a lower incidence of dyskinesias, but they have less benefit on the motor function than dopamine itself, and there are increasing concerns about their side-effect profile [35]. Next possibilities are Catechol-O-MethylTrasnsferase (COMT) inhibitors in conjunction with levodopa for longer lasting treatment and selective MAO-B inhibitors for adjunctive therapy and from 2006 also in monotherapy. An algorithm suggests starting with dopamine agonists in younger patients and only later to combine it with other antiparkinsonian drugs [36]. In patients over eighty, it is recommended to start with levodopa.

Deep brain stimulation is also another approach for treating PD. It is the most commonly performed surgical procedure for PD. It is performed help ease motor symptoms and decrease medication needs in some PD patients [12]. This is normally performed on PD patients who have had the disease for quite some time and received the benefits from medication but continues to experience motor complications, such as symptoms return resulting from poor response from medication, and dyskinesia [37]. Nigral cell transplantation has also been used in the treatment of PD. According to Lindvall [38], the clinical trials with intrastriatal transplantation of human foetal mesencephalic tissue, rich in dopaminergic neurons, in PD patients show that cell replacement can work and, in some cases, induce major, long-lasting improvement. However, owing to poor tissue availability, this approach can only be applied in very few patients, and standardisation is difficult, leading to wide variation in functional outcomes [38].

Physical therapy such as normal physical activity routine, walking, balancing or stability control, posture and pain management, and dancing (rehabilitation and

physical exercises) are used for slowing down the secondary damaging of motor functions [13]. In other words, getting the body moving helps to build strength, balance, endurance, and coordination. However, Cholewa *et al.* [39] cautioned that physical therapists and trainers should take into account neurophysiologic aspects of motor impairment in PD, e.g., akinesia, the inability to perform sequential movements, impairments in the pacing of rhythmic movements, and impairments in the predictability of movements. According to Nakae and Tsushima [40], a quite novel kind of treatment of motor functions in PD patients is the combination of motor imagery and real practice, which seems to be effective, especially for reducing bradykinesia.

Other therapies which have proven beneficial in treating PD encompasses a variety of disciplines, including acupuncture, guided imagery, chiropractic, yoga, hypnosis, biofeedback, aromatherapy, relaxation, herbal remedies, massage, and many others [41]. Music and art therapy have also been used in the treatment of PD. Eating a healthy and balanced diet has been found to lower the risk of developing PD. In addition, caffeine and green tea may lower one's risk of developing PD or slow down the progression of the disease.

2.5 CONCEPT OF QOL IN RELATION TO PD

Table 2. 1: Key conceptualizations of QoL over the course of the last decades [42]

Source	Definition	Comments
Elkinton [42]	"[…] the harmony within a man, and between a man and his world […]"	captures QoL as an ethical construct which guides modern medicine
Ware Jr [43]	"[…] it is important to keep in mind that quality of life, as traditionally defined, is a much broader concept than health. In addition to health, quality of life encompasses standard of living, the quality of housing and the neighbourhood in which one lives, job satisfaction, and many other factors. […] There is good reason to favour a more limited definition when measuring the health of an individual. The goal of the health care system is to maximize the health component of quality of life, namely health status. Measures of health outcomes should be defined accordingly."	captures QoL as a measurement construct
WHO [44]	"[…] a person's subjective perception of their place in life in relation to the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns"	captures QoL as a multifactorial concept, in which the subjective character of many factors is considered includes, besides physical and mental aspects, aspects of independence, social relationships, and personal attitude

Quality of Life (QoL) is a multi-dimensional construct, which consists of at least three broad domains: physical, mental, and social [45]. Researchers use health-related quality of life concept specifically focussing on the impact of an illness and/or treatment on patients' perception of their status of health and on subjective well-being and on how they are satisfied with life.

QoL measures are suitable as well for an outcome measure of a new treatment such as rehabilitation [46]. Subjective factors in QoL in PD patients include perception of symptoms, level of fitness, self-image, satisfaction with family life, work, the economic situation, the interaction with other people, social support, and life in general.

QoL issues are intrinsically linked to the development of PD. This is largely due to the continuous weakening of motor and non-motor activities of PD patients. According to Case [1], the weakening functioning of motor activities of people further cause critical deterioration in their economic and social functions, making them less fit for economic and social activities. Behari *et al.* [47] opined that QoL is a multi-dimensional construct, which consists of at least three broad domains: physical, mental, and social. PD has significant influence on the QoL of patients since the symptoms of the disease cause deterioration in all the three domains of QoL.

Information about QoL in patients with PD is important for a neurologist, as it can help him/her to make appropriate decisions. Hence, it is important to pay attention to study findings in this group of patients and to continue exploring the variables which can indicate changes in their QoL [48]. Improving the overall health status of PD patients and maintaining their independence and active life is one of the challenges in neurology.

The assessment of QoL, defined as self-perceived health status, is increasingly regarded as a distinct outcome measure in patients with many chronic diseases. It adds the patient perspective to the physicians' evaluation and enables the assessment of disease consequences on an individual level. Parkinson's disease is a chronic disease that has consequences not only on patients' functional abilities but also on mental, emotional, and social health domains. When assessing the overall effectiveness of new management strategies, QoL is an important outcome measure. Information on QoL is also used in the decision-making process on the allocation of resources in health care at the national health policy level [49].

2.6 IMPACT OF PD ON QOL

PD is not a fatal diagnosis by itself, but in people seriously disabled, suffering from the disease several years, it will influence their general physical and mental conditions as well as their social functioning, which could decrease the patient's QoL and also reduce the length of his/her life [15, 50]. After 2–5 years from the onset of disease, up to 50% of PD patients develop motor complications which include regular visits to a neurologist and intensive rehabilitation [51]. The progressive nature of PD and its increasing prevalence have resulted in a substantial economic burden to society, health care providers, individual patients, and their families [52].

One of the most important objectives of the treatment and care in PD is the maintenance or improvement of QoL since it is currently incurable [53]. A large number of studies suggest that both motor dysfunction and non-motor symptoms have negative effects on QoL in PD [54].

2.6.1 Physical Domain

In the physical domain, some of the symptoms are tremor, slowed movement (bradykinesia), rigid muscles, and impaired posture and balance. These symptoms affect the ease of movement and also make it difficult for PD patients to perform some basic activities of basic living.

The poorer QoL of PD patients is mainly associated with functional status and disease severity [55]. In a 4-year follow-up study, disease severity was significantly the most important factor for a lower QoL [56]. Altered gait and postural instability also contributed to the worsened QoL of these patients [57]. PDQ39 and UPDRS (Part 3) have extensively been used for evaluating the physical aspect of QoL of PD patients. Nojomi *et al.* [58] used PDQ39 to evaluate the QoL in PD patients in Iran. The study focused on determining the validity and reliability of Persian PDQ39 through translation and psychometric evaluation. It concluded that the Persian version of PDQ39 was a valid and reliable measure of QoL in PD.

Zhang and Chan [59] also used PDQ39 to study the QoL of PD patients in China. The study found the PDQ39 to be a reliable and valid instrument for Chinese PD patients. Nelson *et al.* [60] examined the validation of PD related questionnaires in South Africa

using PDQ39 and UPDRS (Part 3) for QoL. The study demonstrated high internal consistency and correlations with clinical severity of parkinsonism and a timed motor task, suggesting that the instruments were valid. Williams *et al.* [13] used UPDRS to evaluate PD in sub-Saharan Africa. They focused on the epidemiology, genetics, and access to care among PD patients. They concluded that results from UPDRS from sub-Saharan Africa were consistent in measuring QoL of PD patients.

Sławek *et al.* [61] in a hospital based cross-sectional study, profiled 100 PD patients who attend an outpatient clinic using the PDQ-39 to assess their quality of life. They found that their mean PDQ-39 summary index (PDQ-39 SI) score was 34.01 ± 18,63. The factors that affected HRQoL the most were depression, disease stage and clinical fluctuations. Another study by Bang *et al.* [62] profiled 47 PD patients in 2 hospitals in Korea using PDQ-39, The average score of the PDQ-39 SI was 27.7 and found that dependency, especially mobility was the most influencing factor on the HRQoL in these patients.

2.6.2 Psychological Domain

There are several psychological aspects associated with PD decreasing QoL in patients. According to Simons *et al.* [63], depression is the major contributor to the explanation of the variance in QoL scores The rate of depression in community-based samples of patients with PD is approximately 30–40%, ranging from 20 to 70%, but only a minority of these patients (approximately 2.7 to 7.7%) fulfils the criteria of DSM IV for depression [64]. Physical impairment due to disease, such as increased disease severity, recent disease deterioration and the occurrence of falls, is a condition for higher levels of depression in PD patients. It was also found that depression is more strongly associated with patients' perception of being handicapped than by actual disability and can reflect a pessimistic outlook on the future [57]. Worse overall mental condition and patients' memory complaints are also significant factors associated with lower QoL [63].

Scores of QoL are usually supplemented by a study of cognitive function and depression, since these factors significantly affect the sense of quality of life, as well as an important context for the interpretation of test results QoL. Severe cognitive impairment and depressive symptoms may be a contraindication to test for quality of life. Scoring QoL in patients with PD, especially when it is done for scientific

purposes, requires the measurement of the functional status and fatigue, because in addition to depression and cognitive impairment, they are the most important determinants of QoL in patients with PD.

Cognitive impairment (CI) is a common nonmotor complication of Parkinson's disease (PD) and is associated with significant disability for patients and burden for caregivers. Similar to motor symptoms, the characteristics of CI in PD can be quite variable, both in terms of what cognitive domains are impaired, and the timing of onset and rate of progression. A study by Cosgrove *et al.* [65] showed cognitive impairment is a significant non-motor symptom of Parkinson's disease (PD) and postulates that the major pathological correlate of Parkinson's disease dementia is Lewy body deposition in the limbic system and neocortex although Alzheimer's related pathology is also an important contributor. Pathological damage causes alteration to neurotransmitter systems within the brain, producing behavioural change.

A study by Aarsland *et al.* [66] on mild cognitive impairment in Parkinsons Disease showed that the typical cognitive deficits seen include visuospatial, attentional, and executive deficits, but memory deficits have also been shown. The etiology of mild cognitive impairment in PD is not known, but it is likely that mechanisms known to contribute to dementia in PD (ie, limbic and cortical Lewy bodies, amyloid plaques, and cholinergic deficits) play a role, in addition to dysfunction of dopaminergic frontostriatal circuits.

Few studies have evaluated specific cognitive domains with regards to QoL. Klepac *et al.* [67] observed that poorer visual attention/memory was associated with poorer QoL, whilst another study by Barone *et al.* [22] also found that participants with attentional/memory deficits reported increased PDQ-39 scores (denoting poorer Qol). However, neither of these studies examined attention as an isolated cognitive domain.

Arabambi *et al.* [68] found no significant difference in cognition regarding the domains of perceptual problems/hallucinations and attention/memory which is in contrast with the previous study by Akinyemi [24] on cognitive dysfunction in PD patients that reported a higher rate of cognitive dysfunction in PD patients.

Schrag *et al.* [69] explored depression rating scales in PD cases, using Beck Depression Inventory (BDI), Hamilton Depression Scale (Ham-D), Hospital Anxiety and Depression Scale (HADS), Zung Self-Rating Depression Scale (SDS), Geriatric Depression Scale (GDS), Montgomery-As-berg Depression Rating Scale (MADRS), Unified Parkinson's Disease Rating Scale (UPDRS) Part I, Cornell Scale for the Assessment of Depression in Dementia (CSDD), and the Centre for Epidemiologic Studies Depression Scale (CES-D). They concluded that the most appropriate scale is dependent on the clinical or research goal. Okunoye [70] also used BDI to study depression among patients with PD in a Nigerian Tertiary Hospital. Their selection of BDI to measure depression among the PD patients stemmed from the fact that the scale has widely been used and validated in Nigeria. They reported that the validity and retest reliability with the use of BDI in measuring depression in PD has been widely demonstrated in Nigeria.

The Global Parkinson's Disease Survey Steering Committee in 2002 found the BDI score to be the most significant predictor of quality of life, accounting for 58% of the variance in PDQ-39 scores, whereas stage of motor severity and PD medication (levodopa, either alone or in combination with other dopaminergic drugs) together explained only 17% of the variability of quality of life in PD.

Besides depression, anxiety disorders are a clinically significant problem in patients with PD. Richard et 2005 found out that the prevalence of anxiety has typically been found to be of 20–46% of PD patients. Anxiety is thought to have an important impact on motivation, treatment compliance, and cognition and can exacerbate parkinsonian symptoms [71]. Quilty *et al.* [72] found out that the contribution of anxiety to quality of life in PD has been less studied, although anxiety symptoms have been found to have a significant association with poorer quality of life in the general population.

The presence of fatigue in PD patients predicts the worsening of all QoL domains measured by PDQ-39 [73]. Fatigue is one of the most common symptoms of PD and it is associated with reduced quality of life. Herlofson and Larsen [74] reports that fatigue in PD has an increasing frequency. This can be defined as uncontrollable apathy, lack of energy or feeling exhausted with no link to depression, or muscle weakness The problem of fatigue in patients with PD is frequently underestimated, even though as many as every third patient considers it the most disabling symptom, which is manifested in the Health-Related Quality of Life (HRQL) measured by using Parkinson's Disease Questionnaire (PDQ-39) and Short-Form 36 (SF-36).

Ferreira *et al.* [75] showed that 60-98% of the patients with PD suffer from sleep disorders Despite such high incidence, sleep disorders are not included in the routine clinical examinations. The underlying illness and neurotransmission disorders are the most common factors disturbing sleep pattern in patients with PD. Primary sleep disorders associated with disturbed dopaminergic transmission in the CNS, occur in patients with PD more commonly than in the overall population. The Unified Parkinson's Disease Rating Scale (UPDRS) contains only one question concerning sleep disorders, while Parkinson's Disease Quality of Life Scale (PDQ39) only two of them.

2.6.3 Social Domain

The social aspect of PD most negatively influencing the social domain of QoL of patients is isolation, which is due to the embarrassment caused by the symptoms and problems with communication [11, 35]. Patients mentioned that major social problems associated with the disease were the loss of social contact, behavioural problems, family members under strain and communication problems within the family [12, 76].

Lubomski *et al.* [77] conducted a study on the health related QoL of PD patients and their caregivers, using the UPDRS for measuring the social aspect of QoL. The study findings supported the routine clinical screening of HRQoL in PD patients to identify and address modifiable factors associated with the disease. Martínez-Martín *et al.* [78] also conducted a study into the relationship between UPDRS domains and the HRQoL of PD patients. The study found that the UPDRS component was most tightly related to the HRQoL measures.

According to Behari *et al.* [47], the stigma associated with such symptoms makes PD patients feel less fit for the environment which cause them to develop mental health issues such as depression. However, the formal structures and systems for care, treatment, and support help to minimise the pain and emotional challenges experienced by PD patients [8].

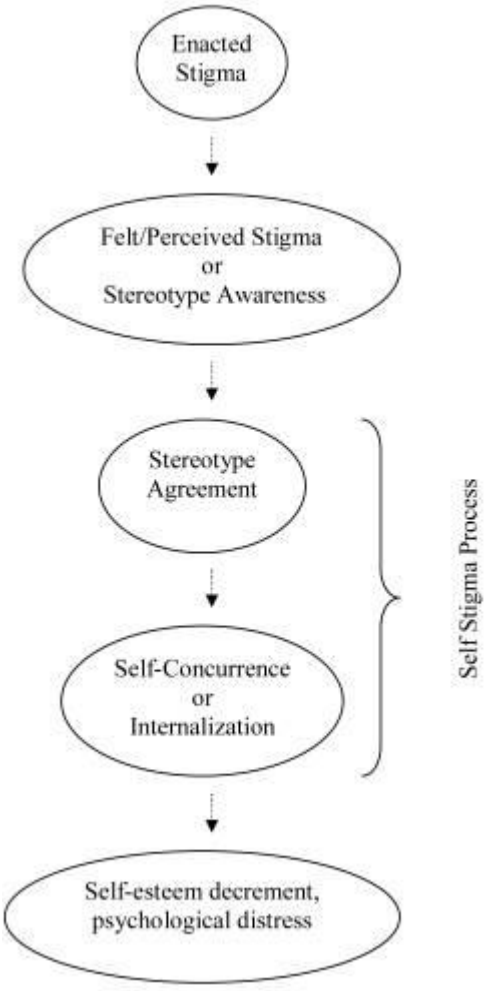


Figure 2. 32: The process by which stigma affects the person with an undesired condition.

Experience of stigma in people with PD has been described vividly and analysed in-depth in qualitative research [79-83]. Stigma emerges from the interaction between the individual with PD and the "outside world". People with PD may experience felt stigma, such as shame, embarrassment, and disgrace, and enacted stigma when encountering responses of others, such as staring, questioning, and avoiding, to their visible features of movement and communication difficulties [84]. Aware that their symptoms transmit a message of social incompetence and deviance, the individual with PD may try to disguise the symptoms and later withdraw from a public into a private world when they can no longer hide their symptoms.

Experienced stigma is defined as experiences of stereotypes, prejudice, and discrimination from others in the past or present by Cechnicki *et al.* [85] and Quinn and Earnshaw [86] and is sometimes referred to as enacted stigma according to Bos *et al.* [87].

Experienced stigma includes both chronic, day-to-day experiences of unjust or unfair treatment (e.g., interpersonal slights) as well as acute, major experiences (e.g., fired from one's job), both of which are related to a range of deleterious outcomes among people with stigmatized identities [116].

Bos *et al.* [87]; Ritsher *et al.* [88]; Corrigan *et al.* [89]; Quinn and Earnshaw [86] defined Internalised stigma as the extent to which people endorse the negative beliefs and feelings associated with the stigmatized identity.

Quantitative research also has validated the source of stigma by examining others' impressions of PD symptoms [90-92]. In addition, Tickle-Degnen *et al.* [92] showed that facial masking may bias health care practitioners' views of people with PD as more depressed, less sociable, and less cognitively competent than their actual attributes. Moreover, Hemmesch [90] and Hemmesch *et al.* [91] reported that higher facial masking or higher abnormal bodily movement (including tremor and related abnormal movement) of individuals with PD elicited more negative first impressions in older adult observers. Due to both personal beliefs and public negative attitudes embedded in our society, people with PD are likely to feel stigmatized and thus suffer from psychological distress. The results suggest the importance of further understanding stigma in PD to develop possible intervention strategies.

Most research in PD have reported that stigma, measured in a subscale of a PD-specific QOL measure, as a determinant of depression [5]. There has been limited research examining the degree to which stigma plays a role in overall feelings of quality of health in PD. In contrast, research about other diseases (e.g., epilepsy [93], HIV [94], lung cancer [95]) has documented that stigma predicted a significant amount of variance of QOL.

2.7 STAGING OF PD

Hoehn and Yahr scale is used to stage the severity of PD cases [96]. The Hoehn and Yahr scale for staging PD cases is broadly organised into five stages.

1. Stage one: symptoms are mild and do not interfere with the daily activities of individuals. It includes movement symptoms such as tremors, rigidity, and bradykinesia. These symptoms affect one side of the body. There are also mild

problems with posture and balance, slight difficulty in walking, and mild changes in facial expressions.

2. Stage 1.5 symptoms of unilateral disease plus axial involvement.
3. Stage two: the symptoms become worse, making daily activities more difficult. The person is, however, able to look after themselves. The person experiences all the symptoms at stage one. However, they affect both sides of the body. They have difficulty in walking, balancing, poor posture, and reduced facial expressions.
4. Stage three: Symptoms at this stage are more severe than those of stage two. Nonetheless, the individual is still independent. Loss of balance and bradykinesia (slowness of movements) are the hallmark symptoms of this stage. Daily activities such as eating, bathing, and dressing are significantly impaired.
5. Stage four: independent living is almost impossible due to limitations in daily activities such as eating, bathing, dressing, sleeping, and waking. The person may be able to stand on their own but need assistance for moving around. A walker may help in the movement without falling.
6. Stage five: symptoms at this debilitating stage become so severe that even standing on one's own may be impossible. The person becomes bedridden and needs a wheelchair to be moved around. All daily activities are impaired, requiring a constant caregiver. Symptoms at this stage may include delusions (false beliefs that do not change despite conflicting evidence), hallucinations (seeing, feeling, or hearing things that are not there), loss of smell, constipation, poor reasoning and memory, weight loss, sleep disturbances, and vision problems.

PD stage using the H&Y scale has been shown to negatively correlate with quality of life [2]. H&Y scale is primarily motor based and does not take non-motor symptoms into account.

CHAPTER THREE

3.0 MATERIALS AND METHODS

3.1 STUDY AREA

This study was conducted at the Komfo Anokye Teaching Hospital (KATH) which is the highest referral facility that provides comprehensive treatment for PD patients in the central belt of Ghana. KATH has a bed capacity of 1000 and has numerous Specialist Outpatient department clinics including a Neurology clinic. The Adult Neurology clinic was established in 2012 and runs once weekly. On average, 80 and 100 adults aged 18 years and above with various neurological disorders including PD are managed at the clinic weekly. The Neurology Unit provides regular treatment for PD patients across the five regions in the central belt of Ghana namely, Ashanti, Eastern, Ahafo, Bono East, and Bono West.

3.2 STUDY DESIGN

This study is a hospital based, analytical, cross-sectional study.

3.3 STUDY POPULATION

The study population were all PD patients receiving treatment from the neurology clinic at KATH.

3.3.1 Inclusion Criteria

1. Age ≥18 years.
2. Diagnosis of idiopathic PD according to UK Brain Bank criteria (Hughes *et al.*, 1992);

Diagnosis of a parkinsonian syndrome

Bradykinesia and at least one of the following:
• muscular rigidity
• rest tremor (4–6 Hz)
• postural instability unrelated to primary visual, cerebellar, vestibular or proprioceptive dysfunction.

3.3.2 Exclusion Criteria

1. Inability to provide written informed consent and absence of a valid proxy;
2. Clinically significant psychiatric illness (e.g., severe depression or psychosis);
3. Hoehn and Yahr stage 5/5;
4. Severe medical conditions (e.g., neoplasms; uncontrolled diabetes mellitus; heart, renal or liver failure);
5. Pregnancy.
6. Patients with atypical parkinsonian disorders, drug-induced parkinsonism, vascular pseudo parkinsonism, and those with parkinsonism after dementia were excluded from this study.
7. Inability to undergo a head CT scan to exclude Vascular PD due to phobia or physical mobility challenges.

3.4 SAMPLE SIZE DETERMINATION

There are 268 PD patients receiving treatment from the neurology clinic at KATH. A total of 161 patients were sampled for the study. The sample size was calculated using the sample size formula for a finite population by Yamane [97]:

$$n = \frac{N}{(1 + Ne^2)}$$

n = required sample size

N = population (268)

e = confidence level (0.05)

Therefore n = 268/(1 + 268(0.05^2)

n= 160

Thus, with the required sample size obtained, valid conclusions or generalization can be drawn from the study.

PD cases for the study were sampled from persons living with PD who are sequentially referred to or attending the Neurology service (Outpatient Neurology Clinic and Movement Disorders Clinic, and in-patient service) at KATH.

3.5 SAMPLING TECHNIQUE

Due to the limited number of PD patients expected to attend the KATH adult neurology clinic during the study period, a consecutive sampling method was chosen to allow as many cases as possible who attended the clinic each week to be approached for potential inclusion in the study. An identifier was added to the patient's record to prevent duplicate assessment.

3.6 STUDY INSTRUMENTS

3.6.1 Scale For Measuring QoL In Patients With PD

Among all the scales for measuring the HRQoL of PD patients, the PDQ-39, has been shown to have good reliability, validity, responsiveness, and reproducibility, and is now used in many trials to assess the effectiveness of treatment [7]. Its disease specificity and the single summary index offer the opportunity to assess the overall impact of illness, and it is easy to interpret. The study used the PDQ-39 to determine which disease-related factors, such as the presence of specific symptoms, degree of impairment, disability, depression, or cognitive impairment, were the most relevant for quality of life in a population-based sample of patients with PD. The extensive use of the PDQ-39 aids cross-comparison with PD studies conducted from different settings. The PDQ-39 comprises 39 questions, each with five different answer options (never, occasionally, sometimes, often, or always). Eight sub-scores (mobility, activities of daily living, emotional wellbeing, stigma, social support, cognition, communication, and bodily discomfort), and one summary index, can be calculated (maximum score of 100 indicating worst level of problem) The PDQ summary index (PDQSI) is derived by summing up the scores of the eight discrete scales after they are converted into percentages. The summed-up scores are then divided by eight to

give a single summary index value which is the PDQSI. Summary scores as well as the sub-dimensions of the PDQ-39 was calculated according to the scoring algorithm.

Internal Validation of PDQ 39 Scale was done on randomly sampled 25 PD patients. Participants answered both the English version and translated Twi version to compare the internal consistency and inter-item correlation of the scale. The item with highest Cronbach alpha ($0.7 < x < 0.95$) was used in main study.

The procedure comprised forward translation, assessment of item comprehension, back translation to English and development of a consensual version. First, forward translation of the original PDQ-39 English version was independently carried out by two well versed linguisitic translators. Reconciliation of these two translations was then performed, followed by back translation into English by a third translator without access to the original version of PDQ-39. Comparison of the back-translation and original versions of the questionnaire was performed and the results were used for the development of the final consensual translation of the twi version of PDQ-39. Distance conversion into the metric system was performed as a part of the translation process when questionnaire items involved such measurements.

The psychometric analysis of the Twi version of the PDQ-39 was performed by evaluating of acceptability, validity, and reliability of the questionnaire using qualitative content analysis and a variety of statistical procedures.

All PDQ-39 domains and general health status data were checked for floor and ceiling effects, and less than 15% of minimum or maximum values per domain were considered acceptable.

Content validity of the questionnaire was tested during the pilot testing of the PDQ-39 translation. Group discussion and interviews followed the completion of the questionnaire regarding how easy it was to understand, whether it measured quality of life and how relevant it was.

Construct validity was assessed using inter-item Spearman rank correlation co-efficient at 95% CI. All test results with an error level of 5% or less ($p \leq 0.05$) were considered statistically significant and consistent between items. Item-total correlations over 0,4 were considered to show an acceptable correlation between the questionnaire items.

Cronbach alpha greater than 0.7 was considered a strong indication of questionnaire reliability.

Reproducibility was tested using test-retest analysis, and a correlation of 0.7 or more determined an adequate result.

Domain Name	Number of items	Scale mean (SD)	ICC (95%CI)	Cronbach's Alpha
Mobility	10	23.08 (9.47)	0.43 (0.37-0.50)	0.884
Activities of Daily Living	6	10.80 (5.54)	0.38 (0.31-0.46)	0.786
Emotional well being`	6	8.29 (6.20)	0.54 (0.47-0.61)	0.877
Stigma	4	6.15 (5.19)	0.57 (0.50-0.65)	0.845
Social Support	3	1.77 (2.37)	0.57 (0.48-0.69)	0.798
Cognition	4	7.14 (4.38)	0.52 (0.44-0.60)	0.811
Communication	3	3.52 (2.87)	0.57 (0.47-0.64)	0.790
Bodily Discomfort	3	4.04 (3.01)	0.50 (0.41-0.59)	0.753

ICC- intraclass correlation coefficient. SD- standard deviation

3.6.2 Other Scales used

The Beck Depression inventory (BDI) was used to assess presence and extent of depressive symptoms among the study participants. The BDI is a widely used 21 item depression inventory with answer options from 0–3 and a maximum score of 63 (See Appendix II). For cultural purposes, the metric form of weighing scale in Ghana was used i.e., in kilogram was used on question 19 on the scale instead of pound. A BDI score of 0-10 is normal, 11-16 is mild mood disturbance, 17-20 is Borderline, 21-30 is moderate and above 30 is severe.

Cognitive performance was assessed using the Montreal Cognitive Assessment Scale (MoCA). A locally adapted (Twi language with local and familiar animals) MoCA was administered to the patients with a cut-off score of 26 or less. Self-perceived stigma evaluated using the four-item stigma subscale of the PDQ-39.

The MDSUPDRS is divided into 4 parts: Part I, Mentation, Behavior, and Mood (4 items); Part II, Activities of Daily Living (13 items); Part III, Motor Examination (27 items); and Part IV, Complications of Therapy (11 items). Each parkinsonian sign or symptom is rated on a 5-point Likert-type scale (ranging from 0 to 4), with higher scores indicating more severe impairment. The maximum total UPDRS score is 199, indicating the worst possible disability from PD.

Parkinson's disease was diagnosed using the United Kingdom brain bank criteria and patients with atypical parkinsonian disorders, drug-induced parkinsonism, vascular pseudo parkinsonism, and those with parkinsonism after dementia were excluded from this study. Socio-economic groups were determined using gender, level of education, and occupation.

The stigma scale for chronic illness (SSCI) is a non-illness specific 24-item scale (allowing for comparison across conditions) including PD with 13 items relating to internalized stigma and 11 items related to experienced stigma 72. According to Rao et al. 72, these subscales can be used independently or combined and are both measured across a 5-point Likert scale (1 = Never to 5 = Always). The felt stigma subscale (13 items) asks questions about the respondent's feelings (e.g., embarrassment, worry, and self-blame). The enacted stigma subscale (11 items) asks questions about the behaviour of others toward the respondent (e.g., avoiding contact, staring, and being unkind). Each item is rated as 1 = never, 2 = rarely, 3 = sometimes, 4 = often, and 5 = always. A higher score indicates a higher frequency of experiencing stigma. Stevelink et al. 73 did a systematic review which suggests that the SSCI has good internal consistency and content validity with a higher score representing more perceived internalized and/or experienced stigma. Rao et al. 72 showed that the reliability for both subscales was very good.

3.7 DATA COLLECTION METHODS

A structured questionnaire interview and a complete neurological examination, including the Hoehn and Yahr scale, the MDS-UPDRS, the Montreal Cognitive Assessment Scale (MoCA), BDI, SSCI and PDQ-39 were performed on the same day of recruitment.

3.8 DATA MANAGEMENT AND ANALYSIS

Each participant was given a special identification number. The special identification protected the personal identity of the research subjects and helped avoid multiple entries of the same data. The data were processed using GraphPad Prism and R software. The data was organized under the research objectives for analysis.

Demographics, clinical history, and medical history were summarized using frequency tables. The Kolmogorov-Smirnov test was used to assess the normality of continuous variables and the variables were summarized using means and standard deviations. For each of the scales used in the study, the mean and standard deviation were used to summarise the responses. The Pearson correlation was used to assess the relationship between the scales. Multivariate linear regression model analysis was used to assess the effects of motor and non-motor variables on QoL of PD patients. ANOVA and independent sampled t-test would be used to analyse differences in QoL among patients with different socio-demographic characteristics. Stepwise multiple regression analysis was used to determine the factors that best accounts for variance in QoL scores. An error margin of five per cent was used for all inferential analysis.

3.9 ETHICAL CONSIDERATIONS

Ethical clearance was from the Kwame Nkrumah University of Science and Technology Institutional Review Board to ensure the safety and protection of patients. Ref No. CHRPE/AP/206/20 (See Appendix 8). Information sheet and consent form were developed to obtain the consent of PD patients to participate in the study. Thus, the consent of PD patients to participate in the study was sought before their engagement in the study. The consent form and information sheet were read and interpreted in the native language of the study participantsin the presence of a witness (preferably a caregiver or family member). The aim was to ensure that the study participantsclearly understood the tenets of the study and willingly availed themselves to participate in the study. Both forms were signed by the study participantsand witnessed by their caregivers or family members before they could be admitted to participate in the study. However, they were allowed to opt out at any time if they feel less comfortable with the research process. Data gathered on the PD patients was password protected to prevent unauthorized access for other uses other than the primary purpose or without permission.

CHAPTER FOUR

4.0 RESULTS

4.1. SOCIODEMOGRAPHIC AND CLINICAL CHARACTERISTICS OF THE STUDY PARTICIPANTS

4.1. Background characteristics of study participants

The number of patients that were approached were 181. Twenty of them were not included in the final study (13 declined inclusion and 7 were excluded because they did not have idiopathic PD). In all, 161 were recruited and data analysed. Among those enrolled, the male and female represented 70.8% and 29.2% respectively. The male to female ratio was 2.4 :1.0 The mean age of men and women were (65.2 ± 4.96years and 65.5 ± 5.01years respectively).

Table 4.1. 1: Demographic characteristics of study participants

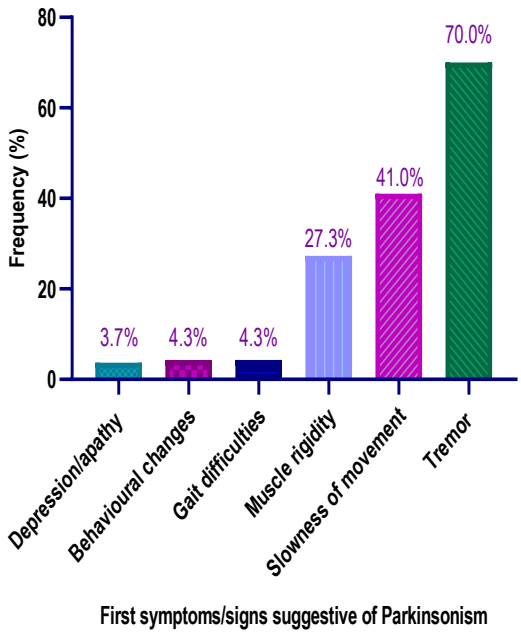
Variable	Category	Count (n)	Percentage (%)
Ethnicity	Akan	131	81.4
	Hausa	14	8.7
	Bono	7	4.3
	Kusaasi	5	3.1
	Dagombe	4	2.5
Gender	Male	114	70.8
	Female	47	29.2
Education	None	5	3.1
	Primary	49	30.4
	Secondary	90	55.9
	Tertiary	17	10.6
Current Employment Status	Unemployed	82	52.2
	Currently working	37	19.9
	Retired	42	28.0
Income Range (GHC)	300 and below	57	35.4
	301-600	70	43.5
	601-1200	33	20..5
	Above 1200	1	0.6
Support from any Government or non-government institution	Medication from PD foundation	143	88.8
	Counselling	18	11.2

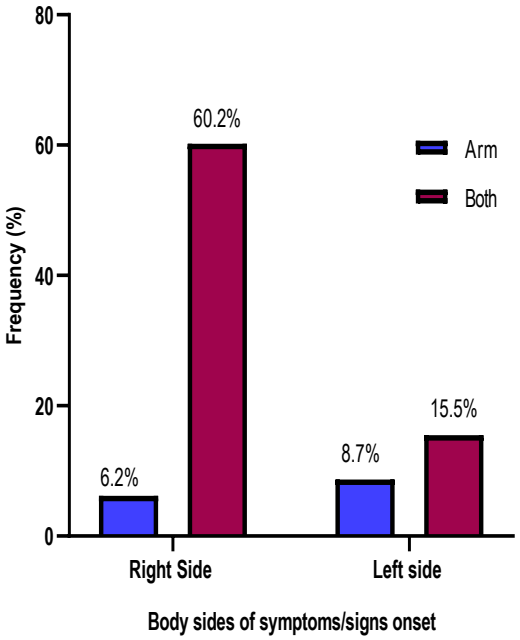
Table 4.1.2 Clinical Characteristics of the study participants

Variable	Category	Count (n)	Percentage (%)
Primary Condition	PD	115	71.4
Other Diagnosis	Hypertension	40	24.8
	Diabetes	6	3.7
Family History of Chronic Condition	None	60	37.3
	Don't know	48	29.9
	Hypertension	40	24.8
	Diabetes	7	4.3
	Hypertension and Diabetes	6	3.7
Family Blood tie	Yes	131	81.4
	No	30	18.6
Presence in the family symptoms/signs of PD	Yes	13	8.1
	No	148	91.9
Relative 1 (n= 13)	Father	9	
	Mother	4	
Relative 1 still living? (n=13)	Yes	3	
	No	10	
Birth Development/Development	Normal	156	96.9
	Problems	5	3.1
Drug of Abuse	Yes: Cigarette	21	13.0
	No: Cigarette moking	140	87.0
Sleeping problems	Yes: Unable to sleep the way I want	28	17.4
	Yes: Waking up intermittently	6	3.7
	Yes: Difficult getting a sleep	6	3.7
	Yes: Unable to sleep well	12	7.5
	No sleep problems	109	67.7

Swallowing problems	Yes: I feel pains when I swallow	14	8.7
	Yes: Chocking food at times	14	8.7
	No swallowing problems	133	82.6
Sexual Problems	Yes: Premature Ejaculation	34	21.1
	Yes: Not able to sustain erection	16	9.9
	Yes: Can't perform as I used to	14	8.7
	No sexual problems	97	60.2
Urinary Problems	Yes: Frequent Urination	11	6.8
	Yes: Prostate enlarged	10	6.2
	Yes: Difficulty urinating	4	2.5
	Nourinary problems	133	82.6
Constipation	Yes: I go to toilet between 1-3 times a week	46	28.6
	Yes: Difficulty passing bowels	31	19.3
	Yes: Unable to empty bowels	20	12.4
	No constipation	64	39.8

Fig 4.1.1 Medical History of the study participants





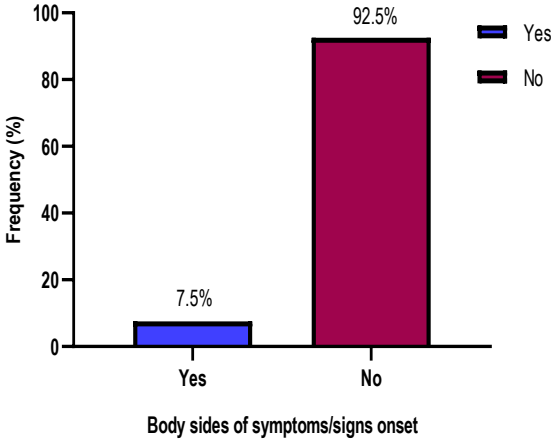


Table 4.1.3 Medication History of the study Participants

Variable	Category	Count (n)	Percentage (%)
Exposure to potential Neurotoxic Agents	Yes	1	0.6
	No	160	99.4
Exposure to Anti-dopaminergic drugs	Yes	0	0
	No	161	100
Current and/or previous diseases/surgical procedures	Yes	46	28.6
	No	115	71.4
Neuroimaging	Yes: CT scan	93	57.8
	No	68	42.2
Year of Levodopa treatment initiation	Before 2016	22	13.7
	2016	15	9.3
	2017	32	19.9
	2018	14	8.7
	2019	30	18.6
	2020	26	16.1
	Don't remember	22	13.7
Response to Levodopa	Responsive	129	80.1
	Not given	32	9.5
Side-effects (n= 148)	Yes: Nausea/Anorexia	14	9.5
	No	134	90.5
Other current or previous parkinsonism medications	Yes	0	0
	No	100	100

4.2. OBJECTIVE 1: ASSOCIATION BETWEEN THE MOTOR AND NON-MOTOR COMPLICATIONS WITH QUALITY OF LIFE

4.2.1 Severity measures of Parkinson Disease among study participants

The PD severity scores for motor and non-motor responses were assessed using the MDS-UPDRS while disease progression was assessed with Hoehn and Yahr Staging scale.

The mean (± SD) non-motor score from the scale was 41.8 ± 21.6 and that for the motor score was 37.1± 20.5. Table 4.2.1 shows the means and standard deviations obtained from an item analysis of non-motor symptoms on the MDS- UPDRS Scale. The top 5 items with the highest means were depressed mood, fatigue, hallucinations and psychosis, constipation problems, apathy, pain and other sensations.

The means and standard deviations of the motor severity scores of MDS-UPDRS showed three items with high means were doing hobbies and other activities, handwriting, and tremor as shown on Table 4.2.2. Regarding disease progression, majority of study participants (31.7%) were found in Stage 3 while 8.1% found in Stage 1.5 as shown in Figure 4.2.1

There was a moderately strong and statistically significant positive correlation between mean non motor score and H&Y stage ($r=0.52$, $p<0.001$, 95% CI 0.39 – 0.62). The mean non motor score was higher in patients at more advanced PD stage. The mean non motor score significantly increased across the stages of H &Y (P-value =0.036) as shown in Figure 4.2.3

Table 4.2. 1: Mean and standard deviations of items responses measuring non motor scores (MDS-UPDRS)

Non-Motor Items	Mean	SD
Depressed mood	2.04	1.25
Fatigue	1.96	1.08
Hallucinations and psychosis	1.93	1.40
Constipation problems	1.87	1.11
Apathy	1.85	1.12
Pain and other sensations	1.85	1.17
Sleep problems	1.81	1.22
Anxious mood	1.79	1.03
Cognitive impairment	1.76	0.81

Features of DDS	1.65	0.96
Daytime sleepiness	1.41	1.39
Light headedness on standing	1.25	1.25
Urinary problems	0.94	1.32

Table 4.2. 2: Mean and standard deviations of items responses measuring motor function (MDS-UPDRS

Items	Mean	SD
Doing hobbies and other activities	2.34	1.44
Handwriting	1.97	1.27
Tremor	1.84	1.17
Walking and balance	1.69	1.16
Dressing	1.59	1.18
Turning in bed	1.55	1.13
Getting out of bed	1.54	1.22
Speech	1.52	1.07
Saliva and drooling	1.36	1.08
Chewing and swallowing	1.16	1.02
Eating tasks	1.10	0.98
Hygiene	0.96	0.82
Freezing	0.72	1.08
Finger tapping Right hand	2.16	1.16
Finger tapping Left hand	2.12	1.14
Hand movements Left hand	1.87	1.14
Toe tapping Right foot	1.83	1.20
Toe tapping Left foot	1.81	1.19
Gait	1.81	0.82
Hand movements Right hand	1.80	1.15
Leg agility Left Leg	1.79	1.14
Leg agility Right Leg	1.79	1.13
Speech	1.76	1.24
Pronation supination movements left hand	1.76	1.11
Postural tremor Right hand	1.75	0.96
Postural tremor Right hand	1.75	0.96
Pronation supination movements Right hand	1.72	1.12
Kinetic tremor Right hand	1.62	0.97
Rigidity RUE	1.62	1.09
Arising Car	1.59	1.11
Rigidity LLE	1.59	0.97
Rigidity LUE	1.58	1.00
Rigidity Neck	1.56	1.03
Rigidity RLE	1.56	1.00
Global spontaneity of movement	1.55	1.12
Rest tremor amplitude LUE	1.54	1.00
Rest tremor amplitude RUE	1.54	0.96
Postural Stability	1.54	0.95
Rest tremor amplitude RLE	1.53	1.00
Facial Expression	1.50	0.82
Posture	1.50	0.97
Kinetic tremor Left hand	1.48	0.93
Rest tremor amplitude LLE	1.43	1.00
Constancy of rest	1.39	1.14
Rest tremor amplitude Lip jaw	1.39	1.03
Freezing of gait	1.37	0.97

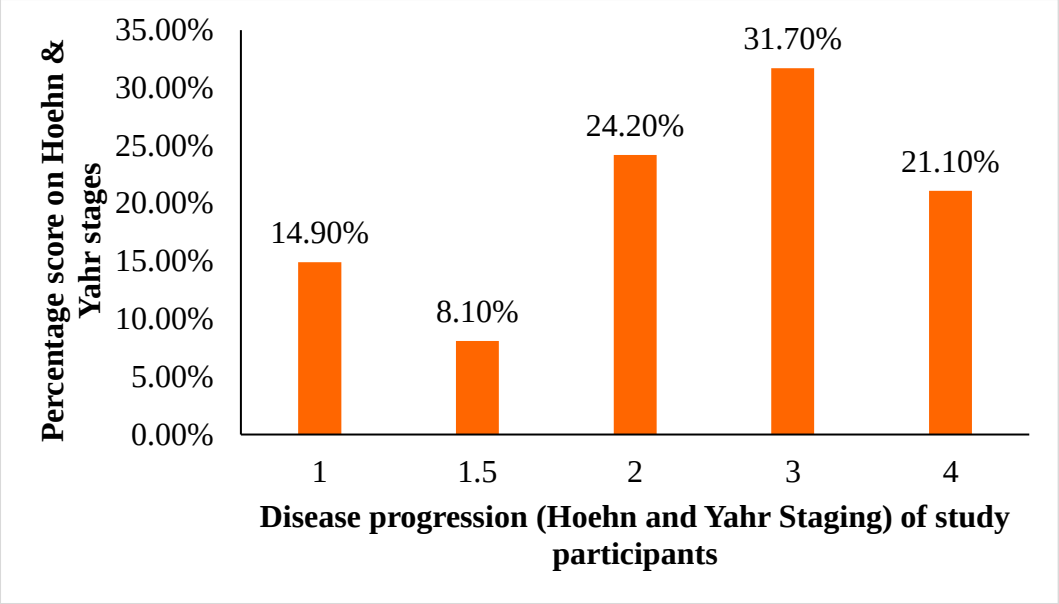


Figure 4.2. 1: Bar Chart of symptom progression of Parkinson disease among the study participants (Hoehn and Yahr Staging)

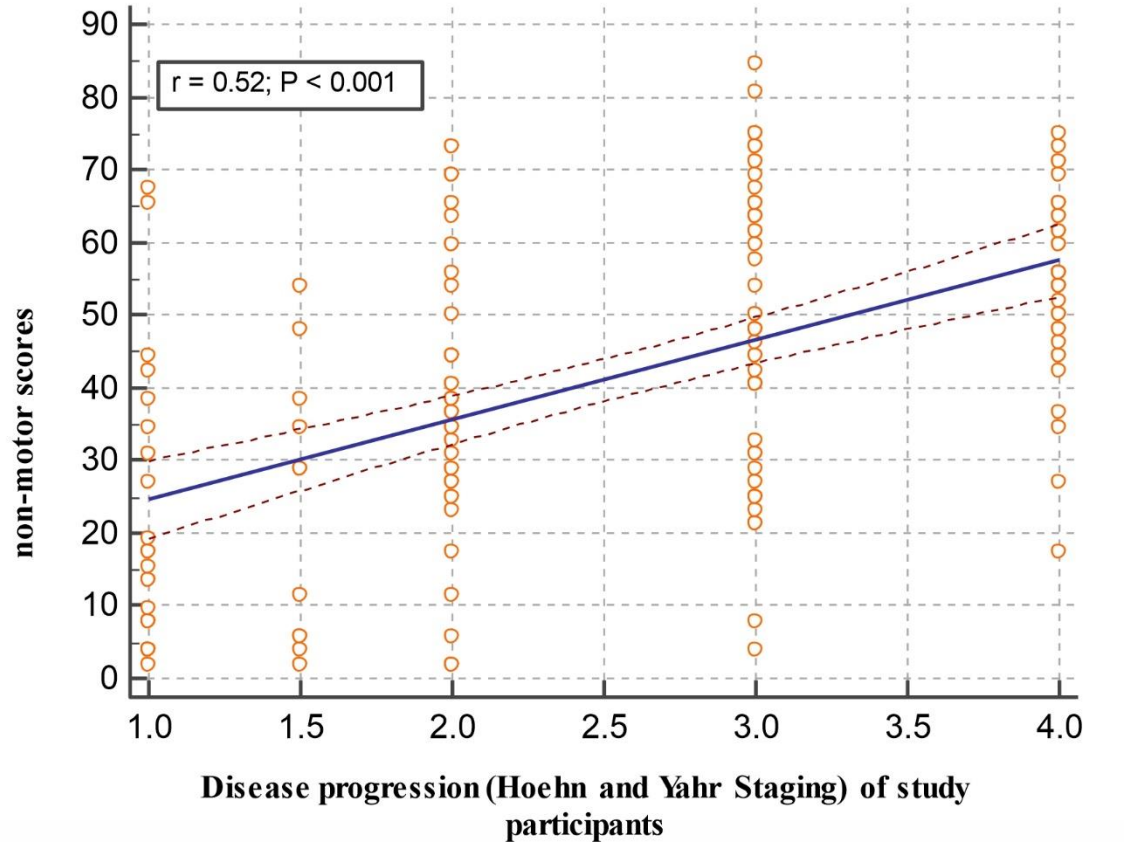


Figure 4.2. 2: Correlation plot between mean non-motor severity score and disease progression.

4.2. 2 Correlation between Motor and Non motor severity Scores with quality of life of study participants

PDQ-39 scale was used to assess quality of life. Overall, the mean PDQ-39 Summary Index (PD8-39 SI) was 37.2 ± 17.1. The domain with the highest mean score was mobility (57.7), followed by activities of cognition (44.6) and daily living (45.0), while the domain with the lowest score was social support 14.8 (Table 4.2.3).

Table 4.2. 3: Mean of the domain score on PDQ-39 scale of the study participants.

PDQ39 Domains	Mean	SD	95% CI of mean
Mobility	57.7	23.6	54.02 to 61.39
Activities of daily living	45.0	23.1	41.44 to 48.63
Emotional Well-being	34.5	25.8	30.53 to 38.57
Stigma	38.42	32.4	33.38 to 43.48
Social support	14.8	12.6	11.29 to 18.22
Cognition	44.6	27.4	40.38 to 48.91
Communication	29.3	23.9	25.62 to 33.07
Bodily Discomfort	33.7	25.1	29.84 to 37.66
PDQ-39 SI	37.3	17.1	34.62 to 39.93

There was a moderately strong and statically significant correlation between quality of life and non-motor severity scores. R= 0.56, $p<0.001$ as shown in Fig 4.2.3 There was a moderately strong and statically significant correlation between quality of life and motor severity score r= 0.43, $p<0.001$as shown in Fig 4.2.5

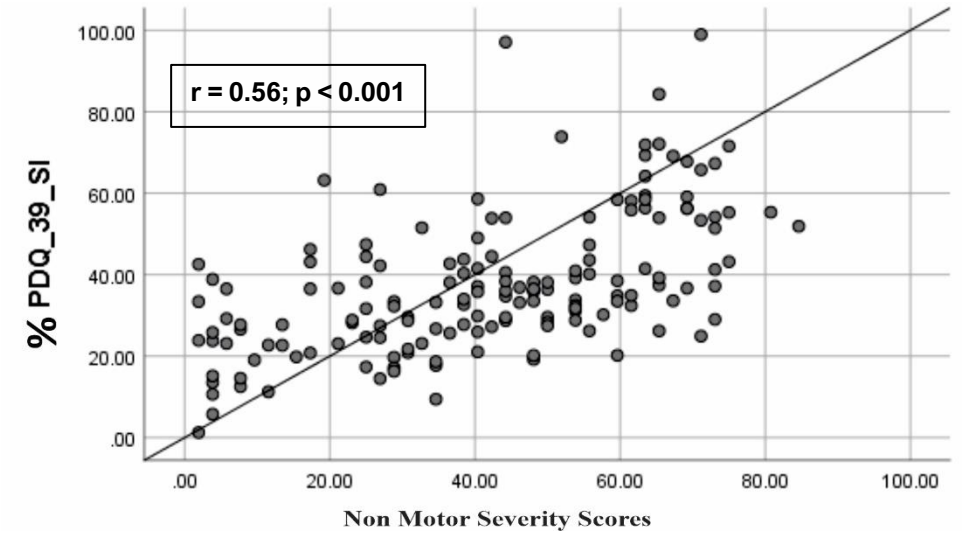


Figure 4.2. 33: Correlation plot between Quality of life and mean non motor severity scores

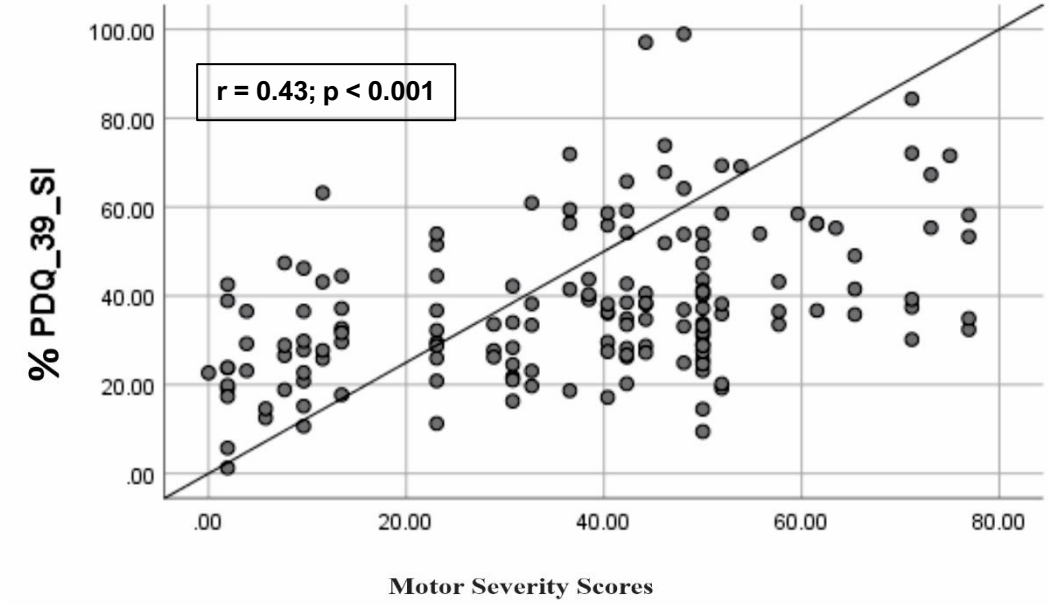


Figure 4.2. 44: Correlation between Quality of life and motor severity scores

4.2.4 Associations between motor and non-motor symptoms and PD Quality of life

To explore the association between socio-demographic characteristics and quality of life, PDQ39-Summary index (PDQ-39 SI) was categorized into quartiles and an ordinal regression analysis was performed with socio-demographic variables. As shown in Table 4.2.3, most had no statistically significant impact on PDQ39 -SI except for level of education, being employed and having income level of 300 to 600 cedis.

Having no formal education significantly results in a higher PDQ39-SI (aβ =-2.4, 95% CI=-4.371- -0.503, p-value=0.014). Being employed and having income level of 300 to 600 cedis was likely to positively impact quality of life at (aβ= 1.22 95% CI=-0.345-2.09, p-value=0.006) and (aβ= 0.82 95% CI= 0.822, p-value=0.036).

Table 4.2. 4: Ordinal regression analysis showing associations socio-demographic characteristics with PDQ39-SI

Variable	Beta Co-efficient(aβ)	95% Confidence Interval		p-value
		Lower Bound	Upper Bound	
Age categories				
45-59 years	ref	-	0.834	0.502
60+ years	0.213	. -0.408	. 0.834	0.502.
Ethnicity				
Akan	0.664	-0.046	1.373	0.067
Other Ethnicity	ref	.	.	.
Sex				
Male	0.249	-0.383	0.882	0.44
Female	ref	.	.	.
Educational Status				
No Education	-2.437	-4.371	-0.503	**0.014**
Primary Education	-1.308	-2.485	-0.132	**0.029**
Secondary Education	-0.926	-1.934	0.082	0.072
Tertiary Education	ref	.	.	.
Employment status				
Unemployed	0.694	-0.08	1.468	0.079
Employed	1.222	0.345	2.099	**0.006**
Retired	ref	.	.	.
Income level				
<300	0.455	-0.338	1.247	0.261
300-600	0.822	0.053	1.59	**0.036**
>600	ref	.	.m	.
Contribution of disease to job loss				
Job loss (no)	0.163	-0.467	0.794	0.612
Job loss (yes)	ref	.	.	

In a multiple linear regression analysis, which adjusted for education level, employment status and income level as covariates, higher mean non motor severity score was associated with a poorer quality of life, (adjusted β coefficient=0.434, p=0.000, (95% CI: 0.27-0.60). However, there was no significant association between motor severity score and quality of life (aβ= -0.079, p=0.391, (-0.26-0.10). Finally, disease progression was significantly associated with QoL (aβ=3.262, p=0.016, (0.61-5.91) as shown in Table 4.2.4.

Table 4.2. 5: Multiple Linear Regression model showing association between non motor score, motor score, Disease Staging and PD Quality of Life measure.

Predictors	**B Coefficient**	**Std. Error**	**CI**		**t**	**P-value**
			Lower	Upper		
Age	0.11	0.24	-0.36	0.57	0.46	0.65
Education	2.16	2.07	-1.90	6.22	1.04	0.30
Job	0.74	1.66	-2.51	3.99	0.45	0.66
Income	0.47	1.67	-2.80	3.74	0.28	0.78
Motor severity score	-0.11	0.10	-0.30	0.09	-1.08	0.28
Non-motor severity score	0.45	0.09	0.26	0.63	4.78	**<0.0001**
Hoehn and Yahr Stage	3.10	1.37	0.41	5.79	2.26	**0.03**

4.3. OBJECTIVE 2: ASSOCIATION BETWEEN STIGMA AND PD QUALITY OF LIFE

4.3.1 The level of Stigma among study participants

The SSCI Stigma Scale was used to assess the level of stigma in the study participants. The overall mean score of the items on the stigma scale was 62.36±14.49. The mean score for Internalised Stigma (Sum of first 13 items) SSCI was 36.8 ± 9.32 and mean score for Experienced Stigma (Sum of last 11 items) of SSCI was 25.58 ± 5.82. Table 4.3.1 shows the mean response for each of the 24 items on the SSCI scale. Scale items that assessed concerns about how people tend to ignore points/suggestions given by patients, being left out of things and people avoiding them, were the top three stigma symptoms reported.

Table 4.3. 1: Mean score of stigma symptoms among the study participants

SSCI Items	Mean	SD
People tended to ignore my good points	3.36	0.93
I felt left out of things	3.27	0.93
Some people avoided me	3.21	0.94
I felt different from others	2.75	0.84
People avoided looking at me	2.74	0.77
Strangers tended to stare at me	2.71	0.74
It was hard for me to stay neat and clean	2.70	0.95
some people seemed uncomfortable with me	2.69	0.79
I felt emotionally distant from other people	2.68	1.54
I tended to blame myself for my problems	2.68	0.82
I felt embarrassed about my illness	2.67	0.91
I felt embarrassed because of my physical limitations	2.67	0.85
I avoided making new friends to avoid telling others about my illness	2.67	0.73
I was unhappy about how my illness affected my appearance	2.62	0.87
I worried that I was a burden to others	2.62	0.73
people made fun of me	2.62	0.81
Some people acted as though it was my fault, I have this illness	2.62	0.81
I was treated unfairly by others	2.60	0.65
People were unkind to me	2.59	0.68
	2.55	1.55
I worried about other people's attitudes towards me	2.28	1.53
I felt embarrassed about my speech	1.83	0.59
People with my illness lost their jobs when employers became aware	1.79	0.63
I lost friends by telling them that I have the illness	1.46	0.94
Internalised Stigma	33.96	9.32
Experienced Stigma	28.40	5.82
Overall Score	62.36	14.49

4.3.2. Correlation between Stigma score and PD Quality of Life measure

There was a moderately strong and statically significant correlation between PDQ-39 and mean SSCI score ($r= 0.687$, $p<0.00$). There was strong and statistically significant correlation between experienced and internalised stigma, and PDQ39-SI at $r=0.550$ and $r= 0.698$. respectively as shown in Fig 4.3.1

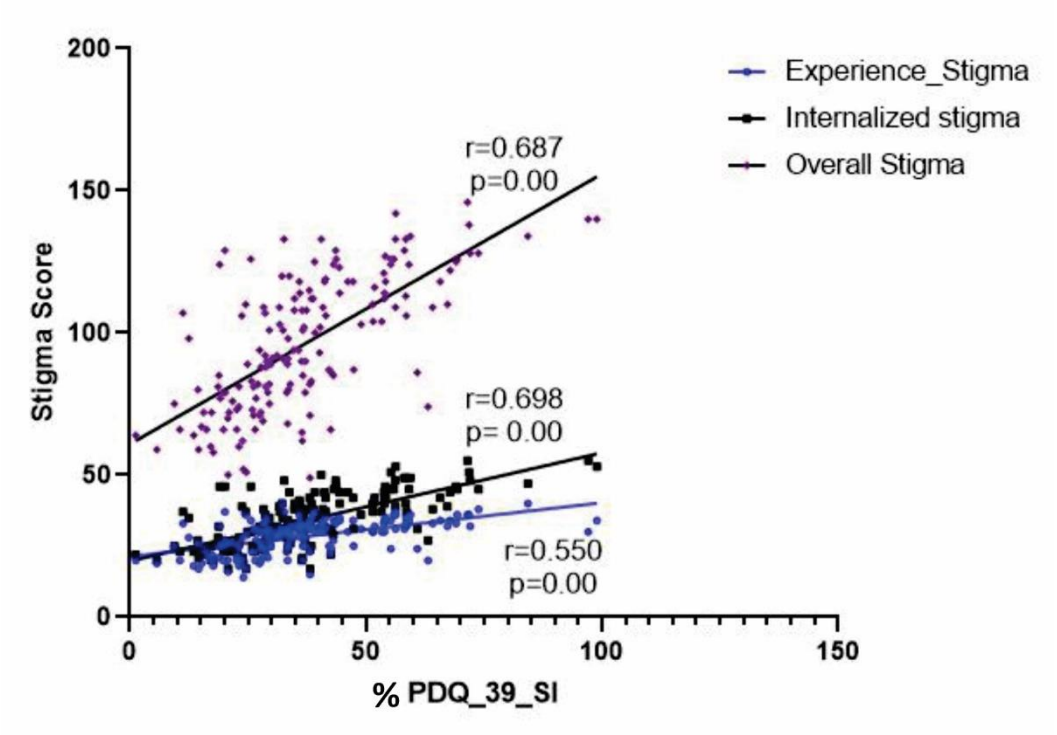


Figure 4.3. 1: Correlation Plot of mean stigma score and PDQ-39 SI

4.3.3 Multiple Regression analysis between SSCI score overall and two main domains) and PDQ-39 SI

In a multiple linear regression analysis with adjustment for education level, employment status and income level as covariates, internalized Stigma was significantly associated with Quality of life (aβ=1.36, p<0.0001, (1.00- 1.72) as shown in Table 4.3.2.

Table 4.3. 2: Multiple linear regression model showing association between stigma and Quality of life

Covariates	β Coefficient	CI		t	P-value
		Lower	upper		
Age	0.22	-0.18	0.62	1.07	0.29
Education	3.36	-0.10	6.82	1.91	0.06
Income	0.92	-1.83	3.67	0.66	0.51
Job	-0.91	-3.52	1.70	-0.68	0.50
Experienced Stigma	-0.16	-0.73	0.41		0.59
Internalised Stigma	1.36	1.00	1.72		<0.0001

4.4. OBJECTIVE 3: ASSOCIATION BETWEEN COGNITIVE PERFORMANCE, DEPRESSION, AND QUALITY OF LIFE

4.4.1 Global Cognitive Performance of PD patients: The MOCA scale was used to assess cognitive function among the study participants. Table 4.5.1 shows the summary statistics of the responses. The mean overall score was 21.3± 4.6. Majority (65.8%) of the study participants had mild cognitive impairment and 10.6% were classified as moderate cognitive impairment (Figure 4.4.1). The MOCA item that scored highest was orientation with mean and standard deviation of 4.9 ±1.6 as shown in Table 4.4.1.

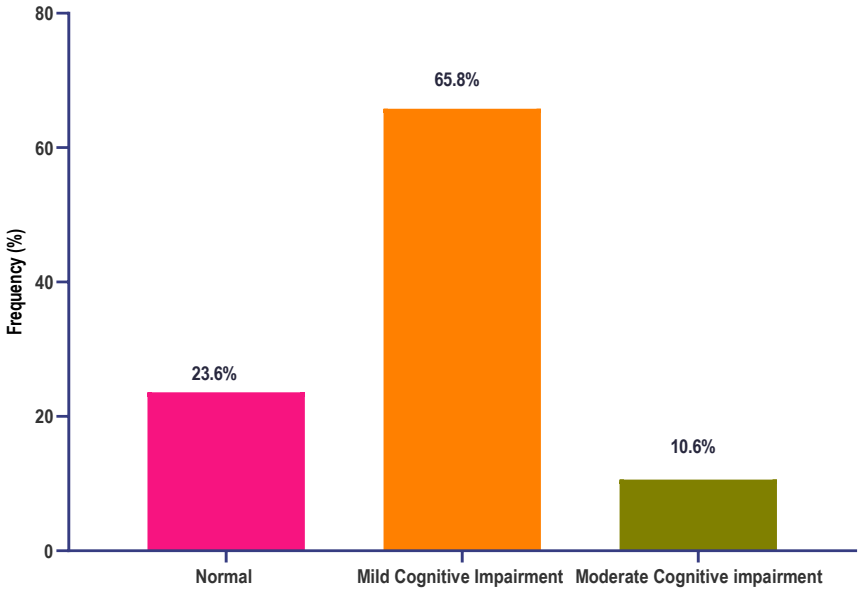


Figure 4.4. 1: Classification of Cognitive Impairment scores of study participants

Table 4.4. 1: Mean and standard deviations of the items on the MOCA scale

MOCA Items	Mean ± SD
Visuospatial/ Executive	2.97±1.51
Naming	2.08±0.94
Attention	1.27±0.79
Read list of letters	0.76±0.43
Serial 7 subtraction starting at 100	1.61±1.07
Language Repeat	1.61±0.67
Language fluency	0.75±0.43
Abstraction	1.57±0.72
Delayed Recall	3.85±1.44
Orientation	4.88±1.57
Overall MOCA score	21.33±4.62

4.4.1. Correlation between mean MOCA score and quality of life

There was a moderately negative and statically significant correlation between QoL measures i.e., PDQ-39 SI and MOCA score (r= -0.51, p<0.05) as shown in Fig 4.4.2

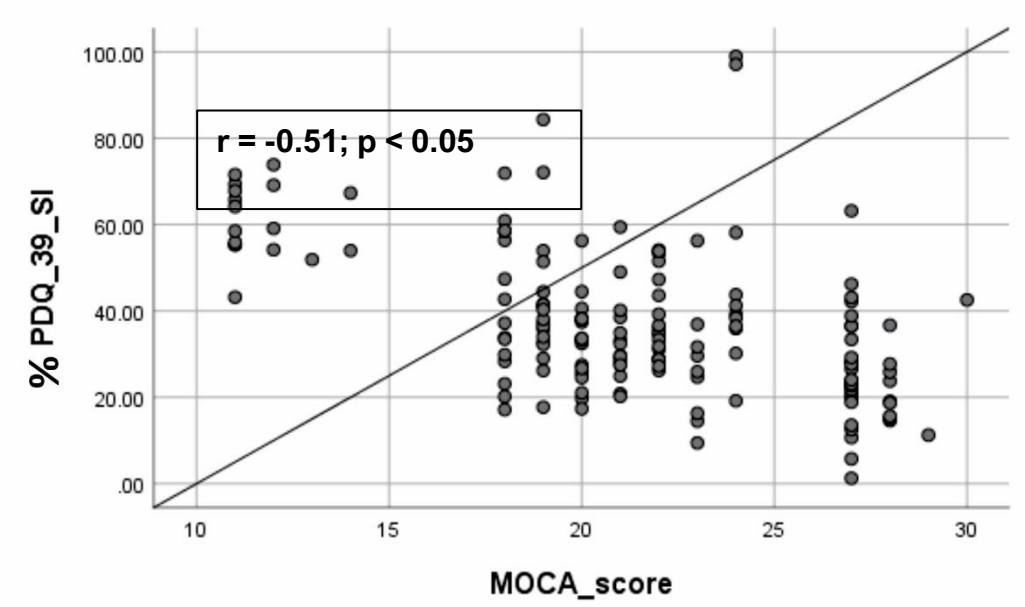


Figure 4.4. 2: Correlation Plot between mean MOCA score and quality of life

4.4.2 Multiple Regression analysis between MOCA score (overall mean score and by domain) and PDQ-39 SI

MOCA domain-specific associations with QoL: There were significant associations in the delayed recall, language fluency, orientation, and visuospatial sub-domains of

the MOCA scale and QoL as shown in model 1 in Table 4.4.2. The domains that had the most significant effect on quality of life within the MOCA scoring were delayed recall (p-value 0.027), language fluency (p-value 0.033), orientation (p-value 0.05) and visuospatial executive (p-value 0.018).

Overall MOCA score associations with QoL: In a regression analysis between total MOCA score and PDQ39-SI, the total MOCA score had a negatively significant association with quality of life (aβ= -1.653, p=0.05, (-3.306-0) upon adjusting for education level, employment status and income level as covariates as shown in Table 4.4.2 (Model 2). In this model, educational level was also associated with QoL.

Table 4.4. 2: Multiple linear regression model showing association between the MOCA score (mean and domain) and Quality of life measure (PDQ-39 SI)

Independent variables	**Coefficient**	**CI**		**t**	**P**
		Lower	**Upper**		
Model 1					
Age	-0.08	-0.56	0.39	-0.35	0.729
Education	4.45	0.27	8.62	2.09	**0.039**
Job	-0.86	-4.08	2.35	-0.53	0.599
Income	-0.15	-3.39	3.09	-0.09	0.930
Abstraction	0.07	-3.60	3.74	0.04	0.969
Attention	-0.28	-3.92	3.37	-0.15	0.882
Delayed Recall	-2.31	-4.34	-0.29	-2.24	**0.027**
Language fluency	-6.60	-12.61	-0.59	-2.15	**0.033**
Language Repeat	-1.31	-5.02	2.39	-0.70	0.488
Naming	-1.42	-4.37	1.54	-0.94	0.349
Orientation	-1.66	-3.31	-0.01	-1.97	**0.050**
Read list of letters	-2.56	-8.99	3.88	-0.78	0.437
Serial_7_substraction	-1.33	-3.73	1.08	-1.08	0.283
Visuospatial Executive	-2.28	-4.14	-0.41	-2.40	**0.018**
Model 2					
Age	-0.07	-0.53	0.39	-0.30	0.766
Education	4.79	0.84	8.74	2.38	**0.019**
Job	-0.90	-3.91	2.11	-0.59	0.560
Income	-0.57	-3.70	2.57	-0.35	0.724
MOCA score	-1.88	-2.37	-1.38	-7.49	**<0.0001**

4.4.3 Depression and its Association with Quality of life of study participants

4.4.3.1. Assessment of Depression among study participants

The Becks Depression Index (BDI) scale was used to assess depression in study participants. Overall, the mean (SD) BDI score was 17.85 ± 8.53 (Table 4.4.3). Among the total participants, 44.1% had moderate depression, 27.3% had mild depression, 3.7% were estimated to have severe depression while those with no depressive symptoms constituted 18.6% (Figure 4.5.2). The item on BDI scale measuring decreased initiative recorded the highest mean (mean=1.63) while loss of appetite had the lowest mean of 0.35. The item measuring depressed mood recorded the highest variance in responses (variance= 1.23) as seen in Table 4.4.3.

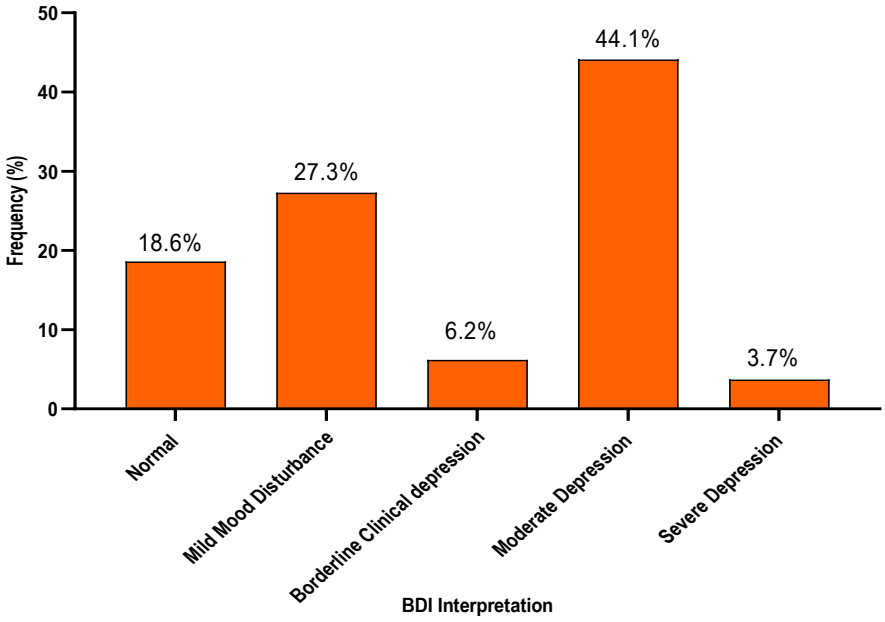


***Figure 4.4. 33: Frequency distribution of depressive symptoms among the study participants**

Table 4.4. 3: Mean, standard deviations of Items on the BDI scale

BDI Item	Mean ± SD
Depressed Mood	1.03±1.11
Pessimism regarding future	0.76±1.05

Sense of Failure		0.65±0.79
Anhedonia		1.36±1.02
Guilty feelings		0.76±1.06
Sense of punishment		0.89±1.10
Self-dislike		0.74±0.93
Self-accusation		0.69±0.82
Suicidal Ideation		0.52±0.86
Crying		0.62±0.87
Irritability		0.62±0.77
Social withdrawal		0.50±0.70
Difficulty making decisions		0.68±0.83
Distorted body image		0.64±0.81
Decreased initiative		1.63±1.04
Sleep disturbance		0.88±0.91
Anergia/fatigue		1.07±0.94
Loss of appetite		0.35±0.60
Weight loss		0.67±0.81
Somatic concerns		1.14±1.01
Loss of libido		1.10±1.09
Mean BDI score	17.85±8.53	

4.4.3.2. Correlation between mean BDI score and quality of life

There was a moderately positive and statistically significant correlation between QoL score on the PDQ-39 SI and mean BDI score ($r= 0.59$, $p<0.001$) seen in Fig 4.4.4.

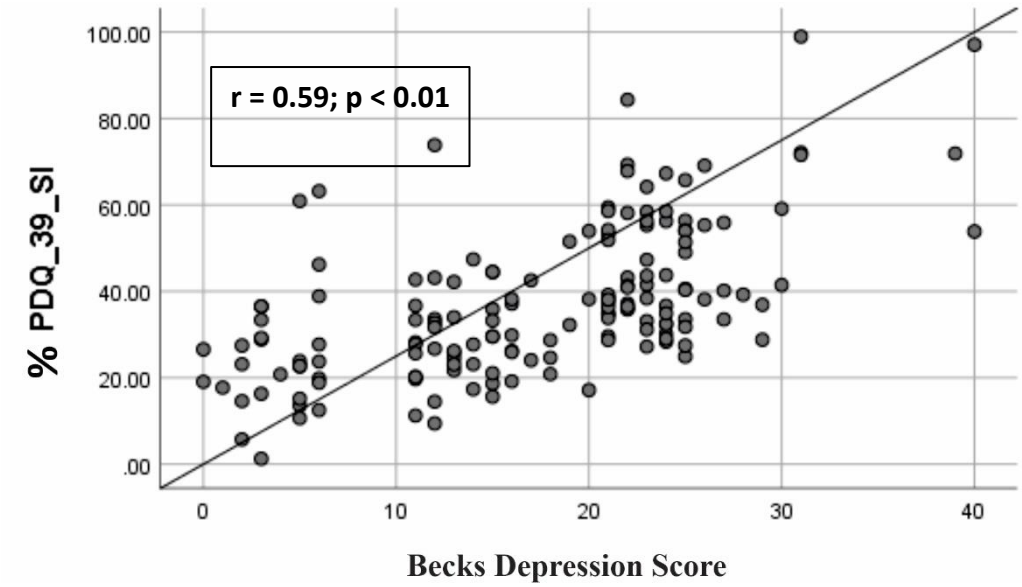


Figure 4.4. 44: Correlation plot between the mean BDI score and PDQ 39 SI

4.4.3.3. Association between Depression and Quality of life

In regression analysis between mean BDI score and PDQ39-SI, the mean BDI score had a positively significant association with quality of life (aβ= 1.19, p=0.0, (0.939-1.442) adjusting for education level, employment status and income level as covariates) as seen in Table 4.4.5

Table 4.4. 4: Multiple linear regression model showing association between depression and quality of life

Independent variables	Coefficient	Std. Error	CI		t	P
			Lower	Upper		
Age	0.11	0.22	-0.32	0.55	0.51	0.609
Education	4.77	1.90	1.05	8.48	2.51	**0.013**
Job	-1.32	1.44	-4.15	1.51	-0.91	0.363
Income	-0.47	1.51	-3.43	2.48	-0.31	0.754
Beck's score	1.16	0.13	0.91	1.42	9.08	**<0.0001**

4.5 MULTIPLE REGRESSION ANALYSIS BETWEEN MOTOR AND NON-MOTOR SYMPTOMS, DEPRESSIVE, COGNITION AND DEPRESSIVE SYMPTOMS AND PDQ-39-SI

In a multivariate linear regression analysis, a participant's cognition (β= -0.65, p-value= 0.031) and stigma status (β= 0.51, p-value <0.0001) were independently and significantly associated with overall quality of life as shown in Table 4.5.1

Table 4.5. 1: Multiple Regression analysis between motor and non-motor symptoms, depressive, cognition and depressive symptoms and PDQ-39-SI

Variables	Beta coefficient	SE	t-value	P-value
Overall QoL (PDQ39-SI)				
Education	3.17	1.42	2.23	**0.027**
Depression	0.52	0.21	2.51	**0.013**
Stigma	0.51	0.09	5.95	**<0.0001**
Non-Motor Severity Score	0.02	0.10	0.21	0.831
Motor Severity Score	-0.10	0.08	-1.21	0.229
Hoehn and Yahr Stage	1.11	1.26	0.88	0.382
Cognition	-0.65	0.30	-2.18	**0.031**

CHAPTER FIVE

5.0 DISCUSSION

The aim of this study was to assess factors associated with the QoL in people living with idiopathic PD attending a neurology clinic in the middle belt of Ghana. The study explored the independent associations of the motor and non-motor complications; stigma, depression, and cognitive impairment on the QoL of people living with PD. Of note, results from this study showed that participant's cognition (β= -0.65, p-value= 0.031), depression(β= 0.52, p-value =0.013) and stigmatisation (β= 0.51, p-value <0.0001) were significantly associated with the overall health related quality of life of individuals living with PD. A summary of key study findings by specific objectives of the study is presented next.

5.1 SUMMARY OF KEY FINDINGS

There were salient observations in the burden and frequency of motor and non-motor complications among people living with idiopathic PD in this study. For the motor complications, experiences with daily living, doing hobbies and other activities, handwriting, and Tremor were the most frequently identified challenges. The major non-motor complications of experiences with daily living were fatigue, hallucinations and psychosis, constipation problems, apathy and pain and other sensations.

Stigmatisation may be described subjectively as a non-motor symptom of PD either by the patients and/or their caregivers. Scale items that assess concerns about how people tend to ignore points/suggestions given by patients, being left out of things and people avoiding them, were the top three stigma symptoms. Other items including feeling different from others, people avoiding looking at them and strangers staring at them were significant symptoms measured. Overall, the level of stigma assessed in this study may be described as moderate and was significantly associated with the QoL of people living with PD.

Depression assessed using the Beck's inventory was significantly associated with a poor QoL. Global cognitive performance scores on the MOCA scale exhibited an inverse association with QoL, with higher cognitive performance associated with lower PDQ-39 scores (suggesting better QoL).

5.2 SOCIODEMOGRAPHIC CHARACTERISTICS OF THE STUDY PARTICIPANTS

In this study, the mean ages for the men and women were 65.2 and 65.5 years respectively. The age distribution was consistent with a similar study in Kumasi, Ghana and a systematic review that reported 65 years and 66.7 years respectively [25, 100]. However, the marginal difference in the ages of men and women does not depict the life expectancy rule of thumb and the purported protective effect of oestrogen among other genetic factors [101]. Nearly three-quarters of participants were male. Similar studies have also reported disproportionately more men than women with PD [2, 102]. Again, the protective effect of oestrogen and the genetics of dopaminergic neurons have been attributed to the gender disparity in the epidemiology of PD [84].

About two-thirds of the participants had post-primary education with 20% still working. Less than a quarter earned at least GHS 600.00 per month while two-thirds of participants reported job losses. These imply low socioeconomic status of these individuals who need regular medical attention. Almost 90% had quit their jobs due to movement challenges and more than a tenth had to resign because of the stigma associated with living with PD. This is similar to other studies which have shown early retirement and loss of income among working-aged individuals and those in various levels of employment [103-106]. In as much as these individuals are considered aged and would have attained the pension age in Ghana in some cases, loss of livelihoods can pose serious socioeconomic challenges and have a cascade effect on their families and the nation. They may have dependents or end up depending on other family members which could have deleterious effect on their health and other aspects of their lives. This was evident in a study by Jennum [103] which showed the adverse health, social and economic effects of PD. It is worth noting that almost all of the participants, ~90% received medication support from the PD Foundation, providing some relief.

5.3 QUALITY OF LIFE OF THE STUDY PARTICIPANTS ASSESSED BY PDQ-39 SCALE

The mean PDQ-39 summary index (PDQ39 -SI) obtained from the PD patients involved in this study was 37.3%. This was higher than what was found in Sławek *et al.* [61] where it was 34.01 and Bang *et al.* [62] which was 27.7. Mobility, activities of daily

living and cognition domain were the most challenging among the study participants. In a similar study by Berganzo *et al.* [102], mobility, activities of daily living, and cognition were also three of the main challenges faced by people living with PD. Difficulty washing oneself was the major challenge in the QoL assessment. As shown in the motor symptoms of the study participants, activities of daily living among other symptoms constituted the main symptom. These are supposed to be the basics of self-care, and the inability of people living with PD to do these can be disturbing. There were problems with writing and getting around in public places. Therefore, improved independence with mobility could be considered an important goal of rehabilitation for PD patients. This study suggests customized treatment options for Parkinson disease patients through goal-oriented rehabilitation treatment may be a viable solution especially after periodic evaluation of factors which affect their quality of life. However, considering pension and job losses in majority of the participants, these challenges may not impact their QoL as much as cleaning oneself. Loss of livelihood and inability to sustainably cater for their dependents can be psychological draining for these patients.

5.4 BURDEN OF MOTOR AND NON-MOTOR COMPLICATIONS AMONG THE STUDY PARTICIPANTS

The major motor and non-motor symptoms identified in this study were doing hobbies and other activities, and depressed moods respectively. Depressive symptoms, chiefly reported in this study, have been well established as the major predictor and influence on QoL of people living with PD. Other non-motor symptoms identified include fatigue, hallucinations and psychosis, constipation problems, apathy and pain and other sensations. In the study by Kadastik-Eerme *et al.* [107], cognitive decline, insomnia, urinary problems, fatigue, pain, and depression were the most frequent non-motor symptoms. Among these, the study showed depression as the main predictor of quality of life among in patients with PD which concurs with findings in the present study. Similarly, in a study by Menon *et al.* [108], an essential finding was that the most important predictor for poor QOL is presence of depression and not the severity of the motor symptoms or the duration of illness. Depression may therefore affect individuals living with PD in numerous ways such as their approach to dealing with the condition, taking their medications, attending family gathering and ultimately their productivity in the community and the nation as a whole.

5.5. STIGMA AND QOL AMONG THE STUDY PARTICIPANTS

Stigmatisation is a common phenomenon with many disease conditions that overtly changes the patients. The disapproval and derogatory comments received by people living with PD can potentially impact their QoL. Statistical analysis showed a moderate correlation between stigma and QoL in this study. Indeed, in a multivariate regression analysis, stigma among the study participants significantly impact their QoL ($\beta = 0.51$, p-value <0.001) as shown in Table 4.5.1 This means that a unit increase in stigma score is associated with a 0.51 unit rise in PDQ-39 score suggesting a poorer QoL. This study showed that internalized stigma was significantly associated with Quality of life ($a\beta=1.36$, $p<0.0001$, (1.00- 1.72). Internalised stigma represents the application of negative stereotypes and prejudice to one's self. For PD patients in this study, this may involve perceiving that they are dangerous, to be blamed for their illness or are incompetent. Culturally informed misconceptions about neurological diseases such as Parkinson Disease may have been internalised, resulting in significant negative self-perceptions A study by Quinn and Earnshaw [109] of mental illness showed that when patients experience negative stereotypes to self, they may believe they are devalued. This may in turn may lead to increased psychological distress or decreased self-esteem. Findings from this study therefore highlights the need for approaches to be developed to overcome internalised stigma by debunking or confronting the negative beliefs through education, and by helping patients through support groups or cognitive behavioural therapy to build self-esteem and empowerment to cope when they feel negative beliefs about themselves.

A study by Hou *et al.* [110] described the level of stigma experienced by people living with PD in their cohort as mild to moderate. The drivers identified included tremor, prolonged disease, severe motor symptoms, and depression. In the study by Ma *et al.* [111] stigma alone explained 13.7% of the variance in QoL. One outcome of these levels of stigma, identified in this study and others, is social isolation which is likely to foster depression. It can be speculated that depression experienced by people living with PD may also stem from stigmatisation. Ma *et al.* [111] and Vanta *et al.* [112] in their studies identified motor impairment as the main driver of stigma. Although motor impairment did not associate with QoL in this study, it is possible that movement challenges faced by people living with PD influenced stigma against them. A descriptive review of qualitative studies by Maffoni *et al.* [113] on Stigma experienced by Parkinson's Disease

patients stated that Stigma could arise from the patient's perception of being a burden to the caregiver and the uncertainty of progression of the disease. This was further bolstered by the feeling of guilt and selfishness due to their increased demand for special attention in daily activities together with reactions from the caregiver towards them. Considering the reasons for job losses such as movement challenges and stigma at the workplace, stigma described as a non-motor symptom by Maffoni *et al.* [113] needs to be included in the core assessment of QoL of people living with PD. This will contribute greatly to finding appropriate interventions to improve the lives of people living with idiopathic PD. AboJabel *et al.* [114] in their study identified three themes of stigma in PD: the stereotypes that typify PD, stigmatizing behaviours towards the person with the disease, and structural stigma. This calls for pragmatic steps to provide systemic interventions to reduce stigma and improve the QoL of people living with PD. Jagota *et al.* [115] used a public video campaign on stigma against people living with PD. They reported the impact of creating public awareness which is likely to reduce stigma and improve social support and consequently improve the QoL of people living with PD.

Stigma has an important negative effect on illness progression and management: it may contribute to avoiding or interrupting treatment and manifesting depressive symptoms. In fact, patients are the most trustworthy witnesses of their lives. They are the main protagonists of their changing illness experience: day after day, they live on with their bodies and continuously come to terms with the PD

Stigma isolates and marginalizes PD patients, causing increased rates of depression. At the population level, anti–mental health stigma campaigns are an effective tool to combat social stigma and provide education to the general public about the disease. With the increasing use of social media and the Internet, connecting to and providing information for difficult-to-reach populations is possible. Indeed, the need to address the psychosocial and biological aspects of Parkinson's disease suggests that a more holistic approach is necessary to treat the patient adequately.

5.6 DEPRESSIVE SYMPTOMS AMONG THE STUDY PARTICIPANTS

More than 80% of participants in this study were identified to have some degree of depression, with a significant proportion of them being moderately depressed. These

individuals no longer find pleasure in activities they used to enjoy, cannot take initiatives, and tend to have low energy to drive activities. These are necessary for self-esteem, and the lack thereof is likely to lead to depression. Considering that some had to quit their jobs or were sacked due to movement challenges is enough to prove their incapability to them. Depression has been identified as the main predictor of poorer QoL among people living with PD [107, 116]. The study by Shalash *et al.* [117] showed that people living with PD had worse depression as a result of the Covid-19 pandemic. The depression was worsened by factors such as decreased physical activity, increased sedentary behaviour and decreased social interaction which are also factors seen in PD patients.

5.7. COGNITION SYMPTOMS AMONG THE STUDY PARTICIPANTS

In this study, almost two-thirds and a tenth of participants had mild and moderate cognitive impairments, respectively. Cognition was also found to be significantly associated with the overall QoL of people living with PD in this study (β= -0.65, p-value= 0.01). This shows that with a unit rise in MOCA, there will be 0.65 units decline in QoL score (which means better QoL given that on the PDQ-39 scale, higher score connotes poorer QoL). Consistent with previous studies by Lawson *et al.* [100], our study found that the more severe the cognitive impairment, the higher the PDQ-39 score.

The domains that had the most significant effect on quality of life within the MOCA scoring in this study were delayed recall (p-value 0.027), language fluency (p-value 0.033), orientation (p-value 0.05) and visuospatial executive (p-value 0.018). This went contrary to previous studies by Vasconcellos *et al.* [118] in which attention, memory and executive function were the domains mostly affected. Klepac *et al.* [67] also reported impairment in attention, memory and executive function as being directly associated with poorer QoL. This study showed more impairment in declarative memory, language and praxis which could be alluded to the fact that cognitive features in PD may be heterogenous, and some patients may exhibit more "cortical" profiles as seen in Emre [119]. Hypometabolism in the temporoparietal areas of the brain could explain why our study participants showed impairment in those affected cognitive domains. Genetic risk (e.g., apolipoprotein E [APOE] epsilon 4 carrier status in Africans which

have not been well investigated largely hitherto may need to be looked in future studies to understand better the cause of these amnestic profiles of cognitive impairment in our study participants.

Though different scales(modified Community Screening Instrument for Dementia (CSI'D') and selected items from the Ibadan Neuropsychological Battery (I-NB)) were used for the assessment of cognitive dysfunction of Nigerians in the study by Akinyemi et al, their patients with PD exhibited significant dysfunction in the core cognitive domains of memory, language, and executive function. Memory deficit in PD is largely known to be a deficit of retrieval of coded information than a deficit of registration, encoding, and storage of information. This may explain the worse performance of Nigerian PD subjects on test items assessing information retrieval (three-item recall and word list recall) and in our study participants in terms of delayed recall scores.

It has, however, been noted that many described language deficits in PD may not reflect a true involvement of language functions since the anatomical regions of the brain responsible for language functions are not primarily affected by the disease process; rather, they may be related to the dysexecutive syndrome that characterizes PD. It has also been suggested that in addition to a dysexecutive syndrome, some patients with PD may develop a pattern of dementing illness with a limbic or hippocampal type of amnesia, which may be associated with early impairment of language functions similar to what is seen in Alzheimer's disease (AD).

Findings from this study are consistent with Berganzo *et al.* [102] who reported mood/cognition domain as the leading non-motor symptom. According to the authors, the impact of these mood and cognitive symptoms far exceeds that of motor symptoms. In a study by Alonso-Recio *et al.* [120], global cognitive decline was shown to impact social cognition, potentially influencing the social interactions of people living with PD. In addition to this, a longitudinal study by Pigott *et al.* [121] followed 141 patients with PD with normal cognition at baseline over a 6 year period and found that nearly half of participants developed cognitive impairment within 5 years, and 100% of individuals who developed mild cognitive impairment progressed to dementia within 5 years. The study by Lawson *et al.* [122] showed that mild cognitive impairment greatly impacted the QoL of people living with PD. The pathophysiology

of cognitive impairment in Parkinson's Disease remains poorly understood. Here, the authors explored the role of serotonin in cognition: its interactions with the cholinergic neurotransmitters systems may be implicated in the cognitive processes [123].Interventions to enhance attention are likely to improve this deficit. Together with depression, cognitive decline in PD adversely affects quality of life greatly.

5.8 RELATIONSHIP BETWEEN PDQ39, MOCA, BDI, SSCI AND MD_UPDRS SCALES

Among individuals with moderate depression, 44.1%, were the poorest mobility status, ADL, emotional wellbeing, stigma and overall, the PDQ-39-SI. These findings buttress the assertion by several studies that depression is the major predictor of QoL in people living with PD [107, 110, 116]. Having higher MOCA score gave a better quality of life.

In this study, cognition and stigma were identified as independent predictors of overall quality of life among people living with PD in the middle belt of Ghana. This is consistent with findings from Berganzo *et al.* [102] and Lawson *et al.* [122] who reported that cognitive symptoms, even mild impairments, greatly impact QoL. Hou *et al.* [110] identified stigma to be common among people living with PD and with the potential to impact QoL.

CHAPTER SIX

6.0 CONCLUSION, LIMITATIONS AND RECOMMENDATIONS

6.1 CONCLUSION

This study has identified stigma,depression and cognitive performance as the two independent factors significantly associated with overall health related QoL of individuals living with idiopathic PD in the central belt of Ghana. While depression and non-motor complications were associated with QoL in limited multivariate linear regression models conducted in our study, their associations were lost in ourthe fully adjusted regression models. Screening for depression, stigma and cognitive impairment should be done routinely at neurology clinics and integration of psychosocial support into the care of PD.

6.2 LIMITATIONS

1. Being a single centre hospital-based study, it may not accurately reflect disease trends in other hospitals with different levels of care and different patient populations. A multi-centre study would be a recommended follow up.

2. Also, KATH being a single hospital located in an urban area, patients who are from rural areas with less access to healthcare may be underrepresented in this cohort.

3. Risk of referral bias due to the study site being a tertiary level healthcare facility and so may be receiving PD cases with more advanced disease.

6.3 **RECOMMENDATION**

Clinical practice

1. PD treatment should focus on both motor symptoms and non-motor symptoms throughout the management of the disease, and this will improve quality of life for PD patients.

2. Patients with Parkinson's disease and their caregivers need to be educated on both motor and non-motor symptoms which will lead to a better understanding of the disease.

3. Health care workers who provide care for patients with Parkinson's disease need to spend more time asking about motor and non-motor symptoms using validated tools.

4. Integration of psychosocial support into the care of PD in clinics and hospitals.

5. Multi-disciplinary team-based care and Parkinson's support groups should incorporate strategies (both pharmaceutical and recreational) that will enable PD patients cope better with their symptoms and other aspects of their disease.

Further research

1. A larger multicentre study will allow for evaluation of motor and non-motor symptoms in a diverse, more representative cohort.
2. It will be pertinent to generate normative data in healthy apparently normal population for all the instruments I used to assess the study population and this can be done as future work.
3. Clinical subtypes of Parkinson's disease, multimorbodities and patients' medications may be introduced as covariates in analysis models of future work on quality of life in pateints with Parkinsons disease

2. Community based studies to assess the burden of motor and non-motor symptoms in the community, especially rural areas.

Policy initiative

The study hihjlights the need for practical steps to be taken in terms of practice and policy. Based on the results of this study,there should be the introduction of multidisciplinary team approach into the running of outpatient clinics for Parkinson's disease patients in Ghana as this will go a long way to improve the quality of life of patients and help them manage disease better.

Establishment of a Ghanaian Parkinson's disease registry will provide data for evidence-based interventions, practice, and policies to improve care for patients with Parkinson's disease in Ghana.

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Conflicts of Interest

None to declare

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8.0 APPENDICES

APPENDIX 1: DATA COLLECTION SHEET

DEMOGRAPHIC AND CLINICAL DATA RECORDS

Data collected by: .....

MINIMUM DATASET – Demographic and Clinical data

Family name: .....**First Name**: .....

Address: .....

Hometown: ..... P.O. BOX.....

Telephone#1.....Telephone#2.....

Date of Birth: ..... Place of Birth: .....

Ethnic group/category.....

Gender: ϒ M ϒ F Height (cm): ..... Weight (Kg): .....

Education: .....

Current/Previous Job (s):.....

Average monthly income (GH¢): □ 300 and below □ 301 – 600 □601 – 900 □ 901 – 1200 □1201 – 1500 □ 1501 – 1800 □ Above 1800

Has your condition as PD patient contributed in any way to lose your job? □Yes □ No

If yes, how? □Was sacked because of mobility and cognitive issues □ Resigned because of stigma □Quit because of movement challenges □Others …….

Do you receive any support from any government institution or nongovernmental organisation in your upkeep? □Yes □No

If yes, what kind of support? □ Physiotherapy □ Counselling □ Finance □Others ……

MAIN DIAGNOSIS: .....

Other neurological disorders 1) ..... 2).....

DEMENTIA: ϒ No ϒ Yes If yes, specify.....

FAMILY HISTORY

Relevant Diseases (including neurological/psychiatric, diabetes, hypertension, neoplasms, etc.)

.....

Family Blood Tie (marriage between siblings, cousins, etc) ϒ No ϒ Yes ϒ Unknown

Presence in the family of any symptom/sign of **Parkinsonism**: ϒ No ϒ Yes ϒ Unknown

Relative	Symptoms/Signs	Still living? (yes/no)

PERSONAL HISTORY

Birth/Development: ϒ Normal ϒ Problems (if yes, specify.....)

Allergies: ϒ No ϒ Yes (if yes, specify.....)

Drugs of abuse (cigarette smoking, alcohol, coca chewing, etc.) ϒ No ϒ Yes (specify.....)

Sleep problems (insomnia, etc.) ϒ No ϒ Yes (if yes, specify.....)

Swallowing problems ϒ No ϒ Yes (specify: solid and/or fluid.....)

Sexual problems (ex: erectile impotence in males) ϒ No ϒ Yes (if yes, specify.....)

Urinary problems (urge, incontinence, etc) ϒ No ϒ Yes (if yes, specify.....)

Constipation ϒ No ϒ Yes (if yes, specify.....)

EXPOSURE to potential Neurotoxic Agents (including: pesticides, herbicides, carbon monoxide, paints/dyes, glues, oil derivatives): if yes, specify

1) how long: hours/day ..... from ..... to ..... (specify years)

2) kind of agent/product and, if farm product, its brand .....

.....

EXPOSURE to Anti-dopaminergic Drugs (including Neuroleptics, Lithium, Metoclopramide, Valproate, Cinnarizine/Flunarizine, etc): if yes, specify agent and treatment duration.....

.....

<u>MEDICAL HISTORY</u>

Current and/or Previous Diseases / Surgical procedures ϒ No ϒ Yes ϒ Unknown

- Infectious diseases (in case of malaria, report only severe episodes with neurological symptoms)

- Neurological/psychiatric disorders (stroke, repeated falls, hallucinations, depression, etc.)

- Others: diabetes, hypertension, heart diseases, neoplasms, bones fractures, etc.

Diagnosis/Procedure: ..... year: .....

.....

NEUROLOGICAL HISTORY

Description of the **first symptoms/signs suggestive of Parkinsonism**

ϒ Tremor ϒ Muscle rigidity ϒ Slowness of movements

ϒ Gait difficulties ϒ Balance instability/falls ϒ Reduced sense of smell

ϒ Depression/Apathy ϒ Behavioral changes ϒ Psychosis

Body side of symptoms/signs onset:

ϒ Right side (specify: arm/leg/both) ϒ Left side (specify: arm/leg/both) ϒ Symmetric ϒ Head

Year of onset of first symptoms: ……..…..; **Year of diagnosis of Parkinsonism**: ……..……;

Signs Suggestive of Another Diagnosis:

ϒ History of strokes ϒ History of head injury ϒ History of Encephalitis ϒ Hydrocephalus

ϒ Neuroleptic treatment at time of symptoms onset ϒ Sustained remission ϒ Cerebellar signs

ϒ Early unbalance/falls o Symmetric onset of symptoms ϒ Gaze palsy ϒ Hallucinations/delusions

ϒ Dysautonomia (orthostatic hypotension, urinary incontinence, erectile impotence, etc.)

TREATMENT (specific type, treatment duration, side effects)

1) **Levodopa:**
- **Year of Levodopa treatment initiation:** …..……;
- **Response to Levodopa:** ϒ Uneffective ϒ Responsive ϒ Partial ϒ Not given

2) **Other current or previous anti-parkinsonian therapy:**
- **Dopamine agonists** (es. Pramipexole, Ropinirole, etc.) ……..……..……..……..……
- **Amantadine**……..……..……..……..……..……..……..……..……..……..……..……..
- **MAO and/or COMT inhibitors** (es. Selegiline, etc) ……..……..……..……..……..…
- **Anticholinergics** (es. Artane, etc.) ……..……..……..……..……..……..……..……

3) **Others** (including benzodiazepines, antidepressants, neuroleptics).…….……..……..……..…

Side effects ϒ No ϒ Yes If yes, specify…….……..……..……..……

NEUROIMAGING:
- Computed Tomography (CT scan) ……..……..……..……..……..……..……..……..……
- Magnetic Resonance Imaging (MRI) ……..……..……..……..……..……..……..……..……
- Others……..……..……..……..……..……..……..……..……..……..……..……..……

City/Country: ……..……..……..…… Date: ……..……..……..……..

Signature of the physician: ……..……..……..……..……..……..……..……..……..……..……

APPENDIX 2: CONSENT FORM

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

INFORMATION SHEET

Title of Research:
Title of the Study: Quality of life of patients with Parkinson's disease in the Central belt of Ghana

Name(s) and affiliation(s) of researcher(s):
Dr Vida Obese, Komfo Anokye Teaching Hospital

Background:
I am the researcher for a study on "Quality of life of patients with Parkinson's disease in the Central belt of Ghana". You are being asked to volunteer as a participant in this study. This form is designed to provide you with information about this study and to answer any of your questions. This is part of a Fellowship Study in Neurology for Ghana College of Physicians conducted by me at the Neurology Department of Komfo Anokye Teaching Hospital (KATH).

Purpose(s) of research (why is the study being done?):
This study aims to identify the factors that determine the quality of life in patients with idiopathic Parkinsons Disease detected in the neurology clinic of KATH.

Selection of participants:
The study population will be all Parkinson Disease patients receiving treatment from the neurology clinic at Komfo Anokye Teaching Hospital (KATH) and patients attending clinic will be sequentially selected and asked for consent to participate.

Procedure of the research
This study will require 161 participants**.** This study seeks to assess the most prevalent quality of life indicators of Parkinson's' disease patients in the central Belt of Ghana, in terms of mobility, activities of daily living, emotional wellbeing, stigma, social support, cognitions, communication and bodily discomfort. After consent is sought, patients' demographic data and Parkinson Disease Scales will be administered.

Risk(s):
The study protocol involves no risks to you.

Benefit(s*)*
The findings of the study are expected to help provide measures that are responsive to the peculiar socio-cultural needs of Parkinson's disease patients in Ghana. The study is expected to help inform policies and structures to enhance the support and care for Parkinson's Disease patients in Ghana for improved quality of life.

Confidentiality:
All data collected during the course of the study will be kept confidential. You will be assigned a code by which you will be identified throughout this study. No third party shall access to the raw data collected about you.

Voluntariness:
Taking part in this study should be out of your own free will. You are not under obligation to. Participation in research is entirely voluntary

Alternatives to participation:
If you choose not to participate, you can receive the usual treatment given for your illness in this hospital.

Withdrawal from the research:
You may choose to withdraw from the research at any time without having to explain yourself. You may also choose not to answer any question you find uncomfortable or private

Consequence of Withdrawal:
There will be no consequence, loss of benefit or care to you if you choose to withdraw from the study. This will not affect your treatment in this hospital/institution in any way.) Please note however, that if you withdraw at the time that some of the information that may have been obtained from you without identifiers (name etc), may have been modified or used in analysis reports and publications, these cannot be removed anymore. We do promise to make all the effort to comply with your wishes as much as practicable**.**

Costs/Compensation*:*
If you agree to participate to this study, there will be no additional costs to you. All the information that will be collected from and on you will be that which your attending doctors have already documented.

Contacts:
In case you have any question(s) concerning this study, please do not hesitate to contact Dr. Vida Obese, the Principal investigator on this phoneline 0209656459

Further, if you have any concern about the conduct of this study, your welfare or your rights as a research participant, you may contact:

The Office of the Chairman

Committee on Human Research and Publication Ethics

Kumasi

Tel: 03220 63248 or 020 5453785

CONSENT FORM

Statement of person obtaining informed consent:
I have fully explained this research to _____ and have given sufficient information about the study, including that on procedures, risks and benefits, to make an informed decision.

DATE: _____ SIGNATURE: _____

NAME: _____

Statement of person giving consent:
I have read the information on this study/research or have had it translated into a language I understand. I have also talked it over with the interviewer to my satisfaction.

I have read the description of the research or have had it translated into language I understand. I have also talked it over with the interviewer to my satisfaction. I understand that my participation is voluntary. I know enough about the purpose, methods, risks, and benefits of the research study to decide that I want to take part in it. I understand that I may freely stop being part of this study at any time. I have received a copy of this consent form and additional information sheet to keep for myself.

DATE: _____ SIGNATURE/THUMB PRINT: _____

WITNESS' SIGNATURE (if applicable): _____

WITNESS' NAME (if applicable): _____

PARENT/GUARDIAN'S SIGNATURE/THUMB PRINT: _____

PARENT/GUARDIAN'S NAME: _____

APPENDIX 3: ETHICAL CLEARANCE

Kwame Nkrumah
University of Science
and Technology, Kumasi

College of Health Sciences
SCHOOL OF MEDICINE AND DENTISTRY

COMMITTEE ON HUMAN RESEARCH, PUBLICATION AND ETHICS

Our Ref: CHRPE/AP/206/20

24th August 2020

Dr. Vida Obese
Directorate of Internal Medicine
Komfo Anokye Teaching Hospital
Post Office Box 1934
KUMASI.

Dear Madam,

LETTER OF APPROVAL

Protocol Title: "Quality of Life of Patients with Parkinson's Disease in the Central Belt of Ghana."

Proposed Site: Department of Internal Medicine, Komfo Anokye Teaching Hospital.

Sponsor: Principal Investigator.

Your submission to the Committee on Human Research, Publications, and Ethics on the above-named protocol refer.

The Committee reviewed the following documents:

- A notification letter of 7th August 2020 from the Head of Directorate, Internal Medicine, KATH (study site) indicating approval for the conduct of the study at the Department.
- A Completed CHRPE Application Form.
- Participant Information Leaflet and Consent Form.
- Research Protocol; MDS UPDRS Score Sheet.
- Demographic and Clinical Data Records; Beck's Depression Inventory.
- PDQ-39 Questionnaire; Montreal Cognitive Assessment (MOCA).

The Committee has considered the ethical merit of your submission and approved the protocol. The approval is for a fixed period of one year, beginning **24th Sept.,2020** to **23rd Sept.,2021** renewable thereafter. The Committee may, however, suspend or withdraw ethical approval at any time if your study is found to contravene the approved protocol.

Data gathered for the study should be used for the approved purposes only. Permission should be sought from the Committee if any amendment to the protocol or use, other than submitted, is made of your research data.

The Committee should be notified of the actual start date of the project and would expect a report on your study, annually or at the close of the project, whichever one comes first. It should also be informed of any publication arising from the study.

Thank you for your application.

Yours faithfully,

Rev. Prof. John Appiah-Poku.
Honorary Secretary
FOR: CHAIRMAN

Room 7, Block L, School of Medicine and Dentistry, KNUST, University Post Office, Kumasi, Ghana
Tel: +233 (0) 3220 63248 **Mobile:** +233 (0) 20 5453785 **Email:** chrpe.knust.kath@gmail.com/chrpe@knust.edu.gh

APPENDIX 4: RESEARCH INSTRUMENTS

PDQ (English)

PDQ-39 QUESTIONNAIRE

Please complete the following

Please tick <u>one</u> box for each question

Due to having Parkinson's disease, how often <u>during the last month</u> have you....		**Never**	**Occasionally**	**Sometimes**	**Often**	**Always** or cannot do at all
1	Had difficulty doing the leisure activities which you would like to do?	☐	☐	☐	☐	☐
2	Had difficulty looking after your home, e.g. DIY, housework, cooking?	☐	☐	☐	☐	☐
3	Had difficulty carrying bags of shopping?	☐	☐	☐	☐	☐
4	Had problems walking half a mile?	☐	☐	☐	☐	☐
5	Had problems walking 100 yards?	☐	☐	☐	☐	☐
6	Had problems getting around the house as easily as you would like?	☐	☐	☐	☐	☐
7	Had difficulty getting around in public?	☐	☐	☐	☐	☐
8	Needed someone else to accompany you when you went out?	☐	☐	☐	☐	☐
9	Felt frightened or worried about falling over in public?	☐	☐	☐	☐	☐
10	Been confined to the house more than you would like?	☐	☐	☐	☐	☐
11	Had difficulty washing yourself?	☐	☐	☐	☐	☐
12	Had difficulty dressing yourself?	☐	☐	☐	☐	☐
13	Had problems doing up your shoe laces?	☐	☐	☐	☐	☐

*Please check that you have ticked **one box for each question** before going on to the next page*

Due to having Parkinson's disease, how often <u>during the last month</u> have you....		***Please tick <u>one</u> box for each question***				
		Never	**Occasionally**	**Sometimes**	**Often**	**Always** or cannot do at all
14	Had problems writing clearly?	☐	☐	☐	☐	☐
15	Had difficulty cutting up your food?	☐	☐	☐	☐	☐
16	Had difficulty holding a drink without spilling it?	☐	☐	☐	☐	☐
17	Felt depressed?	☐	☐	☐	☐	☐
18	Felt isolated and lonely?	☐	☐	☐	☐	☐
19	Felt weepy or tearful?	☐	☐	☐	☐	☐
20	Felt angry or bitter?	☐	☐	☐	☐	☐
21	Felt anxious?	☐	☐	☐	☐	☐
22	Felt worried about your future?	☐	☐	☐	☐	☐
23	Felt you had to conceal your Parkinson's from people?	☐	☐	☐	☐	☐
24	Avoided situations which involve eating or drinking in public?	☐	☐	☐	☐	☐
25	Felt embarrassed in public due to having Parkinson's disease?	☐	☐	☐	☐	☐
26	Felt worried by other people's reaction to you?	☐	☐	☐	☐	☐
27	Had problems with your close personal relationships?	☐	☐	☐	☐	☐
28	Lacked support in the ways you need from your spouse or partner?	☐	☐	☐	☐	☐
	If you do not have a spouse or partner tick here		☐			
29	Lacked support in the ways you need from your family or close friends?	☐	☐	☐	☐	☐

*Please check that you have ticked **one box for each question** before going on to the next page*

Due to having Parkinson's disease, how often <u>during the last month</u> have you....		***Please tick <u>one</u> box for each question***				
		Never	**Occasionally**	**Sometimes**	**Often**	**Always**
30	Unexpectedly fallen asleep during the day?	☐	☐	☐	☐	☐
31	Had problems with your concentration, e.g. when reading or watching TV?	☐	☐	☐	☐	☐
32	Felt your memory was bad?	☐	☐	☐	☐	☐
33	Had distressing dreams or hallucinations?	☐	☐	☐	☐	☐
34	Had difficulty with your speech?	☐	☐	☐	☐	☐
35	Felt unable to communicate with people properly?	☐	☐	☐	☐	☐
36	Felt ignored by people?	☐	☐	☐	☐	☐
37	Had painful muscle cramps or spasms?	☐	☐	☐	☐	☐
38	Had aches and pains in your joints or body?	☐	☐	☐	☐	☐
39	Felt unpleasantly hot or cold?	☐	☐	☐	☐	☐

*Please check that you have ticked **one box for each question** before going on to the next page*

Thank you for completing the PDQ 39 questionnaire

PDQ (Twi)

PDQ-39 HO NSEM A WOBISABISA

Mesrɛ wo hyehyɛ nea edidi so yi yie

Mesrɛ wo,san adaka baako mu ma asɛmmisa biara

Esiane yare a ɛka obi adwene ma ne werɛ firi biribiara a woanya no nti, mpɛn dodoɔ sɛn na bosome a etwaam no....

	Ebi nsii da	*Ɛntaa nsi*	*Esi dakoro Dakoro*	*Ɛtaa si*	*Esi daa anaa wuntumi nnyɛ koraa*
1. Ná ɛyɛ den ma wo sɛ wobɛyɛ nneɛma a woyɛ de gyigye w'ani no?	☐	☐	☐	☐	☐
2. Ná ɛyɛ den ma wo sɛ wobɛnoa aduane,wobɛpra anaa wobɛhohoro nkukuo?	☐	☐	☐	☐	☐
3. Ná wuntumi nkura edwa baag a nneɛma gu mu?	☐	☐	☐	☐	☐
4. Ɛyɛɛ den maa wo sɛ wobɛnante kilomita baako?	☐	☐	☐	☐	☐
5. Ná ɛyɛ den ma wo sɛ wobɛnante anamɔn ahaasa (300)?	☐	☐	☐	☐	☐
6. Ɛyɛɛ den maa wo sɛ wobɛnante nkakrankakra wɔ fie mpo?	☐	☐	☐	☐	☐
7. Ná ɛyɛ den ma wo sɛ wobɛkɔ nnipa dodoɔ mu?	☐	☐	☐	☐	☐
8. Sɛ obi annka wo ho a, wontumi nnkɔ baabiara?	☐	☐	☐	☐	☐
9. Woyɛɛ basaa anaa ehu kaa wo esiane sɛ wohwee ase wɔ nnipa mu nti?	☐	☐	☐	☐	☐
10. Wohyɛɛ fie saa a wammpue sɛnea anka wopɛ?	☐	☐	☐	☐	☐
11. Ná wo ankasa wontumi ndware?	☐	☐	☐	☐	☐
12. Ná wo ankasa wontumi nsiesie wo ho bere a wodware wieeɛ?	☐	☐	☐	☐	☐
13. Ná wontumi nkyekyere wo mpaboa ahoma anaa wontumi nnhyɛ mpaboa no mpo?	☐	☐	☐	☐	☐

Mesrɛ wo,san adaka baako mu ma asɛmmisa biara

Esiane yare a ɛka obi adwene ma ne werɛ firi biribiara a woanya no nti, mpɛn dodɔɔ sɛn na bosome a etwaam no….

	Ebi nsii da	***Ɛntaa nsi***	***Esi dakoro dakoro***	***Ɛtaa si***	***Esi daa anaa wuntumi nnyɛ koraa***
14. Ná ɛyɛ den ma wo sɛ wobɛtwerɛ yie?	☐	☐	☐	☐	☐
15. Ná ɛyɛ den ma wo sɛ wankasa bɛtete waduane?	☐	☐	☐	☐	☐
16. Ná ɛyɛ den ma wo sɛ wubekura kuruwa a biribi gu mu a wo nsa anwoso amma ebi ammɔ anngu?	☐	☐	☐	☐	☐
17. Wotee nka sɛ woaboto anaa woayɛ basaa?	☐	☐	☐	☐	☐
18. Wotee nka sɛ woayɛ ankonam?	☐	☐	☐	☐	☐
19. Nisuo taataa w'ani ase anaa wotee nisuo?	☐	☐	☐	☐	☐
20. Abufuo ne yaw hyɛɛ wo so?	☐	☐	☐	☐	☐
21. Adwendwen hyɛɛ wo so?	☐	☐	☐	☐	☐
22. Wo daakye ho dadwene ho asɛm haa wo?	☐	☐	☐	☐	☐
23. Wunyaa atenka sɛ ɛnsɛ sɛ woma nkurɔfoɔ hu sɛ wowɔ saa yare yi?	☐	☐	☐	☐	☐
24. Wotwee wo firii nipa dodoɔ a wone wɔn bɛbɔ mu adidi anaa anom?	☐	☐	☐	☐	☐
25. Woyɛɛ basaa wɔ nnipa mu esiane yare yi nti?	☐	☐	☐	☐	☐
26. Sɛnea nkurɔfoɔ yɛɛ wo no haw wo?	☐	☐	☐	☐	☐

Mesrɛ wo,san adaka baako mu ma asɛmmisa biara

(Esiane yare a ɛka obi adwene ma ne werɛ firi biribiara a woanya no nti, mpɛn dodoɔ sɛn na bosome a etwaam no….)

	Ebi nsii da	***Ɛntaa nsi***	***Esi dakoro dakoro***	***Ɛtaa si***	***Esi daa anaa wuntumi nnyɛ koraa***
27. Wone wɔn a wɔbɛn wo paa no ntam yɛɛ basaa?	☐	☐	☐	☐	☐
28. Mmoa a wuhia firi wo hokafo hɔ no bɔɔ wo? (Sɛ wonwareeɛ a ,san adaka yi no mu) ☐	☐	☐	☐	☐	☐
29. Abusuafoɔ anaa nnamfoɔ a wone wɔn bɔ kosua tafere yii ɔmo ani maa wo anaa w'amfii wo?	☐	☐	☐	☐	☐
30. Awia bi wodae a na w'ani nna wo ho so?	☐	☐	☐	☐	☐
31. Na wontumi mmfa w'adwene nsi biribi a woreyɛ te sɛ nhoma a worekenkan anaa TV a worehwɛ so?	☐	☐	☐	☐	☐
32. Wohui sɛ wonntumi nkae ade yie?	☐	☐	☐	☐	☐
33. Wo soo daeɛ huhuuhu,anaa,asɛ nneɛma gyinagyina w'ani so?	☐	☐	☐	☐	☐
34. Wobrɛ wɔ kasa ho?	☐	☐	☐	☐	☐
35. Wohui sɛ, asɛ wontumi ne nkurɔfoɔ mmɔ nkɔmmɔ yie?	☐	☐	☐	☐	☐
36. Wotee nka sɛ nkurɔfoɔ abu wɔn ani agu wo so?	☐	☐	☐	☐	☐
37. Ná wote yaw wɔ wo wedeɛ mu anaa ná wo honam twetwe wo?	☐	☐	☐	☐	☐
38. Ná wo honam ne woapɔ so yɛ wo ya?	☐	☐	☐	☐	☐
39. Awɔ anaa hyew te sii wo so maa wo ho yeraw wo?	☐	☐	☐	☐	☐

Beck's Depression Inventory

1. 0 I do not feel sad.
   1 I feel sad
   2 I am sad all the time and I can't snap out of it.
   3 I am so sad and unhappy that I can't stand it.
2. 0 I am not particularly discouraged about the future.
   1 I feel discouraged about the future.
   2 I feel I have nothing to look forward to.
   3 I feel the future is hopeless and that things cannot improve.
3. 0 I do not feel like a failure.
   1 I feel I have failed more than the average person.
   2 As I look back on my life, all I can see is a lot of failures.
   3 I feel I am a complete failure as a person.
4. 0 I get as much satisfaction out of things as I used to.
   1 I don't enjoy things the way I used to.
   2 I don't get real satisfaction out of anything anymore.
   3 I am dissatisfied or bored with everything.
5. 0 I don't feel particularly guilty
   1 I feel guilty a good part of the time.
   2 I feel quite guilty most of the time.
   3 I feel guilty all of the time.
6. 0 I don't feel I am being punished.
   1 I feel I may be punished.
   2 I expect to be punished.
   3 I feel I am being punished.
7. 0 I don't feel disappointed in myself.
   1 I am disappointed in myself.
   2 I am disgusted with myself.
   3 I hate myself.

8. 0 I don't feel I am any worse than anybody else.
   1 I am critical of myself for my weaknesses or mistakes.
   2 I blame myself all the time for my faults.
   3 I blame myself for everything bad that happens.
9. 0 I don't have any thoughts of killing myself.
   1 I have thoughts of killing myself, but I would not carry them out.
   2 I would like to kill myself.
   3 I would kill myself if I had the chance.
10. 0 I don't cry any more than usual.
   1 I cry more now than I used to.
   2 I cry all the time now.
   3 I used to be able to cry, but now I can't cry even though I want to.
11. 0 I am no more irritated by things than I ever was.
   1 I am slightly more irritated now than usual.
   2 I am quite annoyed or irritated a good deal of the time.
   3 I feel irritated all the time.
12. 0 I have not lost interest in other people.
   1 I am less interested in other people than I used to be.
   2 I have lost most of my interest in other people.
   3 I have lost all of my interest in other people.
13. 0 I make decisions about as well as I ever could.
   1 I put off making decisions more than I used to.
   2 I have greater difficulty in making decisions more than I used to.
   3 I can't make decisions at all anymore.
14. 0 I don't feel that I look any worse than I used to.
   1 I am worried that I am looking old or unattractive.
   2 I feel there are permanent changes in my appearance that make me look unattractive
   3 I believe that I look ugly.
15. 0 I can work about as well as before.
   1 It takes an extra effort to get started at doing something.
   2 I have to push myself very hard to do anything.
   3 I can't do any work at all.

16. 0 I can sleep as well as usual.

1 I don't sleep as well as I used to.

2 I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.

3 I wake up several hours earlier than I used to and cannot get back to sleep.

17. 0 I don't get more tired than usual.

1 I get tired more easily than I used to.

2 I get tired from doing almost anything.

3 I am too tired to do anything.

18. 0 My appetite is no worse than usual.

1 My appetite is not as good as it used to be.

2 My appetite is much worse now.

3 I have no appetite at all anymore.

19. 0 I haven't lost much weight, if any, lately.

1 I have lost more than 2.2kg .

2 I have lost more than 4.5kg.

3 I have lost more than 6.8kg.

20. 0 I am no more worried about my health than usual.

1 I am worried about physical problems like aches, pains, upset stomach, or constipation.

2 I am very worried about physical problems and it's hard to think of much else.

3 I am so worried about my physical problems that I cannot think of anything else.

21. 0 I have not noticed any recent change in my interest in sex.

1 I am less interested in sex than I used to be.

2 I have almost no interest in sex.

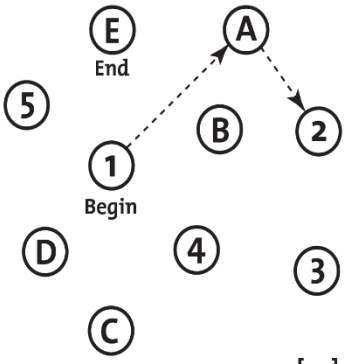
3 I have lost interest in sex completely.

MOCA Test English

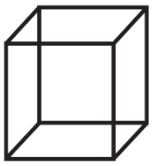
MONTREAL COGNITIVE ASSESSMENT (MOCA)

NAME :
Education : Date of birth :
Sex : DATE :

VISUOSPATIAL / EXECUTIVE — POINTS



Copy cube



[ ] [ ]

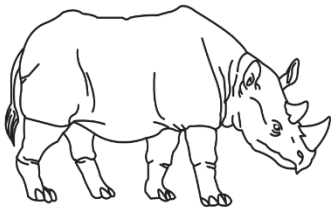
Draw CLOCK (Ten past eleven) (3 points)

[ ] Contour [ ] Numbers [ ] Hands

__/5

NAMING

[ ]



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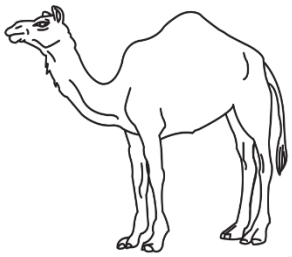

[ ]

__/3

MEMORY — Read list of words, subject must repeat them. Do 2 trials. Do a recall after 5 minutes.

	FACE	VELVET	CHURCH	DAISY	RED
1st trial					
2nd trial					

No points

ATTENTION — Read list of digits (1 digit/ sec.).

Subject has to repeat them in the forward order [ ] 2 1 8 5 4

Subject has to repeat them in the backward order [ ] 7 4 2

__/2

Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors

[ ] F B A C M N A A J K L B A F A K D E A A A J A M O F A A B

__/1

Serial 7 subtraction starting at 100 [ ] 93 [ ] 86 [ ] 79 [ ] 72 [ ] 65

4 or 5 correct subtractions: **3 pts**, 2 or 3 correct: **2 pts**, 1 correct: **1 pt**, 0 correct: **0 pt**

__/3

LANGUAGE — Repeat : I only know that John is the one to help today. [ ]

The cat always hid under the couch when dogs were in the room. [ ]

__/2

Fluency / Name maximum number of words in one minute that begin with the letter F [ ] ____ (N ≥ 11 words)

__/1

ABSTRACTION — Similarity between e.g. banana - orange = fruit [ ] train – bicycle [ ] watch - ruler

__/2

DELAYED RECALL

	Has to recall words WITH NO CUE	FACE	VELVET	CHURCH	DAISY	RED	Points for UNCUED recall only
		[ ]	[ ]	[ ]	[ ]	[ ]	
Optional	Category cue						
	Multiple choice cue						

__/5

ORIENTATION — [ ] Date [ ] Month [ ] Year [ ] Day [ ] Place [ ] City

__/6

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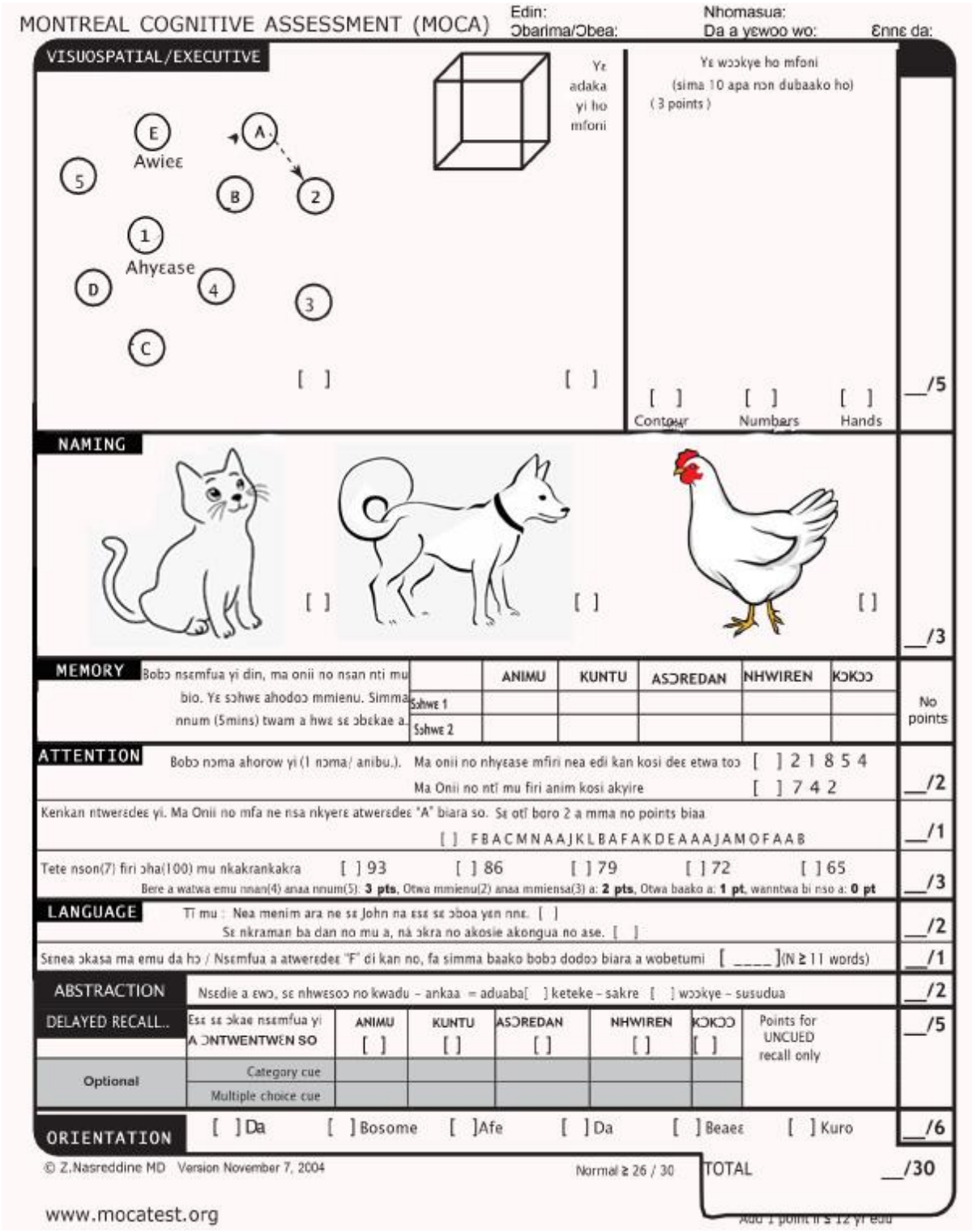
Normal ≥ 26 / 30

TOTAL __/30

Add 1 point if ≤ 12 yr edu

MOCA Test Twi



MONTREAL COGNITIVE ASSESSMENT (MOCA) Edin: Ɔbarima/Ɔbea: Nhomasua: Da a yɛwoo wo: Ɛnnɛ da:

VISUOSPATIAL/EXECUTIVE

Awieɛ Ahyɛase

Yɛ adaka yi ho mfoni

Yɛ wɔkyerɛ ho mfoni (sima 10 apa nɔn dubaako ho) (3 points)

[ ] Contour [ ] Numbers [ ] Hands

__/5

NAMING

[ ] [ ] [ ]

__/3

MEMORY Bobɔ nsɛmfua yi din, ma onii no nsan nti mu bio. Yɛ sɔhwɛ ahodoɔ mmienu. Simma nnum (5mins) twam a hwɛ sɛ ɔbɛkae a.

	ANIMU	KUNTU	ASƆREDAN	NHWIREN	KƆKƆƆ
Sɔhwɛ 1					
Sɔhwɛ 2					

No points

ATTENTION Bobɔ nɔma ahorow yi (1 nɔma/ anibu.). Ma onii no nhyɛase mfiri nea edi kan kosi deɛ etwa toɔ [ ] 2 1 8 5 4

Ma Onii no ntĩ mu firi anim kosi akyire [ ] 7 4 2

__/2

Kenkan ntwerɛdeɛ yi. Ma Onii no mfa ne nsa nkyerɛ atwerɛdeɛ "A" biara so. Sɛ otĩ boro 2 a mma no points biaa

[ ] F B A C M N A A J K L B A F A K D E A A A J A M O F A A B

__/1

Tete nson(7) firi ɔha(100) mu nkakrankakra [ ] 93 [ ] 86 [ ] 79 [ ] 72 [ ] 65

Bere a watwa emu nnan(4) anaa nnum(5): **3 pts**, Otwa mmienu(2) anaa mmiensa(3) a: **2 pts**, Otwa baako a: **1 pt**, wanntwa bi nso a: **0 pt**

__/3

LANGUAGE Tĩ mu : Nea menim ara ne sɛ John na ɛsɛ sɛ ɔboa yɛn nnɛ. [ ]

Sɛ nkraman ba dan no mu a, ná ɔkra no akosie akongua no ase. [ ]

__/2

Sɛnea ɔkasa ma emu da hɔ / Nsɛmfua a atwerɛdeɛ "F" di kan no, fa simma baako bobɔ dodoɔ biara a wobetumi [____](N ≥ 11 words)

__/1

ABSTRACTION Nsɛdie a ɛwɔ, sɛ nhwɛsoɔ no kwadu – ankaa = aduaba[ ] keteke – sakre [ ] wɔkyerɛ – susudua

__/2

DELAYED RECALL..

Optional	Esɛ sɛ ɔkaɛ nsɛmfua yi A ƆNTWENTWƐN SO	ANIMU	KUNTU	ASƆREDAN	NHWIREN	KƆKƆƆ	Points for UNCUED recall only
		[ ]	[ ]	[ ]	[ ]	[ ]	
	Category cue						
	Multiple choice cue						

__/5

ORIENTATION [ ] Da [ ] Bosome [ ] Afe [ ] Da [ ] Beaeɛ [ ] Kuro

__/6

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Add 1 point if ≤ 12 yr edu

24 Item SSCI Scale

SSCI Items	1	2	3	4	5
1=Never; 2=Rarely; 3=Sometimes; 4=Often; 5=Always					
People tended to ignore my good points					
I felt left out of things					
Some people avoided me					
I felt different from others					
People avoided looking at me					
Strangers tended to stare at me					
It was hard for me to stay neat and clean					
some people seemed uncomfortable with me					
I felt emotionally distant from other people					
I tended to blame myself for my problems					
I felt embarrassed about my illness					
I felt embarrassed because of my physical limitations					
I avoided making new friends to avoid telling others about my illness					
I was unhappy about how my illness affected my appearance					
I worried that I was a burden to others					
people made fun of me					
Some people acted as though it was my fault, I have this illness					
I was treated unfairly by others					
People were unkind to me					
I felt embarrassed in social situations					
I worried about other people's attitudes towards me					
I felt embarrassed about my speech					
People with my illness lost their jobs when employers became aware					
I lost friends by telling them that I have the illness					
Overall Score					

Modified Hoehn & Yahr Staging

Modified Hoehn & Yahr Staging

- Stage 0 = No signs of disease
- Stage 1= Unilateral disease
- Stage 1.5= Unilateral plus axial involvement
- Stage 2= Bilateral disease ,no imbalance
- Stage 2.5= Mild bilateral, recovery on pull test
- Stage 3= postural instability but independent
- Stage 4= Severe disability; still able to walk
- Stage 5= Wheelchair or bed bound.

APPENDIX 5: SUPPLEMENTARY RESULTS

MDS-UPDRS Score Sheet

Depressed mood	2.04	1.25	96.9
Fatigue	1.96	1.08	96.9
Hallucinations and psychosis	1.93	1.40	96.3
Constipation problems	1.87	1.11	96.9
Apathy	1.85	1.12	96.9
Pain and other sensations	1.85	1.17	97.5
Sleep problems	1.81	1.22	96.9
Anxious mood	1.79	1.03	96.9
Cognitive impairment	1.76	0.81	93.8
Features of DDS	1.65	0.96	95.0
Daytime sleepiness	1.41	1.39	95.0
Light headedness on standing	1.25	1.25	96.9
Urinary problems	0.94	1.32	97.5
Doing hobbies and other activities	2.34	1.44	97.5
Handwriting	1.97	1.27	97.5
Tremor	1.84	1.17	97.5
Walking and balance	1.69	1.16	97.5
Dressing	1.59	1.18	97.5
Turning in bed	1.55	1.13	97.5
Getting out of bed	1.54	1.22	97.5
Speech	1.52	1.07	97.5
Saliva and drooling	1.36	1.08	97.5
Chewing and swallowing	1.16	1.02	97.5
Eating tasks	1.10	0.98	97.5
Hygiene	0.96	0.82	97.5
Freezing	0.72	1.08	95.0
Finger tapping Right hand	2.16	1.16	100.0
Finger tapping Left hand	2.12	1.14	99.4
Hand movements Left hand	1.87	1.14	100.0
Toe tapping Right foot	1.83	1.20	99.4
Toe tapping Left foot	1.81	1.19	99.4
Gait	1.81	0.82	98.8
Hand movements Right hand	1.80	1.15	100.0
Leg agility Left Leg	1.79	1.14	98.8
Leg agility Right Leg	1.79	1.13	97.5
Speech	1.76	1.24	99.4
Pronation supination movements left hand	1.76	1.11	100.0
Postural tremor Right hand	1.75	0.96	98.1
Postural tremor Right hand	1.75	0.96	98.1
Pronation supination movements Right hand	1.72	1.12	100.0
Kinetic tremor Right hand	1.62	0.97	98.8
Rigidity RUE	1.62	1.09	98.8
Arising Car	1.59	1.11	98.1
Rigidity LLE	1.59	0.97	97.5
Rigidity LUE	1.58	1.00	98.8
Rigidity Neck	1.56	1.03	98.8

Rigidity RLE	1.56	1.00	98.8
Global spontaneity of movement	1.55	1.12	99.4
Rest tremor amplitude LUE	1.54	1.00	97.5
Rest tremor amplitude RUE	1.54	0.96	97.5
Postural Stability	1.54	0.95	98.8
Rest tremor amplitude RLE	1.53	1.00	96.9
Facial Expression	1.50	0.82	98.8
Posture	1.50	0.97	97.5
Kinetic tremor Left hand	1.48	0.93	98.8
Rest tremor amplitude LLE	1.43	1.00	97.5
Constancy of rest	1.39	1.14	98.8
Rest tremor amplitude Lip jaw	1.39	1.03	97.5
Freezing of gait	1.37	0.97	98.1

Post Hoc Analysis of Motor and Non Motor Complications And Quality Of Life

POST HOC ANALYSIS OF MOTOR AND NON MOTOR COMPLICATIONS AND QUALITY OF LIFE						
		Sum of Squares	df	Mean Square	F	Sig.
MOB	Between Groups	36245.306	4	9061.326	26.426	.000
	Within Groups	53491.883	156	342.897		
	Total	89737.189	160			
ADL	Between Groups	19266.386	4	4816.597	11.362	.000
	Within Groups	66133.761	156	423.934		
	Total	85400.147	160			
EMO	Between Groups	8338.827	4	2084.707	3.300	.013
	Within Groups	98555.679	156	631.767		
	Total	106894.506	160			
STI	Between Groups	9155.393	4	2288.848	2.244	.067
	Within Groups	159142.356	156	1020.143		
	Total	168297.748	160			
COG	Between Groups	23790.599	4	5947.650	9.637	.000
	Within Groups	96276.366	156	617.156		
	Total	120066.964	160			
COM	Between Groups	5458.261	4	1364.565	2.469	.047
	Within Groups	86215.865	156	552.666		
	Total	91674.126	160			
PDQ_39_SI	Between Groups	9271.268	4	2317.817	9.671	.000
	Within Groups	37389.815	156	239.678		
	Total	46661.082	160			

Dependent Variable	H&Y	H&Y	Mean Difference (I-J)	Sig.
MOB	1	1.5	5.625	0.903
		2	-5.3365	0.801
		3	-27.6103*	0.000
		4	-35.4779*	0.000
	1.5	1	-5.625	0.903
		2	-10.9615	0.350
		3	-33.2353*	0.000
		4	-41.1029*	0.000
	2	1	5.3365	0.801
		1.5	10.9615	0.350

		3	-22.2738*	0.000
		4	-30.1414*	0.000
	3	1	27.6103*	0.000
		1.5	33.2353*	0.000
		2	22.2738*	0.000
		4	-7.8676	0.312
	4	1	35.4779*	0.000
		1.5	41.1029*	0.000
		2	30.1414*	0.000
		3	7.8676	0.312
ADL	1	1.5	9.84202	0.636
		2	-2.8708	0.983
		3	-21.76287*	0.000
		4	-19.10757*	0.006
	1.5	1	-9.84202	0.636
		2	-12.71282	0.307
		3	-31.60489*	0.000
		4	-28.94959*	0.000
	2	1	2.8708	0.983
		1.5	12.71282	0.307
		3	-18.89207*	0.000
		4	-16.23677*	0.009
	3	1	21.76287*	0.000
		1.5	31.60489*	0.000
		2	18.89207*	0.000
		4	2.65529	0.977
	4	1	19.10757*	0.006
		1.5	28.94959*	0.000
		2	16.23677*	0.009
		3	-2.65529	0.977
EMO	1	1.5	6.70404	0.938
		2	-10.06853	0.536
		3	-14.48181	0.142
		4	-16.15632	0.118
	1.5	1	-6.70404	0.938
		2	-16.77256	0.232
		3	-21.18585	0.057
		4	-22.86036*	0.046
	2	1	10.06853	0.536
		1.5	16.77256	0.232
		3	-4.41329	0.922
		4	-6.0878	0.840
	3	1	14.48181	0.142
		1.5	21.18585	0.057

		2	4.41329	0.922
		4	-1.67451	0.998
	4	1	16.15632	0.118
		1.5	22.86036*	0.046
		2	6.0878	0.840
		3	1.67451	0.998
STI	1	1.5	-7.11138	0.967
		2	-17.84856	0.203
		3	-22.16605*	0.045
		4	-15.7935	0.346
	1.5	1	7.11138	0.967
		2	-10.73718	0.832
		3	-15.05468	0.553
		4	-8.68213	0.920
	2	1	17.84856	0.203
		1.5	10.73718	0.832
		3	-4.3175	0.969
		4	2.05505	0.999
	3	1	22.16605*	0.045
		1.5	15.05468	0.553
		2	4.3175	0.969
		4	6.37255	0.896
	4	1	15.7935	0.346
		1.5	8.68213	0.920
		2	-2.05505	0.999
		3	-6.37255	0.896
COG	1	1.5	-0.64103	1.000
		2	-8.8141	0.649
		3	-18.62745*	0.024
		4	-34.98775*	0.000
	1.5	1	0.64103	1.000
		2	-8.17308	0.842
		3	-17.98643	0.141
		4	-34.34672*	0.000
	2	1	8.8141	0.649
		1.5	8.17308	0.842
		3	-9.81335	0.345
		4	-26.17364*	0.000
	3	1	18.62745*	0.024
		1.5	17.98643	0.141
		2	9.81335	0.345
		4	-16.36029*	0.028
	4	1	34.98775*	0.000
		1.5	34.34672*	0.000

		2	26.17364*	0.000
		3	16.36029*	0.028
COM	1	1.5	-13.64667	0.446
		2	-6.81103	0.798
		3	-14.9298	0.082
		4	-16.40078	0.072
	1.5	1	13.64667	0.446
		2	6.83564	0.894
		3	-1.28314	1.000
		4	-2.75412	0.996
	2	1	6.81103	0.798
		1.5	-6.83564	0.894
		3	-8.11878	0.485
		4	-9.58976	0.414
	3	1	14.9298	0.082
		1.5	1.28314	1.000
		2	8.11878	0.485
		4	-1.47098	0.999
	4	1	16.40078	0.072
		1.5	2.75412	0.996
		2	9.58976	0.414
		3	1.47098	0.999
PDQ_39_SI	1	1.5	0.34702	1.000
		2	-7.26067	0.373
		3	-16.97257*	0.000
		4	-19.28551*	0.000
	1.5	1	-0.34702	1.000
		2	-7.60769	0.542
		3	-17.31959*	0.004
		4	-19.63253*	0.001
	2	1	7.26067	0.373
		1.5	7.60769	0.542
		3	-9.71190*	0.030
		4	-12.02484*	0.010
	3	1	16.97257*	0.000
		1.5	17.31959*	0.004
		2	9.71190*	0.030
		4	-2.31294	0.962
	4	1	19.28551*	0.000
		1.5	19.63253*	0.001
		2	12.02484*	0.010
		3	2.31294	0.962