

# **The experiences of people living with Parkinson's disease**

Mini-dissertation

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MSW (Health Care)

**by**

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*June 2016*

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## **ABSTRACT**

**Title: The experiences of people living with Parkinson's disease**

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Parkinson's disease (PD) is a progressive disorder that affects movement, muscle control and balance. Second only to Alzheimer's disease, PD is one of the most common neurodegenerative disorders in the United States (Lai & Tsui, 2001:135), affecting approximately one million people in the U.S. alone (Parkinson's disease Foundation [PDF], 2009). While the cause of Parkinson's disease remains unknown, there are certain known risk factors associated with the disease. One of the risk factors is increasing age. PD is most frequently associated with older adulthood, affecting one in 100 Americans 60 years and older (PDF). Over the next five decades, the incidence of PD is expected to triple, as the average age of the population increases (Lai & Tsui, 2001:135). Parkinson's disease is a chronic, progressive disorder, with no known cause or promising cure. While substantial information is known about the medical aspect of Parkinson's disease, little is known about the illness experience of living with the disease.

The goal of this study was to explore and describe the experiences of people living with Parkinson's disease. The guiding research question was:

**What are the experiences of people living with Parkinson's disease?**

A qualitative research approach was followed, with a collective case study research design. The population for this study included people who are in the late stage of Parkinson's disease, thus being diagnosed with Parkinson's disease before 2012 and who are receiving support services from Parkinson's Association of South Africa

(PASA). Non-probability purposive sampling was utilized to generate a sample. Ten participants who met the criteria were selected for this study. Semi-structured individual interviews were conducted with participants. Interviews were voice recorded with the permission of the participants and were transcribed. The data gathered were analysed by the researcher and themes and sub-themes were identified. The research findings were presented and critically discussed. Literature control and verbatim quotes were used to support the findings.

The conclusions of this study reflected that the experiences of people living with Parkinson's disease are complex. Throughout the study it was found that Parkinson's disease impacts significantly on the physical, psychological and social well-being of people living with this disease in a number of ways.

The recommendations offered by this study can be used by professionals working in the field of chronic, geriatric and neurodegenerative illnesses to understand the experiences of people living with Parkinson's disease.

## **LIST OF KEY TERMS**

**Parkinson's disease Physical, psychological and social impact of Parkinson's disease**

**Support and interventions**

**Ecosystems perspective**

**Social work in health care**



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## CHAPTER ONE

# GENERAL INTRODUCTION AND ORIENTATION

## TO THE STUDY

### 1.1. Introduction

Epidemiological records have shown that Parkinson's disease is already the second most common neurodegenerative disease of mid-to-late life in developed countries, and it is projected to become increasingly prevalent in developed countries in this century (Burn, 2007:787). Parkinson's disease occurs worldwide, yet little is known about Parkinson's disease in Southern Africa. Great progress has been made in the management of the motor symptoms of Parkinson's disease, but historically little is known about how Parkinson's disease affects people's lived experiences (Dobkin, Allen & Menza, 2007:949).

Parkinson's disease, according to William, Weiner, Shulman and Lang (2013:12), is a degenerative neurologic disease; degenerative meaning the disease increases in severity over time, specifically in the nervous system (William et al., 2013:12). The proposition could then be made that Parkinson's disease is a disease occurring in the nervous system, which progresses over time. Parkinson's disease has been documented since the 19<sup>th</sup> century; it was first described by the English physician, James, as a disease known as "shaking palsy" (William et al., 2013:22).

Once a person is diagnosed with Parkinson's disease, the symptoms of the disease are known to progress slowly over time; it may take years before a person shows the full symptoms of Parkinson's disease, which result to serious disability (William et al., 2013:31). People with Parkinson's disease typically experience a progressive decline in motor function represented by tremors, muscle rigidity, abnormal slowness of movement and postural instability (Jankovic & Asha 2001:113). These symptoms tend to have a significant effect on one's ability to perform daily activities and inevitably affect one's ability to live independently (Schrag, Hovris, Morley, Quinn &

Jahanshahi, 2006:38). Over time, people with Parkinson's disease may lose their ability to navigate through their environment, communicate and perform self-care tasks such as eating and dressing. Further factors complicating self-care are the inconsistency of symptoms and freezing episodes people often experience in the later stages of the disease (Chapuis, Ouchchane, Metz, Gerbaud & Durif, 2005:225). It progressively becomes more difficult for people with Parkinson's disease to perform their daily activities; they often lose the willpower to actually perform them, thus causing a secondary decline in physical function (Bello-Haas, 2002:14; Inkster, Eng, MacIntyre & Stoessel, 2003:158; Scandalis, Bosak, Berliner, Helman & Wells, 2001:40).

Medical and surgical treatments intended to diminish the physical signs and effects of Parkinson's disease are partially helpful, but even with reasonable control of symptoms, people with Parkinson's disease still experience progressive disability (Lieberman, 2002:24). Except for medical writing expounding on the outward manifestations of the disease, there has historically been little exposition in literature with a focus on the psychological and introspective experience of the individual.

Michael J. Fox, the film and television star, has lived with Parkinson's for over two decades. Taking inspiration from the public figure, it is submitted that the combination of a healthy lifestyle, medical intervention and a positive attitude, may render the condition manageable. Michael J Fox discovered he suffered from Parkinson's disease in 1991, but the married father of four did not reveal it publicly for seven years. In his revealing autobiography *Lucky Man* (2003:43), he wrote that his struggles with Parkinson's affected him to such an extent that he started abusing alcohol. Then, in 2000, the year he quit acting full time, he set up the Michael J. Fox Foundation, which, so far, has raised more than R1.56 billion for Parkinson's research.

As the disease progresses and people with Parkinson's disease are less able to manage their own care, the responsibility inevitably falls on family members, friends, or other caregivers who must find ways to deal with the persons' daily needs and functional decline (Charlton & Barrow, 2002:473). Family caregivers are often untrained and unsure of what to do or how to respond to the ever-changing needs of

people with Parkinson's disease; they often feel frustrated, burdened, and depressed (Charlton & Barrow, 2002:473). In addition to motor symptoms, people with Parkinson's disease can experience psychological difficulties such as depression (Reijnders, Weber, Aarsland & Leentjens, 2008:184), anxiety (Walsh & Bennett, 2001:90), apathy (Brown & Pluck, 2002:637), psychosis (Hanagasi & Emre, 2005:140) and problems with impulse control (Weintraub, Koester & Potenza, 2010:590). Such non-motor difficulties can be as, if not more, challenging than motor difficulties, for people with Parkinson's disease (Schneider, Althaus, Backes, & Dodel, 2008:54), as well as for their caregivers. These symptoms and effects are a major contributor to the patients' perceptions of quality of life (Schrag, Jahanshahi & Quinn, 2001:113).

To obtain a better understanding of the psychological difficulties experienced by people with Parkinson's disease, Brown and Pluck (2002:638) highlight that psychological difficulties occur as a direct result of uncontrolled neurobiological progressions within an individual; such as changes in dopaminergic systems (Chaudhuri & Schapira, 2009:470). However, it is argued that there is a need to broaden the understanding of psychological difficulties associated with Parkinson's disease beyond neurobiological models (Lieberman, 2002:32). It is for this reason that the researcher aims to conduct research to gain insight and better understanding of the experiences of people living with Parkinson's disease.

Supporting the need for this study, Frazier (2000:54) confirmed that psychological models have their limitations and their critics and even studies including multiple and comprehensive assessments of psychological and clinical predictors (Simpson, Lekwuwa & Crawford, 2013:167), cannot fully predict psychological outcomes. It therefore appears vital to explore and describe the experiences of people living with Parkinson's disease so as to understand the possible psychological effects it has on a person. This study will be conducted according to the ecological systems theory, which will allow the researcher to include external systems which will provide a broader understanding of the experiences of people living with Parkinson's disease.

## 1.2. Definition of key concepts

The key concepts of the study are defined as follows:

### **Parkinson's disease**

Parkinson's disease is defined by Ronald, Pfeiffer & Wszolek (2009: 21) as "a chronic progressive neurological disease where there is a decreased dopamine production in the substantia nigra and is marked especially by tremor of resting muscles, rigidity, slowness of movement, impaired balance, and a shuffling gait".

### **Experience**

Experience according to Webster's New World College Dictionary (2002:74), refers to "the act of living through an event or events; personal involvement in, or observation of events as they occur." The purpose of this study is to explore and describe the experiences of people living with Parkinson's disease.

## 1.3. Theoretical Framework

Kerlinger in Smart and Paulsen (2011:395), defines theory as a set of interrelated constructs, definitions, and propositions that present a systematic view of phenomena by specifying relations among variables, with the purpose of explaining or predicting phenomena. For the researcher, theory allows for a better understanding of the phenomena and will further enable the researcher to make sense of the research phenomenon. The researcher will make use of the ecological systems theory, propounded by Meyer in 1983 (Ashman, 2011:32).

Ecological systems theory suggests that individuals are embedded in differing levels of expanding environmental settings which, in turn, are surrounded in even larger settings (Bronfenbrenner, 1989 in Silbereisen, Eyferth & Rudinger, 2005:42).

In general, ecological systems theory presents varying levels of environmental influences that impact and interact with an individual's feelings, behavior, and overall

functioning (Okun, 2005:51). Originally conceived by Bronfenbrenner as cited in Silbereisen et al., (2005:41), this theoretical perspective describes one's environment as an ideological Matryoshka doll, each inside the next, with developmental emphasis placed on the relationships and interconnections between each individual and his or her settings. Thus, a person's individual development throughout the life course is strongly affected by ecological influences and the variety of interactions one encounters in his or her environment (Bronfenbrenner, 1989 in Silbereisen et al., 2005:43).

Within ecological systems theory, the predominant environmental context of which an individual develops is comprised of five primary levels: microsystem, mesosystem, exosystem, macro system and the chrono system (Bronfenbrenner, 1989 in Silbereisen et al., 2005:43).

The first system, the microsystem, is defined by Bronfenbrenner as cited in Silbereisen et al., (2005:4), as the system closest to the person and the one in which a person has direct contact, for example a person's work or home. A microsystem typically includes family, peers, or caregivers. Relationships in a microsystem are bi-directional which implies that a person's reactions to the people in their microsystem will affect how they treat them in return. This is the most influential level of the ecological systems theory and as it relates to this study, would be the experiences of people living with Parkinson's disease in their interactions with their significant other and direct family.

The next layer, the mesosystem, is comprised of the linkages and processes taking place between two or more settings, containing the developing person (Bronfenbrenner, 1989 in Silbereisen et al., 2005:44). The mesosystem thus is where a person's individual microsystems do not function independently, but are interconnected and influence one another. This layer could be seen as the general practitioners and specialists from the health sector, working with the person diagnosed with Parkinson's disease.

The third layer, the exosystem, is comprised of settings that do not involve the developing person as an active participant, but in which events occur that affect, or are affected by, what happens in the setting containing the developing person

(Bronfenbrenner, 1989 in Silbereisen et al., 2005:44). This layer includes external decisions that have bearing on the person, but in which they themselves have no participation in the decision making process. In this study this layer could be seen as the development of new technology to improve treatment of Parkinson's disease.

The fourth layer, the macro system, has been redefined by Bronfenbrenner as cited in Silbereisen et al., (2005:44,) as the predominant pattern of micro-, meso-, and ecosystems characteristic of a given culture, subculture, or other broader social context. Bronfenbrenner as quoted in Silbereisen et al.,(2005:44) highlights this system as a societal blueprint for an individual's various levels of cultural and social environments.

Bronfenbrenner's ecological systems theory maintains that the environment is not static and does not affect people uniformly; rather, it is dynamic and ever changing. The last layer suggests that every time the developing person adds or relents some of his/her roles in his/her setting, the entities in the microsystems tend to change (Sven, 2007:42). The contextual shifts, sometimes referred to as ecological transitions, play an instrumental role during lifespan development; examples in this study can refer to early retirement due to incapacity of working. Life changes can either stem from within the developing individual because they choose, recognize and generate their own experiences and settings, or imposed externally. How they respond to these ecological transitions depend on various factors such as their intellectual and physical capabilities, age, personality and environmental opportunities (Sven, 2007:42).

The ecological systems theory will inform the researcher and enable the researcher to explore how systems both determine and are determined by those who make up the system. Once the dynamics of the system are understood, the researcher will then have a better understanding of how best to create positive change in that system, to bring about a better standard of living. Using this theory will assist the researcher to cultivate a holistic view of how different systems are both connected and impacting each other; which consequently will affect the nature of the experiences of people living with Parkinson's disease.

## 1.4 Problem Formulation

The reason for doing this study is to gain insight into the experiences of people living with Parkinson's disease. The researcher's interest in this topic was evoked by personal experience, where a close family member was diagnosed with Parkinson's disease. Observation of changes in different aspects of this family member's life was noted, but the cause, nature and extent of this change was unknown.

The researcher views her study as necessary, as there is a need to develop insight regarding the experiences of people living with Parkinson's disease and expanding literature in this regard. The need for this study was further substantiated with several authors stating that a lack of understanding of Parkinson's disease can manifest as misinterpretation of character (Charlton & Barrow, 2002:474); negative interactions due to stares or avoidance (Hurt, Weinman, Lee & Brown, 2012:1081). These authors explained that such feelings can impact one person's self-identity and self-esteem and this can have as a direct result, reduced social contact and isolation (Frazier, 2000:55). These socially induced experiences are therefore argued to contribute to the psychological difficulties frequently experienced by people with Parkinson's disease, such as depression and anxiety.

The researcher identified that there is a lack of research identifying and discussing the experiences of people living with Parkinson's disease. The need for further study regarding this phenomenon was recently highlighted after the tragic loss of the well-known actor Robin Williams who committed suicide. It is reported that Robin Williams was struggling with depression, anxiety and the early stages of Parkinson's disease. This is one of many examples which make the research imperative, as the diagnosis of this condition can be experienced negatively by people living with Parkinson's disease.

Sekaran (2003:69) defines a problem as any situation where a disparity exists between the actual and the desired ideal states. However, the author makes it clear that a problem is not always something that is wrong within a specific situation or that requires changes to be made immediately. In this study the problem refers to the lack of understanding of the experiences of people living with Parkinson's disease.

While the bulk of the research on Parkinson's disease has focused on the biomedical model, in an effort to understand the medical treatment and focused attempts to relieve symptoms, the research on how people experience Parkinson's disease on a day-to-day basis is much more limited. It is envisioned that this research will contribute to the development of more research studies, specifically focusing on how Parkinson's disease is experienced, through a number of important ways: firstly, by providing a critical review of current research, relevant to the experiences of persons with Parkinson's disease and the effect thereof on the individual and on his or her direct environment; secondly, by critically examining existing opinions and strategies explaining the reality of this challenge in a South African context; thirdly, by obtaining the views and experiences of participants of the study in terms of their experiences of living with Parkinson's disease and the nature thereof. This study will ultimately allow the researcher to improve the understanding of the experiences of persons living with Parkinson's disease, which in turn could be used to postulate ways in which to improve the experience.

Accordingly, the main question this research will attempt to answer is: "What are the experiences of people living with Parkinson's disease?"

## **1.5 The goal and objectives of the research study**

The goal and the objectives for this study were as follows:

### **1.5.1 Goal of the study**

The goal of this study was: to explore and describe the experiences of people living with Parkinson's disease.

### **1.5.2 Objectives**

The researcher aimed to reach the above goal by meeting the following objectives:

- to describe Parkinson's disease;
- to explore and describe the challenges of people living with Parkinson's disease experienced on a daily basis;



- to explore the coping mechanisms of people with Parkinson's disease;
- to identify how environmental factors influencing the management of Parkinson disease;
- to provide conclusions and recommendations for social workers in practice working with people with Parkinsons disease based on the findings.

## 1.6 Research methodology

This research study was qualitative in nature. As stated by Rossman and Rallis (2003:14), qualitative researchers seek answers to questions in the real world by actively gathering their material from the world around them. Bell (2005:6) states that the researcher adopting a qualitative perspective is more concerned with understanding individuals' perceptions of the world. They seek insights rather than statistical interpretations of the world (Bell, 2005:7). This was the predominant approach of the research study.

This study utilised applied research as it has assist ideal, assisting practitioners'toaccomplish tasks. The researcher used applied descriptive research. According to De Vos (2002:109), descriptive research presents a picture of specific details of a situation, social setting or relationship. To realise a qualitative study, the researcher made use of the case study research design. Case study research is focused on examining a unit in its real life context.

In this study, the population refers to the participants about whom the researcher wants to draw a conclusion once the research study has been finalised. For the purpose of this study, the relevant target population were people who are in the late stage of Parkinson's disease, thus having been diagnosed with Parkinson's disease before 2012 and who are receiving support services from Parkinson's Association of South Africa (PASA).The specific sampling techniques in this study was non-probability purposive sampling, as not all members of the population had a chance of being included.

Face-to-face semi-structured interviews were conducted with selected participants who met the criteria for this study. The interview schedule consisted of various themes that focused on the different aspects of Parkinson's disease that can be experienced. The interviews were recorded and transcribed, where after the data were analysed. Themes and sub-themes were generated from the data, which are discussed in depth in chapter three of this research report, together with the research methodology. The research methodology, trustworthiness and ethical considerations are discussed in detail in chapter 3.

## **1.7 Limitation of the study**

Due to the limited scope of the study, the small size of sample (N= 10) and the fact that only a small portion of the Parkinson's disease population could be accessed, the results cannot be generalized. However, the results should provide an indication of what could be expected from a similar sample.

The researcher had to include the main caregivers due to the severe impact on speech of some of the participants. The researcher is of the opinion that, should the interviews have been able to be conducted without the main caretakers, richer descriptive qualitative data would have been generated.

Very little research has been done about the experiences of people living with Parkinson's disease in South Africa, which made it difficult for the researcher to correlate and substantiate the research findings with scientific literature. The researcher, in most instances, had to rely on international studies to control the findings.

## **1.8 Content of the research report**

The contents of the research report have been divided into four chapters. The outlines of these chapters are as follows:

Chapter 1 provided the reader with the general introduction and orientation to the study, including the definition of key concepts, the problem statement and research

question, research goals and objectives, a brief overview of the research methodology, and the limitations to the study.

Chapter 2 will provide an in-depth literature review of Parkinson's disease, namely the incidence, stages, symptoms, management and treatment, and psychological impact on the individual, family and social context.

Chapter 3 describes the research methodology of the study in-depth, including the research approach, type of research and research design. This is followed by the research methods, including the study population, sampling procedures, sample, the methods of data collection and analysis, trustworthiness, pilot study and the ethical considerations. The research findings are discussed according to thematic analysis.

Chapter 4 provides a summary with the purpose of indicating how the goals and objectives of the study were met. Conclusions are drawn and recommendations made for the benefit of social workers in the field of Parkinson's disease.

The following chapter focuses on the literature review.

## CHAPTER TWO

### PARKINSON'S DISEASE

#### 2.1 Introduction

Parkinson's disease is a progressive neurodegenerative disorder that affects 1% of all people over 60 years of age in industrialized countries (Lau & Breteler, 2006:526) and is considered as the second most prevalent geriatric neurodegenerative disorder after Alzheimer's disease (Nussbaum & Ellis, 2003:1356). Parkinson's disease is characterized by motor symptoms, including slowness of movement, shakiness, muscle stiffness, and impaired balance and coordination. In addition to motor features, Parkinson's disease patients also suffer from non-motor symptoms such as neuropsychiatric symptoms (depression, apathy, and anxiety), sleep disorders and autonomic symptoms (bladder disturbances, sexual dysfunction, sweating) as stated by Vingerhoets, Verleden, Satens, Miatton and De Reuck (2003:795). Later during the advanced stages, approximately 80% of Parkinson's disease patients develop dementia, which is an important predictor of mortality in the Parkinson's disease population (Aarmland, Andersen, Larsen, Kragh-Sorensen & Lolk, 2003:389).

The combination of different motor, non-motor, and psychiatric features has made Parkinson's disease a unique chronic condition with lots of question marks and grey areas for the management of patients. Motor disabilities could potentially restrict patients' physical activity and together with non-motor symptoms worsen their quality of life during their lifespan (Andreadou, Anagnostouli & Vasdekis, 2011:915). Moreover, various problems in family life such as increased marital conflict, social isolation, loss of occupation, earlier retirement, and income loss, may also affect their quality of life (Davis, Johnson & Kaltenboeck, 2011:372). Parallel to the normal aging process, Parkinson's disease brings an additional burden for both the patients and the caregivers. Although there is no worldwide consensus on the definition of the elderly, the age of around 60 to 65 is considered to be the beginning of old age, which is roughly equivalent to retirement ages in most countries according to the World Health Organization (2002). Since the average age at onset is 60, the majority of Parkinson's disease sufferers are among the elderly (Van den Eeden, Tanner &

Bernstein, 2003:101), which makes it necessary to adopt Parkinson's disease population with the new concepts on aging.

The phenomenon of Parkinson's disease is quite complex; to get a better understanding of the nature of Parkinson's disease the researcher will critically discuss and analyse relevant literature from various sources. The researcher will look at specific aspects in this chapter such as: The historical development, Parkinson's disease, symptoms, stages, diagnosis, treatment and different care options available to people living with Parkinson's disease.

## 2.2 List of medical terms

The researcher referred to different medical terms throughout the literature review. To avoid confusion and assure clarity these medical terms will be defined next.

**Hypo phonic dysarthria** refers to an abnormally weak voice due to in- coordination of the muscles (Simmons & Tarsy, 2006:56).

**Striatum** is defined in medical terms as a striped mass of white and grey matter in the brain which controls movement and balance (Simmons & Tarsy, 2006:56).

**Akinesia** is a condition characterized by generalized pain associated with movement of any kind (Simmons & Tarsy, 2006:57).

**Dystonia** is a state of abnormal muscle tone resulting in muscular spasm and abnormal posture(Simmons & Tarsy, 2006:57).

**Pallidotomy**is a neurosurgical procedure whereby a tiny electrical probes is placed in the globus pallidus and heated in order to destroy a small area of brain cells(Simmons & Tarsy, 2006:58).

**Restless legs syndrome** is a disorder of the part of the nervous system that causes an urge to move the legs (Goetz et al.,2010:633)

**Ambulation** is defined by Simmons and Tarsy (2006:56) as a technique of postoperative care in which a patient gets out of bed and engages in light activity (such as sitting, standing, or walking) as soon as possible after an operation.

**Pallidotomy** is a surgery aimed at removing cells in the globus pallidus of the brain that are not functioning properly (Goetz et al., 2010:633).

## 2.3 Historical background of Parkinson's disease

Components of possible Parkinson's disease can be found in very early documents, the first clear medical description was written in 1817 by James Parkinson (Parkinson, 1817:7). James Parkinson, an English surgeon, was in 1817 the first to describe the symptoms of the disease as they are known today, named after him in his *Essay on the shaking palsy* (Parkinson, 1817:5), which was based on the observation of six patients. Although he characterized the condition by its motor symptoms, he also recognized non-motor symptoms affecting autonomic function and sleep (Parkinson, 1817:7). It was not until 1861 and 1862 that Jean-Martin Charcot (1825-1893) with Alfred Vulpian (1826-1887) added more symptoms to James Parkinson's clinical description, and then subsequently confirmed James Parkinson's place in medical history by attaching the name Parkinson's disease to the syndrome (Jellinger, 2012:9). Charcot added to the list of symptoms the mask face, various forms of contractions of hands and feet, akathisia as well as rigidity (Jellinger, 2012:10).

In the eighteenth century Jean-Martin Charcot was particularly influential in refining and expanding this early description and in disseminating information internationally about Parkinson's disease. He separated Parkinson's disease from multiple sclerosis and other disorders characterized by tremor, and he recognized cases that later would likely be classified among the Parkinson's syndromes (Jellinger, 2012:11). Early treatments of Parkinson's disease were based on empirical observation, and anticholinergic drugs were used as early as the nineteenth century (Jellinger, 2012:11). The discovery of dopaminergic deficits in Parkinson's disease and the synthetic pathway of dopamine led to the first human trials of levodopa. Further historically important anatomical, biochemical, and physiological studies identified

additional pharmacological and neurosurgical targets for Parkinson's disease and allow modern clinicians to offer an array of therapies aimed at improving function in this still incurable disease (Jellinger, 2012:11).

## **2.4 Symptoms of Parkinson's disease**

Parkinson's disease is referred to as a progressive disorder, this means that the symptoms of the disease gradually worsen over time (a period of years). In Parkinson's disease, symptoms usually appear slowly and, at first, a symptom such as a tremor often only affects one side of the body (Andreadouetal., 2011:918). However, some people will display less common symptom patterns in the early stages of Parkinson's disease, which make their condition less typical and more difficult to recognize. The researcher will focus on both the motor and non-motor symptoms of Parkinson's disease. Reason being that throughout this literature review, the symptoms of Parkinson's disease will become a prominent aspect of how Parkinson's disease is experienced. As already mentioned, there is still no cure for Parkinson's disease to date, thus the treatment of Parkinson's disease primarily focuses on the management of the symptoms of Parkinson's disease. Some of the most common symptoms of Parkinson's disease are described in more detail in this section, in order to better understand the dynamics of Parkinson's disease.

### **2.4.1 Bradykinesia**

Bradykinesia refers to slowness of movement and is the most common clinical feature of Parkinson's disease, although it may also be seen in other disorders, including depression (Berardelli, Rothwell, Thompson & Hallett, 2001:132). Bradykinesia is a hallmark of basal ganglia disorder; it includes difficulties with planning, initiating and executing movement and with performing sequential and simultaneous tasks (Berardelli et al., 2001:2133). The initial manifestation is often slowness in performing activities of daily living and slow movement and reaction times (Cooper, Sagar, Tidswell & Jordan, 1994:518; Giovannoni, Van Schalk Wyk, Fritz & Lees, 1999:626), which may include difficulties with tasks requiring fine motor control (example buttoning, switching gears, writing). Other indicators of bradykinesia include loss of spontaneous movements, gesturing, drooling (Bagheri,

Damase, Lapeyre-Mestre, Cismondo, O'Connell, Senard, Rascol &Montastruc, 1999:15), monotonic and hypo phonic dysarthria (weakness of voice), loss of facial expression, decreased blinking and reduced arm swing while walking (Berardelli et al., 2001:135). Given that bradykinesia is one of the most easily recognizable symptoms of Parkinson's disease, it may become apparent before any formal neurological examination. Bradykinesia can be viewed as symptoms which not only cause physical challenges, but also present emotional challenges to an individual who lives with Parkinson's disease.

#### **2.4.2 Tremor**

Rest tremor is the most common and easily recognized symptom of Parkinson's disease. The most common tremor movement in Parkinson's disease is a back and forth motion of the thumb and first finger known as "pill rolling" (Jankovic & Asha, 2001:38). Rest tremor in patients with Parkinson's disease can also involve the lips, chin, jaw and legs but, unlike essential tremor, rarely involves the neck, head or voice. Characteristically, rest tremor disappears with activity and during sleep. Some people might also report an "internal" shaking that is not associated with a visible tremor (Shulman, Singer, Bean & Weiner, 2004:5).

In addition to rest tremor, many people with Parkinson's disease also have postural tremor that is more prominent and disabling than rest tremor and may be the first manifestation of the disease (Jankovic & Asha, 2001:1614). Parkinson's related postural tremor ("re-emergent tremor") is differentiated from essential tremor in that the appearance of tremor is often delayed after the patient assumes an outstretched horizontal position (Jankovic & Asha, 2001:41). When this symptom reaches its advanced stage, an individual is often faced with daily struggles like handwriting, dressing and other fine motor activities.

#### **2.4.3 Rigidity**

Rigidity is characterized by increased resistance, usually accompanied by the "cogwheel" phenomenon, particularly when associated with an underlying tremor, present throughout the range of passive movements of a limb (flexion, extension or rotation about a joint) (Stamey & Jankovic, 2007:50).



Rigidity may be associated with pain, and painful shoulder is one of the most frequent initial manifestations of Parkinson's disease although it is commonly misdiagnosed as arthritis, bursitis or rotator cuff injury (Stamey&Jankovic, 2007:50).Due to the similarity of symptoms with other diseases besides Parkinson's disease, it is important for individuals presenting this symptom to consult with a specialist to avoid misdiagnosing.

#### **2.4.4 Postural deformities**

Postural deformities resulting in flexed neck and trunk posture and flexed elbows and knees are often associated with rigidity (Ashour & Jankovic, 2006:185). However, flexed posture generally occurs late in Parkinson's disease. Striatal limb deformities (for example striatal hand, striatal toe) may also develop in some people. Striatal hand is characterized by ulnar deviation of the hands, flexion of the joints and extension of the proximal and flexion of the distal joints; striatal foot is characterized by extension or flexion of the toes (Ashour & Jankovic, 2006:185).Through early detection one can argue that individuals suffering from early signs of Parkinson's disease can be informed and educated on the development of postural deformities. Through efficient education and preparation pain management and future treatment can ultimately reduce emotional stressors like accepting one might end up with walking aids.

#### **2.4.5 Postural instability**

Adkin, Frank and Jog (2003:497) stated that postural instability due to loss of postural reflexes is generally a manifestation of the late stages of Parkinson's disease and usually occurs after the onset of other clinical features. The pull test, in which the patient is quickly pulled backward or forward by the shoulders, is used to assess the degree of postural instability(Bronte-Swart, Minn, Rodrigues, Buckley & Nashner 2002:2110). Taking more than two steps backwards or the absence of any postural response indicates an abnormal postural response. Postural instability (along with freezing of gait) may lead to a fall, which is the most common cause of injury in people with Parkinson's disease (Williams, Watt& Lees, 2006:70). Postural instability can be viewed as symptoms which can be manageable in future if the

individual is informed about precautions that can be set in place like avoiding housing with stairs.

#### **2.4.6 Freezing**

Freezing, also referred to as motor blocks, is a form of akinesia (loss of movement) and is one of the most disabling symptoms of Parkinson's disease (Giladi, McDermott & Fahn, 2001:15). Although freezing is a characteristic feature of Parkinson's disease, it does not occur universally (Giladi et al., 2001:15). Freezing most commonly affects the legs of people during walking, but the arms and eyelids can also be involved (Giladi et al., 2001:15). It typically manifests as a sudden and transient inability to move. This may include hesitation when beginning to walk (start hesitation) or a sudden inability to move the feet during specific situations (for example turning or walking through a narrow passage, crossing busy streets, approaching a destination). Freezing is associated with substantial social and clinical consequences for patients. In particular, it is a common cause of falls (Giladi et al., 2001:15).

Five subtypes of freezing have been described: start hesitation, turn hesitation, hesitation in tight quarters, destination hesitation and open space hesitation (Schaafsma, Balash, Gurevich, Bartels, Hausdorff & Giladi, 2003:393). In addition, patients often develop tricks to overcome freezing attacks. This includes marching to demanded activity; stepping over objects (for example a walking stick, cracks in the floor), walking to music or a beat, and shifting body weight (Arias & Cudeiro, 2008:490).

After studying and identifying the most known symptoms of Parkinson's disease, it is evident that Parkinson's disease poses not only physical challenges. Although most of the symptoms can be managed in the future, the importance lies in preparation and precaution. Social workers can assist both the individual and household members on both practical and emotional preparations for the future. The social workers tasks can involve linking families with the right resources, assisting families with possible changes and assuring emotional support throughout this process. Social workers should familiarise themselves with the nature of Parkinson's disease,

in order to provide the most efficient and applicable services to individuals and families.

It is evident that every person with Parkinson's disease is different, not only in how he or she is affected by the disease, but also in how he or she reacts to the life changes that are associated with it. For this reason, treatment of Parkinson's should focus not just on the disease but also on a person's needs and preferences. While a lone physician may be overwhelmed by the complexity involved in treating the many symptoms of

It is evident that every person with Parkinson's disease, a team approach can foster holistic care, drawing on the strengths of individual team members

A team care approach goes beyond treating the movement and non-movement related symptoms of Parkinson's disease. It aims to work "outside the box" to reduce disability, maintain independence and enhance safety. Members of the treatment team concentrate on all aspects of the patient's needs: movement, ability to perform daily activities, communication and social needs, success in relationships, self-awareness, emotional health, wellness and even hobbies. Counselling, education and support are important functions of the team, and comprehensive care is enhanced when the patient takes an active role in his or her care. This combination of individual initiative and group concern can strengthen hope, successfully address issues related to loss and life changes and aid adjustment to daily frustrations and new challenges

## **2.5 Non-motor symptoms**

Despite the emphasis on the motor symptoms of Parkinson's disease, it has been increasingly recognized that Parkinson's disease patients experience several non-motor symptoms (Lim & Lang, 2010:127; Postuma, Aarsland&Barone, 2012:620), which have even greater significance when assessed by quality-of-life measures (Aarsland, Larsen, Tandberg & Laake, 2000:940; Schrag, Jahanshahi & Quinn, 2000:310). The burden of non-motor symptoms tends to increase with age

and disease severity and in the very advanced stage of disease (Erro, Picillo & Vitale, 2013:12). While the progression of motor symptoms has been well characterized, little is yet known about the non-motor symptoms progression (Erro et al., 2013:14).

Non-motor symptoms have been traditionally grouped into different domains, four main domains are recognized, and will therefore be covered accordingly: Neuropsychiatric Sleep; Autonomic (including gastrointestinal, genitourinary, and cardiovascular symptoms), and Sensory and other symptoms (including pain and fatigue). For each of these non-motor domains, the most frequent symptoms will be described.

## **2.5.1 Neuropsychiatric symptoms**

The researcher will briefly discuss below the most well-known neuropsychiatric symptoms associated with Parkinson's disease.

### **2.5.1.1 Depression**

Depression has been found to affect up to 75% of patients with Parkinson's disease (Goetz, Poewe & Rascol, 2004:20; Chaudhuri, Healy & Schapira, 2006:238). A change in mood is a natural reaction to being diagnosed with Parkinson's disease, or developing a particular symptom. However, depression in Parkinson's disease can also be caused by the disease itself lowering the levels of chemicals in the brain that control mood (Pahwa & Lyons, 2013:309). Signs of depression include: a negative view of oneself, the environment and the future; loss of motivation, energy, and interests (including social and sexual); poor sleep and memory; and a decrease in appetite (Poewe, 2006:3). Even though it is common of Parkinson's disease, depression is often not diagnosed and therefore may go untreated (Jankovic as cited in Pahwa & Lyons, 2011:310). Depression is often overlooked by the individual suffering from Parkinson's disease, thus the importance of discussing the possibility of developing depression with individuals and their families is of utmost importance.

### **2.5.1.2 Anxiety**

Anxiety is closely related to the motor fluctuations associated with Parkinson's disease. Patients experience more anxiety in the 'off' period which is a period of akinesia unrelated to the timing of the levodopa dose, and the anxiety may be improved by medication (Chaudhuri et al.,2006:238). Levodopa is the medication most often prescribed by doctors for people diagnosed with Parkinson's disease. The body metabolizes Levodopa to produce dopamine. In addition, patients may experience panic attacks, phobias and generalised anxiety disorder (Chaudhuri et al.,2006:238). Anxiety disrupts sleep, and can also worsen Parkinson's disease symptoms, such as tremor (Chaudhuri et al.,2006:238). Individuals and families should be informed and educated on the possibility of developing anxiety and be provided with appropriate resources on how to manage anxiety should it be experienced.

### **2.5.1.3 Cognitive dysfunction and dementia**

The risk of dementia is approximately six times higher in Parkinson's disease than in a normal, healthy individual (Park & Stacy, 2009:294). A 15 yearlong study, originally directed at determining optimal early treatment for Parkinson's disease, and which subsequently reported on the problems experienced by these patients over the duration of the study period (Hely, Morris, Reid & Trafficante, 2008:838), stated that cognitive impairment was present in 84% of patients and 48% of this group displayed the signs of dementia. Parkinson's disease affects more than one part of the brain and patients experience changes in thought and memory, in addition to the more common movement related symptoms(Hely et al.,2008:838).In early Parkinson's disease, these may include difficulty with concentration, or subtle changes in memory and thinking (Park & Stacy, 2009:294). The ability to plan complex tasks or perform several tasks at once may also be affected. These impairments may gradually progress along with other symptoms of the disease, although it should be noted that medication can also have an effect on thought processes as stated by Hely et al., (2008:838). The possibility of developing dementia as Parkinson's disease progresses should be monitored closely in partnership with the individual, household members and health care teams.

#### **2.5.1.4 Sleep abnormalities**

Sleep disorders are a very common feature of Parkinson's disease with a prevalence ranging from 75% to 98% (Goetz et al., 2004:21). The problem occurs in difficulty in falling asleep, frequent awakening during the night, muscle cramps, dystonia or motor symptoms which involve difficulty turning in bed, motor restlessness or restless legs syndrome (Goetz et al., 2004:21). Features of the sleep disorders of Parkinson's disease includes a fragmented sleep pattern, reduced sleep efficiency, reduced slow-wave sleep, reduced rapid-eye movement sleep and rapid eye movement behaviour disorder (Goetz et al., 2004:21). Although sleep abnormalities can cause tremendous stress on the individual, possible practical management of these symptoms should be discussed in consultation with the specialist and needed should be provided.

#### **2.4.2.5 Rapid eye movement behaviour disorder**

Rapid eye movement behaviour disorder is characterised by a loss of rapid eye movement sleep muscle atonia. It is associated with a disruption of normal REM (rapid eye movement) sleep, as a result of which patients experience jerking and sometimes even violent movements of the limbs which may cause themselves or their partners injury (Goetz et al., 2004:21). Rapid eye movement behaviour disorder poses not only physical challenges but also emotional stressors on intimacy of partners.

#### **2.5.1.6 Excessive daytime sleepiness**

Excessive daytime sleepiness is also a common sleep disorder of Parkinson's disease and affects up to 50% of the population (Ceravolo, Rossi, Kiferle & Bonuccelli 2010: 235). The severity of the excessive daytime sleepiness has no relation to the patients' nocturnal sleep disorders. Factors that contribute to excessive daytime sleepiness include motor disability, the presence of depression or dementia and any concurrent mental illness (Ceravolo et al., 2010:239). Although excessive daytime sleepiness only affects 50% of the population, this symptom should be closely monitored and efficient treatment and education should be accessible to individuals who might suffer from this symptom.

### **2.5.1.7Dysautonomia**

Dysautonomia is a common non-motor symptom of Parkinson's disease. The cause of dysautonomia is degeneration of CNS neurons involved in the control of the autonomic nervous system, as well as the peripheral postganglionic neurons (Ceravolo, et al.,2010:240). Dysautonomia generally presents with the symptoms of orthostatic hypotension, constipation and urinary and sexual dysfunction, all of which can have a negative impact on the patient's quality of life (Ceravolo, et al.,2010:240; Goetz et al., 2004:21). Dysautonomia can be experienced and viewed as a symptom which is not comfortable to communicate about. It is important to not only inform individuals about the possibility to develop this symptom, but also provide a sense of normalcy to lessen the possibility of developing embarrassment.

### **2.5.1.8Constipation**

Constipation is a common symptom of Parkinson's disease. It is caused by the muscles of the bowel moving more slowly than usual, together with the effects of less physical activity and/or a poor diet (Goetz,et al., 2004:21). Constipation is a commonly reported problem of Parkinson's disease and it frequently precedes development of the disease (Ceravolo, et al., 2010:241; Goetz,et al., 2004:21).

### **2.5.1.9Sensory and other symptoms**

#### **Sweating**

Sweating is one of the ways in which the body regulates temperature- the body cools down as water evaporates from sweat on the surface of the skin. Sweating is controlled by the nervous system, and Parkinson's disease (or Parkinson's disease medication) can sometimes interfere with this process, causing the body to produce either too much or too little sweat (Chaudhuri, 2006:241).

#### **Pain**

People with Parkinson's disease may experience cramps, aches, and feelings of numbness, coldness or burning, this most frequently occurs in the legs, although lower back pain and headaches are also common (Chaudhuri, 2006:241).

## Speech and facial expression

Communication between people is an important part of everyday life, making connections outside the home, as well as within in the family. People with Parkinson's disease, might have slow or reduced movement of the muscles, which can result in the face showing less expression than usual (Chaudhuri, 2006:241). These symptoms can sometimes make communication more difficult, and can be misinterpreted as annoyance, disinterest, or as lack of understanding (Chaudhuri, 2006:241). Changes to the function of facial/throat muscles can also affect the voice in some people with Parkinson's disease, producing speech and may be quiet, hoarse, hurried or hesitant (Chaudhuri, 2006:241).

Social workers play an integral role in the multidisciplinary approach to Parkinson's disease and should work collaboratively with the specialist and the rest of the care team to assist individuals in living a quality life. Social workers hone in on the psychological, emotional and logistical coping challenges. As a result, it is expected that social workers support individuals with Parkinson's disease and their families in verbalising and normalizing these experiences and help them plan how to move forward with this complex, chronic disorder.

## 2. 6 Evaluation of Symptoms

A number of rating scales are used for the evaluation of the severity of motor symptoms in patients with Parkinson's disease, but most of these scales have not been fully evaluated for validity and reliability (Ramaker, Marinus, Stiggelbout & Van Hilten, 2002:868; Ebersbach, Baas, Csoti, Mungersdorf &Deuschl, 2006:33).The Hoehn and Yahr scale is commonly used to compare groups of patients and to provide gross assessment of disease progression, ranging from stage 1 (no signs of disease) to stage 5 (wheelchair bound or bedridden unless assisted) Ramaker et al., (2002:869). The Unified Parkinson's Disease Rating scale is the most well established scale for assessing disability and impairment (Goetz, Fahn, Martinez, Poewe, Sampaio, Stebbins, Stern, Tilley, Dodel, Dubois, Holloway, Jankovic, Kulisevsky, Lang, Lees, Leurgans, LeWitt, Nyenhuis, Olanow, Rascol, Schrag, Teresi, van Hilten & LaPelle, 2007:44). Studies making use of Parkinson's disease



scales to track the progression of Parkinson’s disease, suggest that the course of Parkinson’s disease is not linear and that the rate of weakening is variable and more rapid in the early phase of the disease and in patients with the postural instability difficulty of Parkinson’s disease (Jankovic & Asha, 2001:1612; Lang, 2007:950; Post, Merkus, De Haan & Speelman, 2007:1840).The current Parkinson’s scale is undergoing revisions so that the revised scale will be more sensitive to detect small changes and it will integrate non-motor elements of Parkinson’s disease (Goetz et al., 2007:48).

It is evident from current literature that further development in accurate evaluation of symptoms is still posing as an existing need.

## 2.7 Stages of Parkinson’s disease

Parkinson’s disease is classified into stages according to the presentation of symptoms. One way of describing these stages is by using the Hoehn and Yahr scale (Hoehn & Yahr, 1967:433). The Hoehn and Yahr scale breaks down the progression of Parkinson’s disease into different stages, characterised by the symptoms exhibited by the patient and is summarised in Table 2.1. Progression from one stage to the next is thought to occur due to natural disease progression and in the absence of treatment. The researcher will use the scale introduced by Hoehn and Yahr as part of criteria for this study, using only participants who are in/or beyond stage 3 of Parkinson’s disease.

**Table 2.1: Hoehn and Yahr classification of Parkinson’s disease**

STAGE	SYMPTOMS
Stage 1	Unilateral symptoms, minimal or no functional impairment
Stage 2	Bilateral symptoms, but no balance impairment
Stage 3	Bilateral symptoms, mild to moderate disability, but patient still physically independent
Stage 4	Severe disability, but able to walk or stand unassisted
Stage 5	Bed-ridden or confined to a wheelchair unless assisted

Subsequently, each stage will be described briefly.

## **Stage 1**

Stage 1 is the mildest form of Parkinson's disease. At this level, there may be unusual symptoms, but they're not severe enough to interfere with daily tasks and overall lifestyle (Goetz et al., 2007:50). The signs of the disorder are so minimal at this stage that they are often missed. Tremors and other difficulties in movement are generally exclusive to one side of the body during stage 1.

## **Stage 2**

Stage 2 is considered a moderate form of Parkinson's, and the symptoms are much more noticeable than those experienced in stage 1 (Goetz et al., 2007:50). Stiffness, tremors and trembling may be more noticeable, and changes in the facial expression can occur. While muscle stiffness prolongs task completion, stage 2 does not impair balance. Patients at this stage feel symptoms on both sides of the body and sometimes experience speech difficulty (Goetz et al., 2007:50). The progression from stage 1 to stage 2 can take months or even years.

## **Stage 3**

Stage 3 is the mid-stage in Parkinson's disease and it marks a major turning point in the progression of the disease (Goetz et al., 2007:50). Many of the symptoms are the same as those in stage 2, except now loss of balance and decreased reflexes can also occur (Goetz et al., 2007:50). Parkinson's disease significantly affects daily tasks at this stage, but patients are still able to complete them.

## **Stage 4**

In this stage independence separates Parkinson's patients from stage 3 and stage 4. During stage 4 it is possible to stand without assistance, however movement may require a walker or other type of assistive device. Many patients are unable to live alone in this stage of Parkinson's disease because of the significant decreases in movement and reaction times (Goetz et al., 2007:50).

## Stage 5

Stage 5 is the most advanced and debilitating stage of Parkinson's disease. Advanced stiffness in the legs can also cause freezing upon standing. Patients require wheelchairs, and are often unable to stand without falling (Goetz et al., 2007:50).

It is crucial for social workers to familiarise themselves with the different stages of Parkinson's disease, and what each stage entails. Social workers are required to carry out an assessment of needs in order to establish the balances between needs, risks and resources for intervention. Assessment is an ongoing process and, because of the fluctuating nature of Parkinson's disease and the wide variety of symptoms, it may be helpful to access assessment and reviews more frequently, in order to acquire a comprehensive assessment of need. The social worker's role is to develop and establish a package of care that supports choices and needs, while also recognising and negotiate the conflicts that choices and needs can create. The social worker also needs to possess the ability to change approaches if the situation changes over time.

## 2.8 Diagnosis of Parkinson's disease

Patients are diagnosed with Parkinson's disease after a series of neurological examinations and diagnostic tests. Two of the three cardinal symptoms of Parkinson's disease, bradykinesia, tremor and rigidity, need to be present before a diagnosis can be made; however, this is just a guideline (Berg & Poewe, 2012:13).

Parkinson's disease is characterised by the progressive loss of dopaminergic neurons in the substantia nigra of the brain, resulting in dopamine depletion (De La Fuente-Fernandez, 2012:696). Radiotracer neuroimaging such as dopamine transporter (DAT) SPECT (DaTSCAN) is currently being used as a diagnostic tool overseas (De La Fuente-Fernandez, 2012:696). However, the clinical diagnosis of Parkinson's disease has an accuracy of 84% in early disease. This means that the use of the DaTSCAN may not be necessary on a large scale and may be reserved for challenging patients (De La Fuente-Fernandez, 2012:699). In South Africa no tests exist to diagnose Parkinson's disease. The doctor trained in nervous system

conditions (neurologist) will diagnose Parkinson's disease based on the assigned patient medical history, a review of their signs and symptoms, and a neurological and physical examination. According to the NICE (National Institute for Health and Clinical Excellence) guideline, patients suspected of having Parkinson's disease should be referred to a specialist for diagnosis and ongoing follow-up consultations (Stewart, William & Weiner, 2008: 240).

Social workers should be aware of the importance of follow up consultation to monitor the development of the disease. Additional home care visits or follow up appointments may be necessary in order to assist with the continued care.

## **2.9 Managing and treating Parkinson's disease**

The ideal treatment should give brain protection and possibly reversal of the degenerative process that causes the disease (Ahlskog, 2009:21). This is not yet possible and currently, the major emphasis of treatment is on the control of symptoms and prevention or treatment of complications caused by some of the symptomatic medications used. Treatment can be roughly divided into non-pharmacological, pharmacological and neurosurgical approaches, and will be discussed below.

### **2.9.1 Non- Pharmacological treatment**

Because of the highly complex, multifactor spectrum of Parkinson's symptoms, a multidisciplinary team approach is considered to be beneficial to individuals and their families and carers, in order to optimise quality of life and management of symptoms. A brief description of the existed and proposed multidisciplinary services will be discussed next.

#### **2.9.1.1 Physical and occupation therapy**

Jankovic as cited in Pahwa and Lyons (2007:16) state that patients with difficulty in balance and walking should be referred for physical and occupational therapy. The focus here would be on making the patient's environment as safe as possible, and would include walking aids.

### 2.9.1.2 Speech therapy

In instances where there is severe abnormality with speech and swallowing problems, evaluation and treatment by a speech therapist can be of value (Pahwa & Lyons, 2013:16).

### 2.9.1.3 Dietary advice

A well-balanced diet with a high fibre content, as well as sufficient hydration, is advised for all patients (Pahwa & Lyons, 2013:16).

People with Parkinson's disease require access to appropriate food and drinks every day as they can be practically affected by constipation, weight loss and changes to appetite (Miyai, Fujimoto, Ueda, Yamamoto, Nozaki, Saito & Kang, 2000:850). Access to appropriate food facilities should be carefully assessed by a social worker. Possible challenges like the use of kitchen utensils and an oven may present a risk to some people with Parkinson's disease, in this case appropriate referrals to an occupational therapist should be considered.

## 2.9.2 Pharmacological treatment

Pharmacological treatment is central to the management of Parkinson's disease. Unfortunately no treatment has yet been proven to cure the disease, but there are many efficient medications that are able to treat the symptoms of Parkinson's disease and reduce their effects on everyday living (Ahlskog, 2009:79). Medication which is mainly prescribed is summarised below in table format, and those that are often used will be briefly discussed below:

**Table 2.2: Medication prescribed for Parkinson's disease**

NAME	PRESCRIBED	APPLICATION
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<b>Aponorphine</b>	Off day symptoms of Parkinson's disease	Injection under the skin
<b>Pramipexole</b>	Treats Symptoms of Parkinson's disease & Restless Leg Syndrome (RLS)	Tablet
<b>Ropinirole</b>	Treats Symptoms of Parkinson's disease & RLS	Tablet and an extended release (long acting) tablet
<b>Levodopa + Carbidopa</b>	Treats Symptoms of Parkinson's disease	Tablet
<b>Selegiline</b>	Treats Symptoms of Parkinson's disease	Capsule
<b>Bromocriptine</b>	Treats symptoms of hyperprolactinemia	Tablet
<b>Entacapone</b>	Treats Symptoms of Parkinson's disease	Tablet
<b>Rasagiline</b>	Treats Symptoms of Parkinson's disease	Tablet
<b>Co-careldopa</b>	Treats Symptoms of Parkinson's disease & RLS	Tablet
<b>Co-beneldopa</b>	Treats Symptoms of Parkinson's disease	Capsule
<b>Pergolide</b>	Treats Symptoms of Parkinson's disease	Tablet
<b>Talca pone</b>	Treats Symptoms of Parkinson's disease	Tablet
<b>Rotigotine</b>	Treats Symptoms of Parkinson's disease	Patch applied to skin
<b>Amantadine</b>	Treats Parkinson's disease	Capsule & Liquid taken by mouth

(Ahlskog, 2009:79).

The above mentioned medication will be briefly discussed focusing on the purpose and possible side effects of each of these medications.

### 2.9.2.1 Amantadine

Amantadine is used to treat shakiness (tremor), muscle stiffness, and slow movement. Parkinson's disease affects the way a brain co-ordinates the movements of one's muscles, nerve messages to the muscles become slow and abnormal. This leads to symptoms such as shaking (tremor), muscle stiffness, and slow movement. Amantadine is prescribed to help ease these symptoms (Ahlskog, 2009:79). This

medication is usually taken once or twice a day, and might cause blurred vision, dizziness, light-headedness, faintness and trouble sleeping (Ahlskog, 2009:79).

### **2.9.2.2 Entacapone**

Entacapone is used in combination with Levodopa and Carbidopa to treat the end-of-dose “wearing-off” symptoms of Parkinson’s disease, such as stiffness, tremors, muscle spasms, and poor muscle control (Ahlskog, 2009:80). Entacapone is taken with every dose of Levodopa and Carbidopa, up to 8 times a day, and the side effects vary between dizziness, diarrhoea, upset stomach, uncontrollable movements, stomach pain and drowsiness (Ahlskog, 2009:80).

### **2.9.2.3 Tolcapone**

Tolcapone is used in combination with Levodopa and Carbidopa to treat the signs and symptoms of Parkinson’s disease such as stiffness, tremors, muscle spasms, and poor muscle control (Ahlskog,2009:81).Tolcapone increases levels of levodopa in a person’s body. This medication can have side effects of sleep disturbance, excessive dreaming, diarrhoea, dizziness, vomiting and increased sweating (Ahlskog, 2009:81).

### **2.9.2.4 Rasagiline**

Rasagiline improves many of the movement (or motor) symptoms of Parkinson's, as measured by a Parkinson's disease scale. Motor symptoms include tremor, slowness, stiffness, and trouble walking. It works by increasing the amounts of certain natural substances in the brain, which comes as a tablet to take by mouth (Ahlskog, 2009:81). It is usually taken once a day and side effects vary between mild headache, joint or neck pain, heartburn, nausea, vomiting, stomach pain, constipation, weight loss, swollen gums, repeated body movements, lack of energy or sleepiness (Ahlskog, 2009:81).

## **2.9.3 Neurosurgical treatment**

In addition to pharmaceutical medication, other treatments such as brain ablation, deep brain stimulation, cerebral transplantation, and gene therapy have been

suggested as possible avenues of treatment (Shannon,2000:185). Pallidotomy) may help to reduce tremors and abnormal movements (e.g., dyskinesia's, which are often caused by medications), help the effectiveness of dopamine medications, and improve gait and balance (Shannon, 2000:185). However, this procedure does not result in normal functioning, nor does it reduce the need for anti-Parkinsonian medications. The procedure involves a number of risks, including serious injury, personality change, neuropsychological and speech problems. Similarly, thalamotomy may help with tremor and rigidity, but it leaves bradykinesia and gait problems, adding a risk of speech disorder to the list of possible side effects.

Deep brain stimulation is a recent procedure for which there is some evidence for efficacy. Stimulation of the thalamic region helps to alleviate tremors, but other problems may worsen over time and thus require the administration of more medication (Fregni, Simon, Wu& Pascual, 2005:614). Stimulation of the pallidal and sub thalamic nuclei may help bradykinesia and dyskinesia caused by medication side effects. However, there are not many studies attesting to the efficacy of these procedures with the average Parkinson's disease patient, and the studies that do exist indicate that the procedures do not help all impairments (Shannon, 2000:185). A recent meta-analysis found evidence for the efficacy of non-invasive brain stimulation, specifically transcranial magnetic stimulation and electroconvulsive therapy, in improving motor functioning (Fregni et al., 2005:615). Cerebral transplants involve inserting cell tissue into the brain. They are currently of questionable efficacy, and there are numerous ethical and legal issues involved in obtaining and using such tissues (Shannon, 2000:186). Finally, gene therapy is used to control dopamine production, slow the degenerative process, or protect against degeneration. This procedure is currently experimental, and any conclusions about its efficacy may be premature.

In summary, the treatment of Parkinson's disease related impairments involves a balancing of risks of potential side effects against possible benefits. Not one treatment alleviates all of the impairments, and all treatments involve a significant risk of additional physical and/or cognitive problems and side effects. Thus, even when receiving the best treatments available, Parkinson's disease patients are left with a number of impairments (due both to the disease and to the treatment) with



which they must cope. Therefore, additional adjunctive therapies involving diet, exercise, and other physical rehabilitation procedures are often included in the treatment regimen (O'Suilleabhain & Murphy, 2000:198).

Social workers should ensure that home carers are aware of the need to monitor and supervise the correct usage of medication. Social workers should make individuals and their care takers aware of the possibility of forgetting to take medication on time, thus pointing out the importance of close monitoring. Individuals who have no care taker or pose other challenges like no transport should be linked with appropriate to ensure medication is easily accessible and needed support is set in place.

## **2.10 Treatment challenges in South Africa**

Parkinson's disease continues to pose great challenges within South Africa, specifically referring to the economic aspect thereof. Carr, Kies and Fine (2009:756) stated that one of these economic challenges is the significant limitation on availability of newer drugs and surgeries for Parkinson's disease. Substantiating his view is a well-respected professor in the Parkinson's disease community, Dr. Iansek as cited in Carr et al., (2009:757) formulated the following challenges South Africa is faced with regarding the treatment of Parkinson's disease:

### **Lack of specialist in formal training**

There are few neurologists who have trained in Movement Disorder Departments overseas with experience in the management of the condition. The majority of them are general neurologists and provide general neurological services to people in South Africa.

### **Conditions of infrastructure**

There is marked variation in the general condition of public and private hospitals in South Africa. Generally, private hospitals have been found to be better equipped in terms of resources, staffing and infrastructure (McIntyre, Thiede, Nkosi, Mutyambizi, Castillo-Riquelme, Gilson, Erasmus & Goudge, 2007a: 23). Due to a lack of funding

hospital infrastructure is not up to standard, which causes a lack of appropriate services which should be rendered to patients with Parkinson's disease.

### **Lack of specialised health care members**

A major issue of importance to the management of Parkinson's disease is the lack of experienced nurses and allied health professionals in the area. This specifically has an impact on the participation of decision-making regarding matters like drug management. Due to the lack of specialised neurosurgeons, the surgical treatment option known as Deep Brain Stimulation is often utilised by a limited group of patients suffering from Parkinson's disease due to costs as well as the lack of experienced staff.

### **Funding of medical aid scheme**

Lack of funding from both the public and private systems forced patients suffering from Parkinson's disease into situations of major financial restraints. Lack of funding of the government hospitals or the restricted amount of funding available through health insurance schemes for private patients, can result in restriction in medication available to patients suffering from Parkinson's disease.

### **Limited support services in communities**

Although support groups are available the amount of support services available is limited, which often leads to a lack of information to patients and their caregiver's with regards to treatment options. Currently there is only one registered NGO service in South Africa, known as the Parkinson's Association of South Africa (PASA), which offers support services in 3 provinces. These support services are limited in each region due to lack of costs.

## **2.11 Parkinson's disease impact on differ ecological systems**

The ecological systems theory demonstrates the interrelatedness of individuals and their environment. Bronfenbrenner discusses microsystems, mezzosystems and macro systems (Forte, 2007:45). The individual's attitude or personality features can influence the kind of reaction the individual has to a particular environment (Forte,

2007:45). Parkinson's disease affects numerous systems throughout an individual's life. The Ecological systems theory can provide a wider lens that can help explore the multiple factors related to working with people with Parkinson's disease.

### **2.11.1 The micro system**

The micro system is defined as “a term used by social workers to identify professional activities that are designed to help solve the problems faced primarily by individuals, families and small groups. Usually micro practice focuses on direct intervention on a face to face basis or in a therapeutic setting” (Barker, 2005:272). According to Barker (2005:272), within the micro level social workers work to provide direct intervention for the individual, families and small groups. The social worker can help the individual's voice be heard and understood by others. Social workers can assist individuals with education, socialization, and advocacy (Chapin & Opal-Cox, 2001:167). Parkinson's disease can rob individuals of their capabilities. Therefore, social workers can capitalize on the strengths of the unique client and help advocate for the client's needs. Depending on the progression of the disease in a specific individual, the individual could be living in a variety of settings. For example, individuals could be in nursing homes, assisted living or still living in their homes. In order for hope and resilience to be promoted by social worker, the social worker needs to be aware of the certain situations in which the individual is living. By involving the people living with Parkinson's disease with their own care, the client can find their own voice and feel like they have control over their situation.

### **2.11.2 The mezzo system**

The mezzo system is defined as “social work practice primarily with families and small groups. Important activities at this level include facilitating communication, mediation, negotiation, education and bringing people together” (Barker, 2003:272). When working with families, social workers can empower the individuals with the chronic disease and/or the caregiver. The disease causes sudden changes in individual with the disease. Parkinson's disease can significantly alter family dynamics. Sprinzeles (2000:138) and Richardson and Barusch (2006:16) discusses how family members of an individual with a chronic illness like Parkinson's disease often have a negative perception of individual and have feelings of embarrassment or

resentment towards the individual. In many settings, social workers can meet with the family for care conferences to help the family understand the disease and the progression. In these care conferences family members can become disgruntled with each other. The role of the social worker is to mediate discussion about the care of the individual. By bringing the family together and negotiating care, the social worker will help the family feel more supported. Therefore, the family will be able to provide more care to the individual with Parkinson's disease. Feelings of support help promote feelings of hope and resilience. Social workers can also be used throughout the community and in small groups to help educate individuals about Parkinson's and the progression of the disease.

### **2.11.3 The macro system**

The macro system is defined as "social work practice aimed at bringing about improvements and changes in the general society. Such activities include some types of political action, community organization, public education campaigning and the administration of broad-based social services agencies or public welfare departments" (Barker, 2003:257). At the Macro level, social workers can advocate for older adults with policy issues. Parkinson's disease can be costly to the patient and family. The disease can be expensive with medications, doctor's visits, surgeries and fragile care facilities. Social workers can help advocate with changing policies that can help provide more coverage for resources for patients. Some of the resources could include medication, therapies, and surgeries. Social workers can also work to help reduce the stigma associated with having a chronic illness like Parkinson's disease. The symptoms of Parkinson's disease can cause an individual to feel embarrassed or ashamed (Sprinzeles, 2000:139). In order to combat these feelings, social workers can educate individuals within communities to help reduce stigmas that cause these negative feelings. Organizations like National Parkinson's Foundations are able to connect individuals and their families' to resources and other social support systems that can help normalize the experience of the disease.

The ecological framework guided this study in forming the questions used to interview people living with Parkinson's disease. The questions developed for the

qualitative semi-structured interviews in this study will seek to gain reflection of the experiences of people living with Parkinson's disease.

## 2.12 Summary

Parkinson's disease is a chronic and progressive movement disorder, meaning that symptoms continue and worsen over time. The causes are unknown, and although there is presently no cure, there are treatment options such as medication and surgery to manage its symptoms. The incidence of Parkinson's disease increases with age and pose serious implications. Various staging systems have been developed to describe patterns of symptom development in individuals with Parkinson's disease. The five-stage model indicated the subtle onset and progressive nature of Parkinson's disease.

The absence of diagnostic tests for Parkinson's disease makes the early detection of the disease challenging for clinicians. Largely, Parkinson's disease is diagnosed by the magnification of symptoms, clinical examination and psychological assessment. The (DaTSCAN) is currently being used as a diagnostic tool, however, the clinical diagnosis of Parkinson's disease has an accuracy of 84% in early disease.

The major emphasis of treatment is on the control of symptoms and prevention or treatment of complications caused by some of the symptomatic medications used. Treatment vary between pharmacological and neurosurgical options. South Africa is a country faced with significant economic, cultural, political and health-related challenges which evidently negatively impact the management of Parkinson's disease.

The impact of Parkinson's disease on both the individual and family members providing care to a person with Parkinson's disease was found to be multi-dimensional. Parkinson's disease has a powerful physical, emotional and social impact, depending on the severity of the condition.

The following chapter focuses on the research methodology and research findings.

## CHAPTER THREE

# RESEARCH FINDINGS

### 3.1 Introduction

Subsequently, this chapter presents an overview of the research methods, which were utilised to undertake the empirical research of this study, by focusing on the research question, research approach, the type of research, research design, methods of data collection, data analysis and trustworthiness of the qualitative data collected, as well as the ethical considerations. This will be followed by an analysis and interpretation of the research findings.

### 3.2 Goal, objectives and research question

The goal of this study was to explore and describe the experiences of people living with Parkinson's disease.

#### Objectives

The focus of this chapter is specifically on the following objectives, namely: To describe Parkinson's disease; to explore and describe the challenges of people living with Parkinson's disease experience on a daily basis; to explore the coping mechanisms of people with Parkinson's disease; and to identify how environmental factors influence the management of Parkinson disease.

According to Fouché and De Vos (2011:308), researchers need to formulate research questions to guide them in their study. The qualitative approach often utilises research questions, because it is indicative in nature and thus more focused on the understanding rather than explaining the phenomena (De Vos, Strydom, Schulze & Patel, 2011:25).

The following research question has been formulated to reach the goal of the proposed study:

## **What are the experiences of people living with Parkinson's disease?**

### **3.3 Research approach**

As the study envisioned exploring and describing the experiences of people living with Parkinson's disease, a qualitative approach was considered the most relevant and appropriate approach to guide the study, specifically as the focus of the study was on the experiences, opinions and views of the participants. Using the qualitative approach implies that a situation can only be understood and explained by the individuals experiencing it and we, as researchers, can only interpret the findings (Cohen, Manion & Morrison, 2000:66).

Qualitative research helped the researcher to interpret and better understand the complex reality of a given situation and the implications of quantitative data. Utilising the qualitative approach offered more flexibility, allowing greater spontaneity and adaptation of the interaction between the researcher and the research participants.

### **3.4 Research Design**

A qualitative study is based on the research approach being subjective and is aimed at describing the life experiences of the participants and give meaning to those experiences (Burns & Grove, 2005:22). To realise a qualitative study, the researcher will make use of the case study research design. Case study research is focused on examining a unit in its real life context. Case studies investigate and report the complex dynamics and unfolding events, human relationships and other factors in unique instances. A case study also provides the reader with an opportunity to understand how ideas and abstract principles can fit together (Cohen, Manion & Morrison, 2000:80).

Fouché and Schurink (2011) cited in De Vos, Strydom, Fouché and Delport (2011:320), mentions that a case study design should be considered when the focus of the study is to answer "how" and "why" questions; the behaviour of those involved in the study cannot be manipulated; contextual conditions need to be covered because they are believed to be relevant to the phenomenon being studied, otherwise the boundaries between the phenomenon and the context will not be clear.

In this study, the collective case study design was followed to explore and describe the experiences of people living with Parkinson's disease. The collective case study encompasses more than one case "in order to investigate a phenomenon, population, or general condition" (Stake, 2000:437). Since the purpose is to help advance understanding, a collective case study is a grouping of instrumental case studies (Stake, 2000:437). Using a collective case study approach can allow for the possibility of stronger interpretation and "perhaps better theorizing" (Stake, 2000:437). A collective case study was appropriate for this research, seeing that the sample included different people from different areas in Pretoria living with Parkinson's disease and the phenomena under review were the experiences people have regarding living with Parkinson's disease.

### **3.5 Research methods**

#### **3.5.1 Research population, sample and sampling methods**

This section will discuss the research population, sample and sampling methods utilised for this study.

##### **3.5.1.1 Research population**

In this study, the population refers to the participants about whom the researcher wants to draw a conclusion once the research study has been finalised. Identifying the target population requires specifying the criteria that determine which individuals are included and which individuals are not included in the study (Buglear, 2004:20). For the purpose of this study, the relevant target population included people who are in the late stage of Parkinson's disease, thus being diagnosed with Parkinson's disease before 2012 and who are receiving support services from Parkinson's Association of South Africa (PASA) specifically residing in the Pretoria area.

##### **3.5.1.2 Sample and Sample Methods**

In this study the researcher adopted a non-probability sampling technique as it was of more importance to explore and describe the views of people who are living with Parkinson's disease than those who are affected by it. Qualitative researchers use



non-probability sampling as it does not aim to produce a statistical representative sample or draw statistical influences (Ritchie & Lewis, 2003:104). Purposive sampling, which is often employed in exploratory research, was considered the best sampling technique to be followed in this study, because it enables the researcher to select participants who experience Parkinson's disease.

The advantage of using purposive sampling was that it is used in special situations where sampling is done with a specific purpose in mind and where selected cases are especially informative (Maree & Pietersen, 2010:178). One of the disadvantages of using purposive sampling was that the cases selected, are rarely representative of the entire population (Neuman, 2011:268). Nevertheless, the researcher considered purposive sampling to be the relevant sampling technique because the selected participants, i.e. people living with Parkinson's disease, were able to provide valuable information that provided answers to the research question.

The research study was guided by specific selection criteria in the recruitment of the participants, as purposive sampling is guided by parameters that guide the researcher (Strydom, 2011b:329). For this study ten participants were recruited by means of purposive sampling.

The participants were selected based on the selection criteria below:

- Clients of the Parkinson's Association of South Africa (PASA)
- Persons who have lived with Parkinson's disease, classified as the late stage of Parkinson's disease for a minimum of 3 years.
- Must reside in Pretoria
- Must be conversant in English or Afrikaans.
- Can be of any gender, race, and age.

### 3.5.2 Data collection methods

Data collection is a term used to describe the process of preparing and collecting of information as part of a particular study. This information is kept on record and is used to make decisions about the research question (Burns & Groove, 2005:16). Data collection in qualitative research is aimed at creating a comprehensive record of the participants' words and actions to make sure that as little as possible is lost in data analysis (Willig, 2001:10). Semi-structured face-to-face interviews will be used to collect data for this study. Galletta (2013: 62) has noted that semi-structured interviews involve a series of open-ended questions based on the topic areas the researcher wants to cover. Galletta (2013: 62) further noted that the open-ended nature of the question not only defines the topic under investigation, but also provides opportunities for both the researcher and the participants to discuss some topics in more detail. Patton (2002:54) commented that if the participants have difficulty answering a question or provide only a brief response, the interviewer can use cues or prompts to encourage the interviewee to consider the question further. Semi-structured interviews are useful as the research is exploratory and it is not possible to draw up a list of possible pre-codes because little is known about the subject area, which is the motivation for this study (Patton, 2002:55).

Willig (2001:22) argues that well planned and well conducted semi-structured interviews are the result of rigorous preparation. The development of the interview schedule, conducting the interview and analysing the interview data all require careful consideration and preparation. Patton (2002:62) further adds that the comprehensive recording of information in data collection leads to large volumes of data which can be difficult to manage. To prevent data from being lost, confused or misinterpreted the researcher will compile an interview schedule with questions which will guide the interview. Each interview will be voice recorded with the permission of participants.

The researcher's role in this specific aspect of the study is to engage with and encourage participants to share their experiences of living with Parkinson's disease, but to avoid becoming personally involved.

Some of the questions that were included in the interview schedule in order to explore, and understand the experiences of a person with Parkinson's disease, included (see Appendix 3):

- How do you understand Parkinson's disease?
- Since being diagnosed with Parkinson's disease how has life been for you?
- What would a typical day in your life entail, please describe?

On the other hand some of the questions that were asked to participants to identify possible challenges which can be identified included the following:

- What physical changes have you noticed living with Parkinson's disease?
- Are there any challenges you experience in your environment – physical, emotional, cognitive?
- Is there any financial constraint due to Parkinson's disease?

### **3.5.3 Data analysis**

Schurink et al.,(2011:398) state that with computerised data in the age in which we live, quantitative data analysis has become relatively easy. The data, as mentioned by the authors, can be primary data (data collected by the researcher) or existing data (data collected by someone else). For the purpose of this study, the researcher will be using primary data. It has been said that “the purpose of analysis is to reduce data to an intelligible and interpretable form so that the relations of research problems can be studied, tested and conclusions drawn” (Schurink et al.,2011:398). Data analysis is the process of working with the collected data. It involves deciding what to do with the data and how it will answer the research question. Data analysis also includes information on how data will be processed and analysed. In qualitative research, data analysis begins when the data collection commences (Cohen, Manion & Morrison, 2000:36).

### **Step 1: Planning for recording of data**

The question of how to record the interviews is one that has been given much consideration in this study. Schurink et al., (2011:400) state that if the recording of data is systematic and appropriate to the setting and research participants, the result will facilitate the analysis of data. To facilitate the process and ensure richness of data, the researcher will also plan to take notes as participants talk. The researcher feels that taking comprehensive notes may hinder the interview process and prevent the researcher from building rapport with the participants. To address this difficulty, the researcher will note summary comments while the interview is voice recorded. Voice recorded interviews will subsequently be transcribed. The researcher will in so doing, eliminate the possibility of misinterpretation of the summary comments after the interview, as summary comments will be supplemented by transcriptions.

### **Step 2: Data collection and preliminary analysis**

In a qualitative inquiry data analysis is a twofold approach. Firstly it involves the analysis of data at the research site during data collection and secondly it involves data analysis away from the research site. Data analysis tends to be an on-going and interactive (non-linear) process in qualitative research (Schurink et al., 2011:405). The researcher will adopt this two-fold approach.

### **Step 3: Managing and organising the data**

According to Schurink et al., (2011:408) managing of data is the first step in data analysis away from the site. Managing data is a process described by Schurink et al., (2011:406) during which one gathers the volume of material one has collected, and devises some or other system to organise or file it. The researcher will organise the data received into appropriate typed units.

### **Step 4: Reading and writing memos**

After organising the data the researcher will continue to analyse the data to get a feel for the entire database (Schurink et al., 2011:409). To organise data collected through interviews, the researcher will listen to the recorded interviews repeatedly to

get a holistic view of the participant's experiences, thereafter the researcher will identify possible themes and categorise the data according to those themes. Notes will also be made to help the researcher with the analysis of data.

### **Step 5: Coding the data**

Coding data refers to the process where the researcher identifies salient themes, recurring ideas and patterns of belief (Schurink et al., 2011:410). This means that after data is collected the researcher will carefully read the data, line by line, and divide the data into meaningful analytical units.

### **Step 6: Testing emergent understandings**

At this juncture, firstly, the researcher should determine that the relevance of the data is in terms of the research question being explored and secondly, the researcher should determine the probative value for the phenomena being studied (Schurink et al., 2011:415). The researcher will evaluate and determine what data is relevant and what probative weight should be attributed to the data.

### **Step 7: Interpreting and developing typologies**

Interpretation involves the process where the researcher categorises concepts in an effective way (Schurink et al., 2011:418). Data will be interpreted by comparing and contrasting perspectives of the participants, and to reflect on the results with respect to the findings in the literature review.

### **Step 8: Visualising, representing and displaying the data**

The final step in the data analysis process is to represent the data found in the study, in tabular or figure form (Schurink et al., 2011:418). After data is analysed the researcher will write a report on the findings and present it in the report.

#### **3.5.4 Trustworthiness**

Lietz, Langer and Furman (2006:444) purport that trustworthiness is important in qualitative studies as a way of preserving scientific rigour and also managing

subjectivity, by engaging in activities that assist the researcher in giving priority to the meaning of participants over those which are their own. Guillemín and Gillam (2004:275) also agree that social work has an ethical responsibility to conduct qualitative research that is rigorous, and that efforts taken to manage issues or reactivity and bias can help social work researchers to describe qualitative data in a way that is credible. Fawcett and Hearn (2004:205) state that the approach to quantitative research necessitates researchers' values, prejudices, beliefs and attitudes being stated and interrogated, and their likely influence on the research being appraised.

The researcher used the following strategies at different stages of the research process to ensure trustworthiness of the data to reflect that the qualitative research is conducted as closely as possible to reflect the thoughts, feelings and experiences of participants.

#### **3.5.4.1 Reflexibility**

Reflexibility is defined by Horsburg (2003:308) as active acknowledgement by the researcher that his/her own actions and decisions will inevitably impact upon the meaning and context of the experience under investigation. This reflection occurs both in individual thought and perspectives (Johnson & Waterfield, 2004:122).

In order to produce valid and accurate research findings, the researcher conducted a process of introspection regarding her viewpoint and experience as a social worker, working at times with people who are diagnosed with Parkinson's disease. The researcher went through this self-reflection process to ascertain if there was a possibility to be biased in the way research data will be analysed. The researcher took notes, during the interviews and also recorded the interviews conducted with participants. The interviews were recorded so as to allow the researcher to review and verify during data analysis to avoid the influence of the researcher's predetermined knowledge and experience.

The researcher engaged in an extensive dialogue regarding the goal and purpose of the research study with the participants via presenting each participant with an overview of the study and situating herself socially and emotionally in relation to the

participants as a way to ensure reflexivity as purported by Mauther and Doucet (2003:419). The flexibility was a critical part to establish trustworthiness in this study, because acknowledging that one's identity could both help and hinder interpretation of the narrative data, is important (Reich, 2003:353).

#### **3.5.4.2 Peer Debriefing**

Peer debriefing as a strategy, whereby the researcher engages in dialogue with colleagues outside the research study who have experience with the topic or research population, was also implemented to enhance trustworthiness (Lietz, Langer, & Furman, 2006:451). The researcher attended a seminar which PASA on 12 September 2015 to introduce typical characteristics and challenges to experts who provide both therapeutic and medical treatment services to people who are diagnosed with Parkinson's disease. The input provided by these experts led to further reflexivity and questioning that enhance trustworthiness of data (Leitz et al., 2006:452). Researcher used a colleague as a sounding board throughout studies to ensure her empirical findings were accurate.

#### **3.5.4.3 Voluntary participation and guarantee of confidentiality**

The researcher used voluntary participation and guaranteed confidentiality as another strategy for establishing trustworthiness of the research study. According to Lietz et al., (2004:303) in order to encourage subjects to be truthful in their responses and to minimise the chances of subjects intentionally supplying data they believe in being sought, the investigator needs to brief the subjects about the purpose and the method of the study, especially what the subjects are required to do in the experiment, what will happen to the data, and how their confidentiality will be ensured during and after the study. The subjects' participation should be voluntary.

The researcher ensured that information provided by the participants was kept confidential; this process was enforced by the signing of a confidentiality agreement by the researcher. To protect their identity participants included in the research were not called by names but were assigned codes, a method which protected them from possible identification.

The researcher also ensured that all participants who were partaking in the study did so from their own free will and without coercion. The researcher achieved this by informing the participants through the informed consent form that participation in the study is voluntary and that participants have a right not to participate in the study or to withdraw their consent at any given stage of the research study.

### **3.6 Pilot study**

Strydom (2011c:206) mentions that even though the researcher may plan the investigation carefully, the practical situation will never be known until entered into, hence the need for a pilot study process, namely conducting a pilot study (Strydom, 2011c:205). The pilot study can be viewed as the 'dress rehearsal' for the main investigation; a small-scale implementation of the planned investigation as an attempt to bring possible deficiencies to the fore timeously.

The researcher will identify two participants to participate in a pilot study. The researcher will test the interview schedule and the voice recorder and will evaluate the effectiveness thereof. The selected participants who reside in Pretoria used in the pilot study, complied with the sampling criteria. The data gathered was not included part of the main study. Possible challenges and faults in the interview schedule were addressed and adjustments made.

#### **3.6.1 Feasibility of Study**

According to Leedy and Ormrod (2005:110), a "brief pilot study is an excellent way to determine the feasibility of your study." As has already been indicated above, ascertaining the feasibility via a pilot study formed part of the research planning.

Strydom (2011c:238-239) refers to the relevant literature and to interviews with experts in his discussion of the feasibility of the studies. He emphasises that it is important to obtain an overview of the actual, practical situation where the prospective research will be undertaken.

Rubin and Babbie (2001:119) point out that the financial costs of a study are easily underestimated. They have compiled a list of costs, but not all these costs were



relevant to the study. The researcher foresaw that there would be costs in terms of data processing, printing and copying expenses, costs in terms of data collection instruments and professional editing. Allowance for unforeseen costs were made as well. All the cost were personally covered by the researcher.

Time constraints were a major concern for the researcher, who works full time in a timeconsuming working environment. Dedication and motivation were required to implement each additional phase of the research process. Careful planning and strong motivation on the part of the researcher to do the research study, made the research feasible.

According to Rubin and Babbie (2001:119), the need to obtain authorisation in advance for a study can influence its feasibility. As discussed under 'ethical considerations', the researcher obtained informed consent from the participants selected to participate in the study. Before the researcher started to conduct the research study, the research sought the approval from the ResEthicsCommittee of the Faculty of Humanities, University of Pretoria, and ethics approval was granted (see Appendix 1).

## **3.7 Ethical Aspects**

### **3.7.1 Avoidance of harm**

The researcher was obligated to protect participants from physical or emotional harm that may emerge from the study (Strydom, 2011a:115). Babbie (2005:63) mentions that social research should never injure the people being studied. The injury referred to in this sphere of social sciences is mainly of emotional nature (Strydom, 2011a:58).

To ensure that the participants in this study were not harmed the participants have been informed about the purposes and procedures of the study. Should the interview have caused any emotional harm the researcher would have referred the participants to a social worker at Parkinson's Association of South Africa (PASA) branch in Pretoria East.

### **3.7.2 Voluntary participation**

Participation in the study should at all times be voluntary and no one should be forced to participate in a project (Strydom, 2011a:116). This study only included participants who gave consent to participate in the research. Participants were informed that they could withdraw from the study or refuse to answer any questions at any time, should they so wish, without any consequences.

### **3.7.3 Informed consent**

No participants were forced to take part in this study. The researcher ensured that participants had adequate information regarding the research study, by explaining the purpose of the study and the procedure to be followed, before they provided their informed consent (see Appendix 4) (Strydom, 2011a:115). Participants agreed that the research data would be archived for a period of 15 years on UP premises in accordance with UP Policy. Participants consented to the use of an audio recorder in the interviews.

### **3.7.4 Violation of confidentiality/anonymity**

The researcher, as proposed by (Strydom, 2011a:119) ascertained that the information provided by the participants was kept confidential: signing of a confidentiality agreement by the researcher enforced this process. As mentioned previously, in order to ensure anonymity, participants included in the research were not called by name but were assigned codes so that they were protected from identification. However, it was communicated to participants that due to personal interviews, anonymity could not be protected like anonymity of the data. It was explained to participants that data will be securely stored for 15 years by the Department of Social Work and Criminology at the University of Pretoria, according to the stipulations of the University.

### **3.7.5 Debriefing of participants**

Debriefing refers to a specific session at the end of the research study in which the researcher has a debriefing session with every participant. During this session the

participant was provided with the opportunity to work through their experiences (Strydom, 2011a:122). The researcher used this opportunity to minimise harm and to place everything discussed during the interview in context of the research. A social worker at Parkinson's Association of South Africa (PASA) branch in Pretoria East was available for further referral should the participant have required or requested further counselling.

### 3.7.6 Publication of Findings

The researcher informed the participants that the research findings will be submitted through a mini-dissertation and that the findings might be released through publication in a scientific journal. The participants were also informed that if the opportunity arises the research findings might be presented at a relevant conference, because as Fernandez, Kodlish and Weijer (2003:12) contend, results should be offered to all participants, both those who may directly benefit and those who may not benefit directly.

## 3.8 Empirical findings

This section will discuss the research findings. The researcher will present the data obtained from the participants and provide an interpretation thereof. Ten semi-structured interviews were conducted with a total of 10 research participants. The first section, 3.8.1 will focus on the biographical information and the second section 3.8.2 the empirical findings.

### 3.8.1 Biographic information

Subsequently Table 3.1 will provide the biographic information of the participants.

**Table 3.1: Biographic information**

	Age	Gender	Race	Language	Marital status	Mobility	Occupation
<b>Participant 1</b>	72	Male	White	Afrikaans	Married	Walks with walking aid	Retired

<b>Participant 2</b>	75	Female	White	Afrikaans	Married	Walks without walking aid	Retired
<b>Participant 3</b>	76	Female	White	Afrikaans	Single	Walks without walking aid	Retired
<b>Participant 4</b>	70	Male	White	Afrikaans	Married	Walks without walking aid	Retired
<b>Participant 5</b>	70	Male	White	Afrikaans	Married	Walks without walking aid	Retired
<b>Participant 6</b>	69	Male	White	Afrikaans	Married	Walks without walking aid	Retired
<b>Participant 7</b>	76	Male	White	Afrikaans	Divorced &Single	Walks without walking aid	Retired
<b>Participant 8</b>	65	Female	White	Afrikaans	Married	Walks without walking aid	Retired
<b>Participant 9</b>	70	Male	White	English	Married	Walks without walking aid	Retired
<b>Participant 10</b>	69	Female	White	Afrikaans	Married	Walks with walking aid	Retired

As specified in Table 3.1, the average age of the participants was above the age of 60 years at the time of the research. There were ten participants, of whom six were male and four females. Afrikaans was the common language spoken by the participants. Most of the participants were able to walk by themselves, although half of the participants needed walking aids at times. Two participants were living alone with no significant partner to take care of them, whereas eight were married. All of the participants were retired.

### 3.8.2 Themes and sub-themes

Qualitative data is presented according to the themes and sub-themes that were identified during the process of data analysis. In order to voice the views, perceptions and experiences of the respective participants, verbatim quotations will be presented to support the themes and literature substantiation will also be used.

**Table 3.2: Themes and sub-themes**

THEMES	SUB-THEMES
Theme 1: Participants' view on what Parkinson's disease is	Sub-theme 1.1: Participants view on the process of diagnosing the disease Parkinson's.
Theme 2: Participants' view on the impact of Parkinson's disease on their daily lives	Sub-theme 2.1: Participants' view on daily activities. Sub-theme 2.2: Implication on daily life activities.
Theme 3: The emotional effects of Parkinson's disease	Sub-theme 3.1: The effects of Parkinson's disease on self-esteem Sub-theme 3.2: Development of anxiety and fear Sub-theme 3.3: Denial
Theme 4: Physical effects of Parkinson's disease	Sub-theme 4.1: Participants' view on the physical challenges
Theme 5: The social effect of Parkinson's disease	Sub-theme 5.1: Withdrawal from friends Sub-theme 5.2: Loss of quality in friendships Sub-theme 5.3: Loss of interest in activities
Theme 6: Participants' view on their support systems	Sub-theme 6.1: Participants' view on the nature of their support systems
Theme 7: The effect of Parkinson's disease on the family	Sub-theme 7.1: Participants' view on their functioning in their family Sub-theme 7.2: Participants' view on their role in their family
Theme 8: Participants' view on the treatment they receive	
Theme 9: Participants' view on how Parkinson's is perceived by society	
Theme 10: Participants' view on their future	Sub-theme 10.1: Hopes and dreams for the future Sub-theme 10.2: Fear for the future
Theme 11: Advice on coping with Parkinson's disease	Sub-theme 11.1: Accept the diagnosis Sub-theme 11.2: Utilize support systems Sub-theme 11.3: Maintain a positive mind set Sub-theme 11.4: Educate yourself on Parkinson's disease

### 3.8.2.1 Theme 1: Participants' view on what Parkinson's disease is

Participants view on what Parkinson's disease is was predominately linked with physical symptoms of the disease. The overwhelming view seemed to be that Parkinson's disease is best understood as a progressive disorder, which over time takes total control over one's body. This is illustrated by the following verbatim quotes:

- "...Dit is 'n proses wat jou aftakel wat jou fisies aanbetref, jou fisiese vermoë neem heeltemal af..." ("It is a process which affects you physically, your physical abilities decline")
- "...It's a disruption of the signal between the brain and the core muscle responsible for that particular movement..."
- "...Ek verduidelik dit as 'n stadige afbreek van jou vermoëns, dinge wat jy nog kon doen in 'n kort tyd begin nou langer neem, dit raak moeiliker. Asof jou spiere net nie meer wil doen wat jy normaalweg doen..." ("I explain it as a slow breakdown of your abilities, things that you used to do in a short time takes longer now, things become more difficult. It is as if your muscles just do not want to do what you would normally have done")

These views correlate with Welsh (2008:33) who defines Parkinson's disease as "a chronic progressive neurodegenerative disease with main motor symptoms in the form of rigidity, rest tremor, bradykinesia, and postural instability.

Two participants expressed limited interest in the understanding of what Parkinson's disease is. The following comments illustrate this:

- "Ek weet nie juis nie" ("I don't really know")
- "Ek het nog nie baie navorsing gedoen nie,so ek kan nie eintlik sê dit is vir my so ernstige saak nie" ("I haven't done that much research, so I really can't say that it is a serious matter for me")

These comments concur with Stewart et al., (2008:209) who identified a lack of crucial information between neurologists and patients, the authors state that there are 8760 hours in a year and a neurologist's visits for the year may be less than 2

hours, leaving patients with 8758 hours of responsibility to educate themselves on what Parkinson's disease entails, but often these statistics are forgotten.

What the researcher noticed was that participants who struggled to explain what Parkinson's disease means to them, also added that they were either the first generation in their family who was diagnosed with Parkinson's disease or have never known anyone who suffered from Parkinson's disease. In this regard Larsen and Lubkin (2009:25) explained that often information and education about a chronic illness occurs during the acute phase of an illness or during hospitalization or consultation. During this period a person and their family members are often overwhelmed and struggle or are not able to grasp the concept of their illness. Niven and Scott (2003:101) agree by adding that although a person may have listened intently to the instructions and education, he or she may not have been able to internalize and actualize the contents.

### **Sub-theme 1.1: Participants' views on the diagnosis of Parkinson's disease**

When exploring the topic of Parkinson's disease the researcher observed one distinct sub-theme emerge, namely the unexpectedness of the final diagnosis, where the process of diagnosis of Parkinson's disease was mainly linked with a different reason for consultation. The following statements are examples of how this view was voiced:

- "...Ek het eers begin by 'n sportdokter wat 'n sonar gedoen het, ons het gesien daar is 'n klein snytjie in my bi-sep en toe vir 'n lank tyd gedink dit veroorsaak die spontane beweging in my arm..." ("I first went to a sports doctor who did a sonar and we saw that there was a small tear in my bicep and we thought for a while afterwards that, that was the reason for my spontaneous muscle movements in my arm")
- "...Ek het 'n heupvervanging gehad, dit was my tweede een. Met die herstelproses het ek agtergekom ek loop nie soos wat ek gewoonlik geloop het nie. Ek het soveel keer vir die Ortopeed gesê ek loop nie reg nie, hy het nie geweet wat was fout nie..." ("I had a hip replacement, it was my second one. With the recovering process I realised that I wasn't walking like I used to. I told the doctor multiple times that I am not walking normal and he did not know what was wrong")

- “...Ek het in 2012 my dokter gaan sien oor my epilepsie, deur die besoek het ons agtergekom ek het Parkinson’s...” (“I went to see the doctor in 2012 regarding my epilepsy and with this consultation we realised that I had Parkinson’s”)

“...Die dokters het so geraai en geraai ek het een more wakker geword en seer gehad onder my arm, ek was dokter toe, ek het gladnie gebewe nie. Hulle het vir my twee jaar so gehou, hulle het gesê ‘n werwel sit vas. In my derde jaar toe begin ek weer lam raak, en my spraak word aangetas, toe ek weer dokter toe gaan toe sê hy dit is Parkinson’s...” (“I woke up one morning and had pain under my arm and I went to the doctor. I did not shake at all. For two years they kept me like that and told me a vertebra is stuck. In my third year I became numb and my speech was impaired, so I went to the doctor and he told me I have Parkinson’s.”)

Stewart, et al., (2008:791) substantiates the above mentioned challenge by stating that part of the difficulty with making the diagnosis with certainty is the heterogeneity of the disease. Parkinson’s disease comes in many shapes and sizes, and it changes unpredictably which often leads to physicians not recognizing early onset symptoms (Stewart et al., 2008:791).

Participants who specifically noted early signs of Parkinson’s disease before diagnosis made the following statements:

- “...As ‘n mynboukonsultant het ek altyd my ‘laptop’saam metmy gevat, ek het agtergekom ek druk knoppies tweekeer...” (‘As a mining consultant I always took my laptop with me and I realised that I was pressing some buttons twice.’)
- “...Ek kon mos sien en voel wat in my liggaam aangaan en iets was nie reg nie...” (“I could of course see and feel that something was going on with my body and it wasn’t right.”)
- “...Deur die simptome te bestudeer kom ek tot die gevolgtrekking dat die siekte reeds in sedert 1995 sy kop uitgesteek het toe my reuksintuig verdwyn het...” (“When I started researching the symptoms, I came to the conclusion that I already had symptoms of this illness in 1995 when I lost my sense of smell.”)

These views are confirmed by Mosley (2010:250) stating that the diagnosis of Parkinson’s disease will still rely dually on a patient’s awareness that something is not right.



## **Discussion of theme 1**

When diagnosed with a chronic disease it is difficult not to hope for a cure or for a miracle to relieve the symptoms and progression of the disease. Boss (2006:46) discussed how an individual with a chronic illness like Parkinson's disease is often left wondering why they were diagnosed instead of someone else. The participants in the current study also discussed the grief and frustration associated with a Parkinson's disease diagnosis. Boss (2006:46) explained the importance of helping the individual process and find meaning in the diagnosis. These findings correlate with the literature of the ecological systems theory, specifically the microsystem in terms of an individual's exposure to chronic illnesses prior diagnosis.

The empirical findings could be linked to the ecological systems theory by means of specifically focusing on the microsystem. In this system the findings indicated that the individual's experiences, feelings and thought ultimately affected the individual's perspective towards living with Parkinson's disease.

### **3.8.2.2 Theme 2: Participants' view on daily activities as a crucial aspect of their lives**

Activities of daily living is seen as routines what we normally do as part of our daily lives. Pfeiffer, Wszolek and Ebad (2013:1256) explained that in advanced Parkinson's disease, the routine activities of dressing, hygiene, and feeding become increasingly slow and ponderous. Depending on the severity of the disease, many people with Parkinson's disease are able to go independently about their activities of daily living (Stewart et al., 2008:783). The views on participants' daily activities were obtained by exploring the nature of daily activities and the adjustments made to their daily lives after being diagnosed with Parkinson's disease.

#### **Sub-theme 2.1: Participants' view on their normal daily activities**

Daily activities and routines are important to the lives of people living with Parkinson's disease. Participants therefore had very specific views on detailed identified struggles they have to overcome daily in their normal activities. The nature of daily activities and the manner in which these activities are conducted have

changed radically. Whereas daily activities are normally viewed as a subconscious activity, it became evident that the participants changed this mind-set to a conscious level. Almost all participants had similar views on the nature of their daily activities on their lives and the frustration experienced in these activities. They highlighted the following:

- “...Ek staan op met ‘n gesukkel want my spiere is baie styf dan gaan maak ek tee en ek en my man eet beskuit. Partykeer kan ek dit dra, partykeer nie ek wil nie hê hy moet my altyd help nie. Ek gaan sit dan op die bed en kyk tv, wat verskriklik erg is. Ek is ‘n buitemens, diere, plante ens...en nou moet ek sit en tv kyk...” (“I struggle to get out of bed in the morning, because of the stiffness in my muscles. Then I go and make tea and my husband and I have rusks. Sometimes I can carry it and sometimes not. I don’t want to depend on him to help me all the time, then I usually go and sit on the bed and watch television which is terrible for me. I am a nature person, animals, plants etc. and now I have to sit and watch television.”)
- “...Elke dag is daar ten minste een ding wat ek probeer doen...” (“Everyday there is at least one thing I try to do.”)
- “...Wat my pla is daar is so baie dinge wat ek wil doen, maar my liggaam voel nie dat ek dit kan doen nie...” (“What bothers me is that there is so much I want to do, but my body doesn’t feel like I can do it.”)
- “... Ek stap gereeld, gister het ek alleen gestap en ook ‘n ander roete gestap wat ‘n erge steil was ek het toe geval. So het ek agtergekom ek kan nie meer stap soos wat ek gestap het nie, mens se stap kan binne ‘n week verander...” (“I walk regularly and yesterday I went for a walk on my own at a new walking trail that was very steep, and I fell. So I realised that I can’t walk anymore like I used to. Your walking can change in a week.”)
- “...As ek klaar ontbyt geëet het moet ek gaan lê omdat ek so moeg is, een ding van Parkinson’s is mens kry baie krampe, so erg dat ek ook meestal deur die dag moet gaan lê...” (“When I finished eating breakfast I always have to go and lie down, because I am tired. One thing about Parkinson’s is that you get a lot of cramps, so bad that I have to go and lie down in the middle of the day.”)

## **Sub-theme 2.2: Participants' views on adjustments made to their daily activities**

The needed adjustment to daily activities due to Parkinson's disease was implied in the abovementioned sub-theme. This is an important aspect that requires more in-depth discussion. Reference was made to the predominant experience of fear in relation to the impact on daily activities. In this regard participants mentioned that Parkinson's disease often leaves one with more challenges than opportunities. The following comments were echoed by more than one participant:

- "...Ek het ophou geleenthede aan te gryp om rede ek twyfel in my vermoens..." ("I stopped taking opportunities, because I started doubting my abilities.") "Ek dink Parkinson's skep meer uitdagings, om nog te kan by bly met jou eie verwagtinge" ("I think Parkinson's creates more challenges to try to keep up with your own expectations.")
- "...I've been an active sportsman all my life, giving up my sport abilities was a big disappointment for me because I still have the passion for sports and the willingness to exercise, but I can't..."

Participants further mentioned that it is quite common to at times still try activities even with the knowledge that the likelihood of success is null and often attempts might result in hurting themselves. This behaviour is often rooted in the denial of how severe Parkinson's can impact one's ability to perform what was once seen as normal activities as illustrated by the following quotes(Ahlskog, 2009:9).

- "...ek en my man sit baie keer vas as ek aantrek, hy sê ek gebruik verkeerde hand en ek sal dan vir hom sê"los my", want dit is hoe ek oorspronklik dit gedoen het al die jare...Parkinson's voel of hy alles van my wegvat..." ("My husband and I will have quarrels when I have to get dressed. He says I use my wrong hand and I will tell him to leave me alone, because that is the way I did it originally all the years.")
- "...ek het my tweede kar afgeskryf voor ek die breinstimulasie operasie gekry het, ek hoofsaaklik weet ek het daai ongeluk veroorsaak ek wou nie aanvaar ek verloor beheer oor my simptome nie..." ("I wrote off my second car before I had the brain

stimulation operation. Mainly I know what caused the accident, but I didn't want to accept that I was losing control over my symptoms.”)

- “...when I was forced to stop doing martial arts I thought fine, I'll keep myself busy with cycling, but I used to faint while cycling I had to accept that sport was out of the picture...”

It seems as if the impact of Parkinson's disease on a person's daily activities can be summarised in the words of one participant:

- “...Ek dink jy moet taamlik guts hê om saam met Parkinson's te leef...” (“I think that you should have guts to be able to live with Parkinson's.”)

## **Discussion of theme 2**

It is evident from the above mentioned findings that participants suffering from Parkinson's disease are constantly losing aspects of their daily living capabilities, dignity and ultimately their identity. The progression of the disease is ambiguous and can occur slowly or very quickly. The individual's attitude or personality features can influence the kind of reaction the individual has to particular environment. Parkinson's disease can rob individuals of their capabilities. Therefore, social workers can capitalize on the strengths of the unique client and help advocate for the client's needs. Depending on the progression of the disease in a specific individual, the individual could be living in a variety of settings. For example, individuals could be in nursing homes, assisted living or still living in their homes. In order for hope and resilience to be promoted by social worker, the social worker needs to be aware of the certain situations in which the individual is living. By involving the client with their own care, the client can find their own voice and feel like they have control over their situation. Thus this supports the appropriateness of the ecological systems stating that individuals constantly engage in transactions with other humans and with other systems in the environment, and that these individuals and systems reciprocally influence each other (Hepworth, Rooney, Rooney, Strom-Gottfried & Larsen, 2013:15). Considering this perspective, comprehensively understanding and actively considering your client's environment is a crucial social work skill.

### 3.8.2.3 Theme 3: The emotional effects of Parkinson's disease

The feelings elicited by the questions dealing with emotional well-being, present a range of responses from participants. The emotional effect on participants was obtained by exploring the effects of Parkinson's disease on the self-esteem and the development of fear and anxiety.

#### Sub-theme 3.1: The effects of Parkinson's disease on self-esteem

The participant's responses with regards to the effect of Parkinson's disease on their self-esteem were divided. Some of the participants were overwhelmed by the effect of Parkinson's disease on their self-esteem and made them feel different to the view they once had of themselves. The majority of participants realized that Parkinson's disease had the potential to lower their self-esteem; however they were aware of the possibility and consciously decided that they would not allow it to affect their views on the self.

Three out of the ten participants were deeply affected by Parkinson's disease and described how it greatly affected their self-esteem and consequently their emotions. Participants described how Parkinson's disease overtook their identity and how this made them feel:

- "...jy is soos 'n kind...mens se ego kry baie seer..." ("You're like a child, your ego gets bruised.")
- "...Parkinson's voel of hy alles van my af wegvat..." ("Parkinson's feels like it takes everything away.")
- "...ek het baie meer negatief geraak vandat ek gediagnoseer is..." ("I became much more negative after I was diagnosed.")

Participants, who portrayed that Parkinson's disease contributed to a stronger sense in their identity, described this as related to their initial positive self-esteem and the fact that they felt in control. They knew that they will be able to overcome the potential impact Parkinson's disease might have on their self-esteem. Participants described their experiences as follows:

- “...ek het dit baie positief benader van die begin af, dit is watse mens ek is...alles het nie altyd positief uitgewerk nie maar as dit nie was vir my positiwiteit was ek lankal nie meer hier nie...” (“I approached it very positively from the start as that is the sort of person I am. Everything did not always work out positively, but if it wasn’t for my positive nature I would have been gone a long time ago.”)
- “...ek dink die manier hoe ek dinge nog altyd verwerk het, het my baie gehelp om deur Parkinson’s te kom...ek dink dit moet baie moeilik wees om dinge nie te kan aanvaar nie...” (“I think the way I have always processed things helped me to get through Parkinson’s. I think it must be very difficult not to be able to accept things.”)

Self-esteem is best understood as the holistic evaluation of the overall worth that people feel about themselves (Steiger, Allemand, Robins & Fend, 2014:325). The self-esteem of a chronically ill person can be very delicate and easily influenced by a number of factors (Wild & Swartz, 2012:334). The study supported the risk mentioned by the above authors. It also indicated that people suffering from a potential threat to their self-esteem; like Parkinson’s disease, would withstand the negative effects of Parkinson’s disease by means of a deliberate decision not to have Parkinson’s disease affect their views of themselves.

### **Sub-theme 3.2: Development of anxiety and fear**

A number of participants have indicated that they struggled with anxiety as a result of living with Parkinson’s disease. For some participants the anxiety manifested in isolating themselves from society. One participant stated that her dependency on her husband resulted in her fear to be alone and doubting herself constantly. Participants specifically stated that they suffer from anxiety due to the fear of physical challenges. The following comments illustrate this point:

- “...ek wil nie meer ry nie al kan ek, ek is onseker oor myself ...” (“I don’t want to drive anymore even if I am still able to. I doubt myself.”)
- “...ek kry angsaanvalle...alles voel net altyd te naby aan my...” (“I get anxiety attacks; everything just always feels too close to me.”)
- “...ek sonder myself vreeslik af, ek was altyd ‘n laggende, liefdevolle helpende mens en nou maak mense my bang...” (“I isolate myself completely, I was always a friendly, compassionate and generous person and now people scare me.”)

The researcher explored the development of fear amongst participants' as it became evident that this was a prominent feeling shared by a majority of participants. Fear was initially developed due to physical harm like injury, however developed into anxiety as time went on. The following verbatim quotes illustrate this point:

- "...ek lewe in so 'n vrees, wat gaan met my gebeur as my man nie meer daar is vir my nie..." ("I live with such a fear of what is going to happen to me when my husband isn't there for me anymore.")
- "...daar is 'n konstante onsekerheid binne my wat my keer om geleenthede aan te gryp..." ("There is a constant uncertainty in me that stops me from taking opportunities.")
- "...ek kan nie eers meer kerk toe gaan nie as gevolg van my vrees vir val..." ("I can't even go to church anymore, because of my fear of falling.")

Researchers believe that anxiety in Parkinson's disease may be due to the underlying changes in brain chemistry and circuitry that are caused by the disease itself (O'Suilleabhain & Murphy, 2000:197). Depression and anxiety can be treated with medication, lifestyle changes and therapy or counselling from a qualified practitioner (Ahlskog, 2009:). All the participants are currently involved in a support group, however only one participant is taking anti-depressants as a way of dealing with feelings of anxiety and depression.

### **Sub-theme 3.3: Denial**

Most of the participants expressed that they are still in disbelief of being diagnosed with Parkinson's disease. The following verbatim quotes illustrate this:

- "...Hoekom ek hoekom nie iemand anders nie...en dan besef jy dat jy niks daaraan kan doen nie, die werklikheid tref my elke oggend dat ek nie meer 'n kwaliteit lewe kan lei nie..." ("Whyme and not someone else, then you realise that there is nothing you can do about it. The realities hit you every morning that you can't have a quality life anymore.")
- "...my vriende is nog baie beïndruk met my want dit lyk vir hulle of ek alles so goed hanteer, maar wat hulle nie weet nie is my uitdagings is baie kere, meeste van die kere baie groot..." ("My friends are still very impressed with me, because it looks like I

am handling things very well, but what they don't know is that my challenges are more often than not, very big.”)

- “...ek rebelleer nog dag tot dag...” (“I still rebel day-to-day.”)
- “...ek vra myself dikwels nog baie hoekom moes dit met my gebeur het, ek het dan niks kwaad aan iemand gedoen nie...” (“I still ask myself often why did this have to happen to me, I haven't done anyone harm.”)

Two participants stated that they went as far as trying to hide their symptoms as a form of refusing to accept they had been diagnosed with Parkinson's disease. Their reason for doing this was explained in the following manner:

- “...ek het dit probeer wegsteek, al het ek geweet iets is nie reg nie...” (“I tried to hide it even though I knew something was wrong.”)
- “...my familie het vir die eerste 3 jaar nie geweet ek het Parkinson's nie, ek was in 'n ontkeningsfase (“my family did not know for the first three years I had Parkinson's. I was in the denial phase.”)

Falvo (2005:5) explained that denial is a coping strategy some individuals use to negate the reality of a situation. In this study it was evident that at times, participants denied the implications of the condition. Ahlskog (2009:16) further mentioned the correlation between denial and anxiety in the early stages of adjustment to a chronic illness, where denial can be viewed as beneficial in that it enables individuals to adjust to their situation at their own pace, preventing excessive anxiety. Some participants are still in denial which ultimately prevents them from following medical recommendations or from learning new skills that would help them reach their maximum potential (Ahlskog, 2009:79).

### **Discussion of theme 3**

Parkinson's disease had an extremely negative impact on participant's holistic functioning. It affected, amongst others, participants' self-esteem and emotions, their social functioning as well as their support systems. Additionally, participants indicated that Parkinson's disease was often followed by normal aging symptoms. However, a lack of understanding of the seriousness of the matter resulted in the



phenomenon of Parkinson's disease being viewed as an illness which is not serious, specifically due to the fact that it does not cause death. Falvo (2005:5) discussed how physical disabilities could negatively influence individuals' psychological perception of themselves. The stigmatization and negative psychological perception of oneself can foster feelings of loneliness. The above mentioned empirical findings correlate strongly with the ecological systems theory, which states that the experiences in the microsystem ultimately affect the experiences in the macro systems.

#### **3.8.2.4 Theme4: Physical effects of Parkinson's disease**

It became evident through the discussions that participants experienced both physical and emotional challenges.

##### **Sub-theme 4.1: Participants' view on the physical challenges**

The inability to do basic things in daily life constituted one of the most notable challenges related to participants' physical functioning. Participants with caregivers seemed to have the most severe physical difficulties, usually requiring assistance in carrying out basic daily activities, such as dressing, bathing, and grooming. It was common for patients to be acutely aware of their increasingly deteriorating physical functioning. The following verbatim quotes illustrate this:

- "...my stem raak moeg, ek het nie krag nie, ek kan nie meer goed oopmaak soos 'n doppie oopdraai van 'n koeldrank...ek het ook wat hulle noem 'n gesigmasker waar my gesig net stom raak en ek staar net vir mense, ek kom nie agter as dit gebeur nie..." ("My voice gets tired; I don't have the power to open a bottle cap anymore. I also have what they call a facemask where my face freezes and I just stare at people. I don't realise when this happens.")
- "...ek sukkel om 'n deur oop en toe te sluit of om 'n motordeur van binne af oop te druk...dit is 'n gesukkel om te verkleef of om te draai op 'n bed...my spraak het verander dit voel vir my of ek skreemaar klanke kom saggies uit..." ("I struggle to open or lock doors or to open a motorcar door from the inside. It is a struggle to get dressed or to turn in bed. My speech has changed - it feels like I'm yelling, but the sounds come out softly.")

- "...ek bewe baie en het geen krag in my handenie...ek moet my hare kort dra want 'n haardroër is te swaar om te hanteer..." ("I shake a lot and have no power in my hands, I have to wear my hair short, because a hair dryer is too heavy to handle.")
- "...ek sukkel om te loop, my rug raak seer..." "ek sukkel om vir lang tye stil te staan..." ("I struggle to walk, my back aches. I struggle to stand still for long periods of time.")
- "...'n algemene lomtheid, ek val gereeld..." ("a general clumsiness, I fall regularly.")

Two male participants complained that the illness has made them unable to have sex with their spouses due to erectile dysfunction.

Participants commented on a wide range of aspects pertaining to challenges associated with the disease, especially concerning loss of motor control, lack of facial expression, and difficulties due to impaired cognitive functioning and processing. However, symptoms are likely to increase over time, which result in a gradual decrease in independence to almost total disability. With the exception of pharmacological treatment of symptoms, there is no curative therapy (Gustafsson, Andersson, Andersson, Fjellstrom & Sidenvall, 2003; Parkinson's Victoria Inc., 2006; Schenkman, Cutson, Zhu & Whetten-Goldstein, 2002; Thommessen et al., 2002).

#### **Discussion of theme 4**

The overall findings in this theme demonstrated that individuals with physical disabilities tended to experience an increased level of emotional distress, social inadequacy and alienation and self-isolation. The empirical findings showed that individuals with physical disabilities are more likely to experience feelings of inner turmoil, hopelessness, social detachment, and rejection. The results of this theme were able to highlight the importance of understanding the intense feelings and experiences of individual's with physical disabilities with regard to loneliness and quality of life. This discussion of physical disability and ability created a spectrum that recognized that some individuals interactions created disabilities, while others disability created abilities. These experiences were mainly influenced by the individuals' environments. This view highlights the importance of individual and environmental resources. The relationship between the individual and the larger social and physical environments, is a key component of the ecological model. The

individual and the broader social and physical structure are interrelated. It is not possible to understand one without a consideration of the other. Put differently, the interaction is both constraining and enhancing.

### **3.8.2.5 Theme5: The social effects of Parkinson's disease**

The findings of the study indicated that Parkinson's disease greatly influenced the social environment of the participants. The following sub-themes were identified with regard to the influence of Parkinson's disease on the participants' social environment: withdrawal from friends, loss of quality in friendships, and the loss of interest in activities.

#### **Sub-theme 5.1: Withdrawal from friends**

The majority of participants indicated that Parkinson's disease resulted in them withdrawing from their friends. They explained that they decided for themselves that they would rather distance themselves from their friends than maintain the relationship. There were various reasons for this decision. Some participants felt that their friends did not understand their situation, while some participants felt they did not receive the needed support from their friends and family. Their reasons for withdrawal from friends and family are clear in the following quotes by the participants:

- "...ek en my man het onlangs besluit om liewers ons tyd te spandeer en onself te omring met mense wat ook Parkinson's het of wat versorgers is van mense wat Parkinson's het en weet waaroor dit gaan, dit is net soveel gemakliker as jy jouself nie hoef te verduidelik die heelyd nie..." ("My husband and I decided recently to rather spend our time with people who also have Parkinson's and or who much easier if you don't have to explain yourself the whole time.")
- "...when they look at me they are totally ignorant and that irritates me to the extent that I just want to distance myself from "those" people..."
- "...baie mense kon nie verstaan hoe kon ek so vinnig verander nie...dit het my laat voel hulle stel nie regtig belang om my kondisie te verstaan nie..." ("Many people couldn't understand how I changed so quickly and it made me feel that they are not really interested in understanding my condition.")

One participant specifically indicated how isolated she feels, she was in awe during the end of the interview and made the statement to her husband that she has forgotten what her name sounded like due to the fact that she no longer socialised.

Opposing this view was O'Suilleabhain and Murphy (2000:199) explains that disengaging from social situations may also be a result of the fatigue often experienced by people with Parkinson's disease or a feeling that they are a burden to those around them.

### **Sub-theme 5.2: Loss of quality in friendships**

It became evident that there was a mutual feeling among participants that the quality of their existing friendships was greatly influenced due to the physical symptoms of Parkinson's disease. Participants especially found it hard to communicate with friends due to difficulty in speech. The following verbatim quotes illustrate this:

- "...ek het baie mense verloor weens die feit dat ek nie meer kan kommunikeer nie, die kwaliteit van my vriendskappe het verswak weens die simptome van Parkinson's..." ("I lost a lot of people due to the fact that I can't communicate anymore, the quality of friendships weakened as a result of the symptoms of Parkinson's.")
- "...ek kan nie meer so betrokke wees in aktiwiteite soos wat ek begeer nie..." ("I can't be involved in activities anymore as I would like to.")
- "...ek kan nie meer bel nie net boodskappe tiken dit verg baie tyd weens die rukkings..." ("I can't call anymore, just type messages and it takes a lot of time due to the shaking.")
- "...ek kan nie meer in die publiek wees soos byvoorbeeld om 'n koffie saam met iemand te drink nie...dit is so 'n gesukkel want ek bewe net te veel..." ("I can't be in public anymore for example drinking coffee with someone. It is too much of a struggle and I shake too much.")

Wild and Swartz (2012:334) stated that as Parkinson's disease progresses, symptoms worsen and the severity of the symptoms experiences increase, in fact,

these changes can affect overall communication skills, interactions and relationships with other people.

### **Sub-theme 5.3: Loss of interest in activities**

Participants shared that they were forced to let go of activities in their lives which they truly enjoyed due to the severe impact of Parkinson's disease. Activities which were seen as hobbies and which brought a sense of satisfaction to them, have now become unbearable and impossible to pursue. The following comments illustrate this:

- "...Ek kan nie meer naaldwerk doen nie, ek het baie daarvan gehou en dit is vir my baie sleg om dit nie meer te kan doen nie..." ("I can't do needlework anymore and that is very sad for me, because I used to love it.")
- "...ek is lief vir skryf maar my hand ruk so dat ek moes ophou skryf, dit is baie moeilik om te aanvaar ek kan nie meer skryf nie..." ("I love to write, but I had to stop writing as a result of the shaking in my hands and it is difficult to accept that I can't write anymore.")
- "...wat vir my voorheen genotvol was soos reis per vliegtuig of teater besoek, het nou in 'n geveg met engtevrees verander..." ("which was previously eventful for me like travelling by airplane or visiting the theatre, has now become a struggle with my fear of claustrophobia").
- "...ek het gespesialiseer in motorwerktuigkunde, ek kan glad nie meer die tipe werk doen nie want dit verg baie keer fyn werk met jou hande en jou oë..." ("I specialised in mechanics, I can't do this anymore, because you need to be able to work on fine detail with your hands and eyes.")

The above-mentioned comments were evident in literature. O'Suilleabhain and Murphy, (2000:199) explained that in the context of Parkinson's disease, a person suffering from this disease often finds it very difficult to make new adjustments in the ways they usually pursued activities or hobbies.

### **Discussion of theme 5**

In line with Bronfenbrenner's ecological systems theory Kernohan, Waldron, & Hardyway, (2011:23), regard the effects of Parkinson's disease with regard to the effects of various systems in a person's life and point to interrelatedness of systems in the participant's lives. The findings of the study revealed that Parkinson's disease affected the participants as a person and also in relation to different areas in their lives. Participants, living with Parkinson's disease, were faced with both physical and emotional challenges daily. They specifically struggled with the acceptance that they no longer can function on the level they used to despite the need to do so. Rokach, Lehcier-Kimel and Safarov (2006:682) discussed the need for future research in providing emotional coping strategies for individuals with physical disabilities. The empirical findings confirmed that experiences of loneliness can occur in individuals with Parkinson's disease and coping strategies are important when faced with a chronic illness. To increase an individual's quality of life and increase coping strategies a social worker must understand how individuals with Parkinson's disease view themselves.

### **3.8.2.6 Theme6: Participants' view on their support systems**

When exploring the topic of support systems the researcher observed one distinct sub-theme emerging, namely the importance participants placed on their support system.

#### **Sub-theme 6.1: Participants' view on the nature of their support systems.**

The majority of participants' identified their significant partner as the main support system. A significant number of participants' emphasised how Parkinson's disease brought them closer to their partner:

- "...ons is volgende jaar 50 jaar getroud, ek sê altyd as ek deur hierdie 50 jaar vir 40 jaar nie geweet het wat ek in my vrou het nie weet ek nou en Parkinson's het..." ("I always say that if I didn't know in this 50 years for 40 years what I had in my wife, I know now and I know Parkinson's had a big role to play in that.")
- "...my verhouding met my vrou het baie verbeter, ons is meer bedagsaam met sekere dinge..." ("My relationship with my wife has improved a lot, we are more considerate with certain things.")

- “...sy was saam met my deur dik en dun, ons verstaan mekaar beter...” (“She has been with me through thick and thin, we understand each other better...”)

A few participants had an opposite opinion on how they viewed their support system. These participants were either divorced or single. The following verbatim quotes will illustrate this:

- “...My jongster suster is my hoofondersteuningstelsel, partykeer dink ek, ek sal by die dood omslaan en niemand sal eers weet nie...” (“My younger sister is my main support system, sometimes I feel that I would die and no one would even notice.”)
- “...Ek is enkellopend...ek het besef hoe “tough” is die lewe eintlik na my diagnose...” (“I am single. I realised how tough life actually is after my diagnosis.”)

Some participants further mentioned that other people are necessary in their lives in order to overcome the psychological difficulty of living with Parkinson’s disease:

- “...Die eerste ding wat ek gedoen het nadat ek uitgevind het ek is met Parkinson’s gediagnoseer, was om rond te bel op soek na ondersteuningsgroepe. Ek het gedink dit is ‘n ongeneeslike siekte en het nodig gehad om met mense te praat...” (“The first thing I did when I knew I had Parkinson’s was to phone around to get support groups. I thought to myself this is an incurable disease so I needed people to speak to”)
- “...As dit nie was vir my vrou, vriende en ondersteuningsgroepe waar ek betrokke is nie sou ek dit nie kon maak nie...” (“If it wasn’t for my wife, friends and support group where I am a part of I don’t think I would’ve made it.”)
- “...Ek en my man het besluit om onself te omring met mense wat ook Parkinson’s het of wat versorgers is van mense wat Parkinson’s het en weet waaroor dit gaan...jy kan net ontspan jy hoef nie jousef die heletyd te verduidelik...” (“My husband and I decided recently to rather spend our time with people who also have Parkinson’s and or who are caretakers of people with Parkinson’s and know what it’s about. It’s just so much easier if you don’t have to explain yourself the whole time.”)

There seemed to be consensus amongst participants that a shift in their support system was needed in order to adjust to their current needs experienced with living with Parkinson's disease. Wild and Swartz (2012:337) explained that the experience of Parkinson's disease, while diminishing the quality of life of both patients and caregivers, also appears to sometimes enhance the sense of appreciation of life and of each other. Even though the above represents the majority of views, a few participants referred to the fact that their religious beliefs serve as their main support. A comment to illustrate these views is:

- "...maar as jy nie in jou geloof vashou nie het jy niks om aan vas te hou nie..." ("but if you don't hold on to your faith, you don't have anything to hold on to.")

## **Discussion of theme 6**

It is evident that family is the closest unit here. Participants who had limited support due to circumstantial situations such as being single reported that the support they are receiving is limited. Due to the ensuing lack of appropriate support, these individuals felt stressed, and helpless. Participants with sufficient support showed less stressed levels, due to being able to vent their feelings within their micro and meso systems, if these systems are experienced as supportive, stress levels decreased. There are family, relatives, friends, peers, colleagues, and community, work, school, and neighbour, social and religious structures with whom a person interacts on a daily basis. This exposes the person to several daily challenges, while providing them with resources innate in their ecology. Although disharmony with any agent in the system can be a potential stimulation to trigger disturbance in individual's perceived view of their functioning, an awareness of the individuals existed ecology may provide additional resources for management of the condition and person for higher levels of function and for primary, secondary or even tertiary level prevention.

### **3.8.2.7 Theme7: The effect of Parkinson's disease on the family**

During the discussion of roles and interaction, participants identified different roles that they had to adapt to. The perceived impact and roles within the family were identified as sub-themes.



### **Sub-theme 7.1: Participants' view on their functioning in their family**

It is known that chronic illness often creates shifts in interdependence, independence, and dependence within family relations (Roberto, 2001:69), and whereas some families transform with ease, others experience a lack of understanding or acceptance, and/or poor communication. Most participants identified the role of dependency on their care-taker as the most prominent. Comments to this effect were:

- "...my man moet baie doen vir my..." ("My husband has to do a lot for me.")  
"...sommige goed moet my man nou doen vir my want ek het nie meer krag in my hande nie..." ("Some things my husband has to do for me now, because I don't have any power in my hands anymore.")

A sense of guilt was evident in the discussions where participants felt that their dependency on others was viewed as added stressors in the care-takers lives. The following comments suggest this:

- "...I struggle with pride and have to admit that I've become more dependent on everyone....I just don't want to bother them with my problems..."
- "...ek kry my man baie jammer want hy het sy eie dinge en nou nog my dinge ook...dit is eintlik onregverdig, ek kan sien hy raak ook moeg..." ("I feel very sorry for my husband, because he has his own matters and now mine as well. It is actually unfair and I can see he gets tired.")

The above findings substantiate the statement of Roberto(2001:70)of that the interpretations of chronic illnesses by people living with a chronic illness, may promote or decrease identity and interaction and this may determine how they address, resolve, or avoid conflict within their family.

### **Sub-theme 7.2: Participants' view on their role in their family**

According to Papadopoulos, families often grieve the loss of role definitions, physical functioning, responsibilities, dreams, and the prospect of a long life span for their ill family member. Adaptations to the demands of a chronic illness may exceed a

family's expectation for what life should be like at this stage of the illness. With progressive chronic illnesses "families must be prepared to keep reforming its system to keep pace with the changing picture of illness" (Rolland, 1994:25).

- "...my kinders ry karre en weens my kwalifikasie het ek hulle altyd gehelp en dinge reg gemaak en ek kan dit nie meer doen nie..." (My children drive cars and because of my qualification I always helped them and I can't do it anymore.)
- "...my seun het eendag vir my 'n kaartjie gestuur wat hy se ek is sy hero...dan dink 'n mens watter rol kan mens speel in jou kinders se lewe as jy niks meer kan doen vir hulle nie..." ("my son once sent me a card to tell me that I am his hero, then you think what role you can play in your children's life if you can't do anything for them anymore.")
- "...ek kan nie meer my lippe mooi rooi maak nie vir my man, ek kan nie as ma meer lekker kos kook nie en ek kan nie meer as ouma speel met die kinders nie...jy voel lelik..." ("I cannot make my lips red anymore, I can't as a mother cook delicious food anymore and I can't as a grandmother play with my grandchildren anymore. One feels ugly.")

A minority of participants did however feel that Parkinson's disease had no effect on the functionality within their families; their opinions were voiced in the following manner:

- "...as man en pa dink ek nie daar is enige veranderinge nie..." ("as a husband and father I don't think there are any changes.")
- "...my rol as 'n pa dink ek ek het nogsteeds 'n baie leidende rol, hulle kom vra my gereeld vir raad..." ("my role as a father, I think I still have a very leading role, they still ask me frequently for advice.")

Carter and McGoldrick (2005:495) argues that individuals suffering from a chronic illness, will often have limited effects on their perceived role in the family, if the family is flexible with regards to internal role reorganization and a family's willingness to use outside resources.

## Discussion of theme 7

Individuals with Parkinson's still have desires to connect, interact and be involved within the community. However, individuals with physical disabilities find it difficult to interact with the general public because of their impairments due to the progression of the disease. The experience of loneliness can occur in individuals with Parkinson's disease and coping strategies are important when faced with a chronic illness. To increase an individual's quality of life and increase coping strategies a social worker must understand how individuals with Parkinson's disease view themselves. The core of the ecological systems theory stems from the interaction taking place within the various layers of the structures and the interaction taking place between the various layers. In the context of the microsystem, bidirectional interactions are extremely strong and have the most significant influence on the individual. The findings above indicate the effectiveness of using the ecological systems theory as the researcher's theoretical framework.

### **3.8.2.8 Theme8: Participants' view on the treatment they receive**

Participants shared that what makes Parkinson's more difficult to manage is the confusion regarding what is considered as normal aging symptoms or symptoms of Parkinson's disease. The following statements of participants substantiate the researcher's point of view:

- "...mense is so lief om vir jou te sê alle ou mense is so...nou weet ek nie of is dit regtig ouderdom of is dit Parkinson's nie..." (" People love to tell you that all old people are like this, now I'm not sure if it is really aging or if it is Parkinson's")
- "...baie kere is die simptome so verwarrend teenoor die simptome van ouderdom, daar is 'n grens so na aan mekaar..." ("Sometimes the symptoms are confusing with the symptoms of aging, they are very similar.")

One participant shared that she currently struggles to receive the right medication due to no stock currently available in South Africa, which ultimately results into severe negative impact on her symptoms:

- "...dit gaan al 'n maand slegter met my omrede daar nie voorraad van my een medikasie is in Suid-Afrika nie...die gevolg is ek is op ander medikasie en dit werk glad nie vir my nie..." ("it's been getting worse the last month, because the one

medication isn't in stock anymore in South Africa, the result is that I am on different medication now and it doesn't work for me.”)

A few participants refused to take any medication after either using it and not being satisfied with the results, or having been exposed to people using medication and felt that there is no guarantee that the medication will help one in anyway. The following verbatim quote illustrates these views:

- “...my siening oor medikasie is ook dat ek my hele lewe probeer wegbly van pille af...”  
 (“My view on medication is always that I try to stay away from pills my whole life.”)

There is currently no cure for Parkinson's disease, but treatments are available to help relieve the symptoms and maintain people's quality of life, these mainly included medications and, for some people, surgery (Wild & Swartz, 2012:333). Treatment decisions were reached either solely by the participants themselves, or in collaboration with their experience or perception regarding medication.

Another factor emerged throughout the interviews with some participants indicating that they are seriously considering alternative medication, like marijuana oil to experience less pain associated with Parkinson's disease. The participants made the following comments regarding this option of treatment:

- “...ek het ons homeopaat gaan sien en hy het genoem dagga-olie kan dalk help...ek sal enige iets doen, ek oorweeg sterk om dit te kry...” (“I went to see our homeopath and he said that cannabis oil could help, I will do anything and consider strongly getting it.”)
- “...I am seriously considering using dagga oil, just to feel that relaxation in the body...”

Participants voiced that the financial costs involved also plays a significant role in the type of treatment they will consider. Affordability involves costs for transport to and from hospital, paying for consultations and medication. Some participants said that they had not been going to their check-up appointments with their neurologist as often as they would like to because of limited funds available in their medical aids. The above mentioned views correlate with Bhatia and Gupta (2003:209), stating that there is no standard treatment for the disease, the treatment for each person with Parkinson's is based on his or her symptoms.

## Discussion of theme 8

It was evident that the symptoms of Parkinson's disease were not recognisable to the general population as being a particular illness; often, participants thought it is part of the inevitable consequences of ageing, which ultimately affected the type of treatment participants sought. This was a viewpoint shared by most of the participants. By understanding the disease and the progression, individuals and families will be able to recognize and cope with the changes of the disease. The participants discussed the importance of community education in order to promote hope and resilience. The information provided to the community about Parkinson's' disease is able to assist individuals with empathy and compassion for individuals and their families struggling with this disease. This ripple effect clearly illustrates how the microsystem affects the macro systems.

### 3.8.2.9 Theme9: Participants' view on how Parkinson's is perceived by society

The majority of participants viewed their experience regarding how society perceived Parkinson's disease as positive. Participants were specifically in awe of the amount of help they receive daily from strangers. The following verbatim quotes illustrate this:

- "...dit gebeur gereeld dat mense my graag wil help in die publiek en dit vang my steeds onkant...ek het al hoe meer besef daar is baie goeie mense in die wêreld..." ("it happens regularly that people want to help me in public and it still surprises me. I realise how many good people there are in the world.")
- "...mense is baie vinnig om hulp aan te bied..." ("People are very quick to offer help.")

In contrast, the minority of participants were of the opinion that, due to the lack of awareness and education on Parkinson's disease amongst outsiders, they tend to look away, ignore and judge them. The following comment illustrates this:

- "...ek voel mense verstaan nie die siekte nie en weet nie altyd hoe om my te help nie..." ("I feel people don't understand the illness and don't always know how to help.")
- "...daar is 'n groot leemte in die opvoeding oor die algemeen in die publiek..." ("There is a massive void in the education of the public in general.")

A few studies to date have investigated how the public perceives neurodegenerative diseases such as Parkinson's, Alzheimer's, and Multiple Sclerosis (MS). One example of a published study is by Moore (2006:17) who explored public beliefs of Parkinson's disease and found stigma to be attached to people with this disease. The author has demonstrated the importance of studying public responses toward physically disabling diseases by highlighting that negative reactions can have worse implications than functional limitations. More recently Moore (2006:19) has argued that it is important to study the diseases that may resemble mental retardation or are socially unpleasant such as Parkinson's, Alzheimer's and MS since the public may stigmatise against such diseases.

It was evident through this discussion that people with Parkinson's disease acknowledge that due to an inability to perform basic daily tasks; and associated disease symptoms such as masked facial expressions, lack of affect with speech, and problems with articulation can make communication difficult and leave open the way for social misunderstanding (Moore, 2006:20).

### **Discussion of theme 9**

The research participants discussed the importance of education about the disease for the individual, family and community. The research participants discussed how it is difficult for family members to separate the patient's actions, functioning, and masking from their personality or the disease. Throughout the interviews there were many examples of the importance of education for more effective interactions with individuals with Parkinson's disease. Three experiences discussed by the research participants demonstrated the importance of education throughout the micro, mezzo and macro levels regarding Parkinson's disease

#### **3.8.2.10 Theme 10: Participants' view on their future**

The topic of how participants viewed their future triggered a discussion on possible hopes, dreams and possible fears emerged.

All of the participants in this study were retired and above the age of 60, which literature views as the later life phase in the stage of the Family Life Cycle (Carter

&McGoldrick, 2005:333). This life phase characterises the experiences of the elderly as a sense of peace, knowing that all is in order.

### **Sub-theme 10.1: Hopes and dreams for the future**

In terms of long term hopes and dreams the comment was made that long term has become much shorter. Comments illustrated that most of them were linked with simple enjoyable activities they want to pursue again in life.

- “...ek wil so graag weer gaan kamp...” (“I really want to go camping again.”)
- “...Om in te trek in ons nuwe huis, alsuit te pak sodatons woonstel soos ‘n huis voel...” (“To be able to move into our new house, to unpack everything so that our flat can feel like a home.”)
- “...Ek wil die huis regmaak...” (“...I want to fix up the house...”)

There was however, overwhelming support for the fact that participants live in the here and now, focus on today and do not think about the future too much. Carter and McGoldrick (2005:338) refer to this mind-set as one of the characteristics of people who are in the later phase of life, as people often feel that in this life phase they have already achieved their desired long term goals. Comments to illustrate the focus on the present were:

- “...ek het nie ‘n doel vir myself nie...” (“I don’t have a goal for myself.”)
- “...ek dink ek het alles bereik wat ek graag wou bereik...” (“I think I have achieved everything I wanted to.”)
- “...weens die ouderdom en ‘n vol lewe, voel ek, ek het reeds alles bereik...” (“Because of my age and a full life, I feel I achieved everything I wanted to.”)

### **Sub-theme 10.2: Fear for the future**

The primary concern among participants was that they would become a burden to loved ones, evoking fears regarding the loss of independence. One participant evocatively compared the experience of Parkinson’s disease and the underlying fear

over its advancement, to a roller coaster ride of sorts, the outcome of which would be unpredictable: “You know you’re on this roller coaster and you know you’re going downhill, but you don’t know whether it’s the kiddie coaster or the rocket from hell”. Comments to illustrate the fear experienced by participants were:

- “...ek is bang om afhanklik te raak van ander mense...” (“I am scared to be dependent on people.”)
- “...ek is bang mense dink wie ek nou is, is wie ek is en dit is nie so nie...” (“I am afraid that people think who I am now, is who I have always been and that is not true.”)
- “...ek wil nie in ‘n rystoel sit en kos deur ‘n strooitjie inneem nie...” (“...I don’t want to be in a wheelchair sucking food through a straw...”)
- “...om te beland in frail care...” (“to be in frail care.”)
- “...Ek het nooit regtig vrese in my lewe gehad nie, maar ek begin al hoemeer vrees of ek dit finansieël sal kan bekostig in die toekoms omrede ons land so agteruitgaan...die agteruitgaan van die land maak dit vir my moeiliker omdat ek weet ek gaan ook fisies agteruitgaan...” (“I never had any fears in my life, but I do now fear if I will be able to afford it financially, because our country is moving backwards. The decline of the country makes it difficult for me, because I am also declining physically.”)

Carter and McGoldrick (2005:496) stated that for illnesses with highly unpredictable courses, such as Parkinson’s disease, individual coping and adaption, especially future planning, are hindered by anticipatory anxiety and ambiguity about what will happen.

## **Discussion of theme 10**

From the above mentioned comments it is clear that participants share a sense of fear towards their capabilities of their daily activities in the future. What stood out was the fear of uncertainty regarding where individuals will be in the future. Social workers can assist individuals and families with future planning, making members aware of the possibility of disability and provide them with the needed resources. By using the ecological systems theory as the theoretical framework for this research



study, it is understandable why external resources in an individual's community ultimately affects the individual's experiences on a daily basis.

### **3.8.2.11 Theme 11: Advice on coping with Parkinson's disease**

The advice given by participants to people who also suffer from Parkinson's disease included suggestions to accept one's diagnosis, utilize support systems, try to maintain a positive mind set and to educate oneself on Parkinson's disease

#### **Sub-theme 11.1: Accept the diagnosis**

Most of the participants believed that the best option for a person who also lives with Parkinson's disease would be to accept the disease. Participants were of the opinion that by accepting the diagnosis will make the road to recovery much easier. Participants admitted that even though they struggled to follow the advice themselves, they've learned from their experience. Participants' views were explained in the following verbatim quotes:

- "...probeer normaal aangaan, jy kan dit nie weg wens nie dit sal altyd daar wees aanvaar dit..." ("try and go on normally with your life, you can't wish it away.")
- "...moet jousef nie jammer kry nie, aanvaar dit..." (Don't feel sorry for yourself, accept it.)

The views stated above have been reflected in literature. Acceptance is the necessary step for returning to a healthy perception of the situation (Lieberman, 2002:22). It was evident that the acceptance process differs from participant to participant, depending on the person's typical methods for processing challenges and difficulty (Bhatia & Gupta, 2003:207). Acceptance acknowledges the truth and reality of the Parkinson's diagnosis and initiates realistic expectations about its treatment and prognosis.

#### **Sub-theme 11.2: Utilize support systems**

A number of participants suggested that people should speak about their emotions regarding their experiences with Parkinson's disease. Participants expressed that by

utilizing their support system it made them feel more confident to overcome challenges and ultimately made them feel that they are not alone in this. The following comment illustrates this:

- “...jy sal elke dag oorbrug en as jy regtig sukkel praat met mense...” (“you will overcome everyday and if you struggle talk to people.”)
- “...jy sal deur ‘n stadium van depressie gaan, vrede daarmee maak, dit aanvaar en met mense daaroor praat...” (“...you will go through a state of depression, deal with this, accept this and speak to people about this...”.)

Participants further recommended that a person who lives with Parkinson’s disease should seek professional help in order to have support to work through all the emotions surrounding their experiences of Parkinson’s disease. One participant recalled that he went to the support group where he learned that by taking one’s medication for Parkinson’s disease on a specific time allows one to predict when the symptoms will be the most severe during the day.

In the literature it is suggested that people living with Parkinson’s disease need to be encouraged to get involved with professional support systems in order for them to receive the necessary support (Bhatia & Gupta, 2003:211). This support could also be provided in a group context.

### **Sub-theme 11.3: Maintain a positive mind set**

The majority of participants explained that the best advice to deal with the experiences of Parkinson’s disease was to adapt a positive mind set.

- “...My raad sal wees bly positief...” (“my advice is, stay positive.”)
- “...probeer om positief te wees, en doen wat jy kan...” (“try and stay positive and do what you can.”)
- “...sien die goeie dinge raak in die lewe mens is maklik geneig om te fokus op die negatiewe, daar is baie meer dinge waarvoor jy kan dankbaar wees as dinge waarvoor

jy kan bekommered wees...” (“see the good in life, we are used to focus on the negative, there is a lot more that we can be thankful for than we can worry about.”)

A number of the participants explained that they dealt with their experiences of Parkinson’s disease by utilizing positive self-talk. They would for example, express calmness because they were able to determine the good in the bad. Two participants explained that they looked at the positive lessons that they learnt from their experience of Parkinson’s disease, namely that there are bigger things to worry about in life.

Positive self-talk is recognized as a strategy to deal with the experiences of Parkinson’s disease. It can be helpful to use positive self-talk to deal with negative emotions as well as look for positive factors in negative situations (Zimmer-Gembeck, 2011:135).

#### **Sub-theme 11.4: Educate yourself on Parkinson’s disease**

A number of participants suggested that one should educate oneself on what Parkinson’s disease entails. Participants stated they benefited from being proactive and finding out as much as possible about the disease in order to alleviate fear of the unknown and to take a positive role in maintaining their health:

- “...jy hoef nie heelmal blind in te gaan in die ding nie, doen jou navorsing vooraf...” (“you don’t need to go into the thing blind, do your research beforehand.”)
- “...moenie skrik nie, vra meer vrae vir jou dokter en as jy nie antwoorde kry nie soek harder...” (“don’t be scared, ask your doctor more questions and if you can’t find answers, look harder.”)

Lieberman (2002:30) reported that a physical therapist must be aware of the patient’s living environment, current services and care partner availability in order to develop the most appropriate plan. Factors such as culture diversity, financial resources, geography and access services, personal beliefs and education also may influence an individual’s response to recommended interventions.

#### **Discussion of theme 11**

The participants discussed how their unique story and experience with Parkinson's inspired them to be resilient. The participants also discussed how the small successes or victories in the participants' life gave the participants hope in their own life. The participants also discussed the importance of self-care for themselves in order to reduce feelings of burnout and compassion fatigue. The ecological systems theory suggests that influences between people and their systems go both ways. This is very evident in the experiences of people living with Parkinson's disease. The individuals had to rely on their social environment (family and friends) to provide them with emotional support. There was a constant give-and-take between individuals and their surrounding systems. Participants believed that they would not have been able to survive the daily challenges they are faced with, if it was not for the support they received from their family, close friends and ultimately the support from the Parkinson's Association. This aspect was also experienced by the researcher throughout the recruitment phase and arranging appointments with participants, the importance the care-taker played in the participants' daily lives, was noted. Bronfenbrenner explained that when one member in a system undergoes change, the other member will also undergo change. In order to overcome any change an individual and family members will need to be able to adapt. This process was evident throughout the empirical findings.

### **3.9 Summary**

In this chapter, the researcher was exploring the experiences of people who live with Parkinson's disease. This chapter presented an overview of the research methods, which were utilised to undertake the empirical research of this study.

Subsequently, this chapter focused on the analysis and interpretation of the research findings. Through this chapter the researcher presented the empirical findings from the participants for this study, namely people who have been diagnosed with Parkinson's disease. The empirical findings were presented along eleven themes and sub-themes which were presented in the manner of direct verbatim quotes, substantiated with literature and linked to the theoretical framework of this study.

In the next chapter, the researcher will summarise the findings of the study, determine whether the goal and objectives of the study were reached, and provide conclusions and recommendations.

## CHAPTER FOUR

### CONCLUSIONS AND RECOMMENDATIONS

#### 4.1 Introduction

This chapter concludes the research report. In this final chapter, the researcher will outline the research results with regard to what the experiences are of people living with Parkinson's disease. In presenting the empirical findings of the study, the researcher will indicate whether the goal and objectives of the study were accomplished, and will thereafter answer the research question. The researcher will then proceed to present the key findings, conclusions and recommendations

#### 4.2 Summary

The focus of this section is on the objectives, goal and research question of the study and how they were met.

##### 4.2.1 The objectives of the study

The following objectives were pursued to accomplish the goal of the research study:

- To describe Parkinson's disease;
- To explore and describe the challenges experienced by people living with Parkinson's disease on a daily basis;
- To explore the coping mechanisms of people with Parkinson's disease;
- To identify how environmental factors influence managing Parkinson disease;
- To provide conclusions and recommendations for social workers in practice involved in working with people with Parkinsons disease based on the findings.

#### **4.2.1.1 Objective 1: To describe Parkinson's disease**

This objective was achieved through an in-depth literature review that was conducted on Parkinson's disease and the needs and experiences of people living with Parkinson's disease. The literature review was presented in chapter two of the research report and provided a description of the medical terms and the key concepts used in the literature review and the empirical study. The ecosystems perspective as theoretical framework for the study was described in chapter one. Furthermore, the literature review explored the concepts of Parkinson's disease, the historical background of the disease, the symptoms and impact of symptoms on the physical, emotional and social aspects of people's lives, the different treatment options and the support available to people living with Parkinson's disease. Parkinson's disease was further discussed in terms of prevalence and the stages of development of the disease. The last section discussed the burden Parkinson's disease placed on patients, families and communities. The literature review provided the researcher with a comprehensive understanding of Parkinson's disease as a neurodegenerative disease and the impact Parkinson's disease has on a person diagnosed.

#### **4.2.1.2 Objective 2: To explore and describe the challenges of people living with Parkinson's disease experience on a daily basis**

The objective was achieved by means of the literature study and the empirical research. The literature study explored the physical, psychological and social impact of Parkinson's disease on the individual living with Parkinson's disease. It was found that the person living with Parkinson's disease faces numerous challenges resulting in frustration, isolation and additional psychological stressors to the individual. The results yielded by the empirical study found that people living with Parkinson's disease very often experience challenges both within their home and public environments. In addition, the lack of appropriate support structures and the lack of understanding among the public was found to be a significant challenge for the showed that the severe physical impact of Parkinson's disease often leads to an increase of dependency on others, which ultimately affects people's psychological wellbeing. Despite the negative impact Parkinson's disease has on a person, a

number of positive aspects associated with Parkinson's disease and the experiences thereof were also reported.

Each of these themes was divided into sub-themes to explore and describe the experiences of people living with Parkinson's disease. A total of eleven themes were generated from the data. These themes can be seen in Table 4.1.

#### **4.2.1.3 Objective 3: To explore people with Parkinson's disease coping mechanisms**

The objective was achieved through the literature review and the empirical study. The literature study focused on different support systems available to people who suffer from Parkinson's disease, to better manage the disease. Such interventions and support systems included physiotherapist and occupational therapy, speech therapy, dietary advice and practical treatment options. Literature further identified challenges often experienced within South Africa regarding the support services available to people living with Parkinson's disease. The research data collected from the face-to-face, semi-structured interviews revealed that, although participants living with Parkinson's disease have access to public health care services, they reported little interest to these additional support services. Support groups services were found to be utilized by most of the participants living with Parkinson's disease together with their main caretaker. Religion and a positive mind set were found to be significant support systems for people living with Parkinson's disease.

#### **4.2.1.4 Objective 4: To identify factors influencing the quality of life of people living with Parkinson's disease**

The objective was achieved through the literature review and the empirical study. The literature study identified that people living with Parkinson's disease require continual re-adjustment as the disease slowly progresses to severe disability. Depending on the level of impairment, daily activities such as getting dressed, driving and eating may become more challenging. Literature further identified that the possibility of role shifting within the family is highly likely. The research data collected throughout this study substantiated these views, where participants' sense of quality of life was ultimately challenged in the way they experienced daily



challenges as a result of Parkinson's disease. It was evident that although medical treatment helped control symptoms and improve their functioning, careful management to minimize potential side effects was crucial. The results encountered permit a better comprehension of the influence of Parkinson's disease on the quality of life of those who suffer from it, being that a better perception of the quality of life can produce positive effects in health.

#### **4.2.1.5 Objective 5: To provide conclusions and recommendations for social workers in practice working with people with Parkinsons disease based on the findings.**

This objective was achieved and is discussed at the end of the current chapter. Recommendations for practice and further research are based on the research findings and conclusions drawn from the study regarding the needs and experiences of people living with Parkinson's disease.

#### **4.2.2 Goal of the study**

The goal of the study was to explore and describe the experiences of people living with Parkinson's disease. This goal was achieved by means of the objectives as discussed above.

The first chapter explored the ecosystems perspective as the conceptual framework for understanding the relationship between Parkinson's disease and the patient and family's social environment, the needs, challenges and strengths of individuals; and the resources and support in the environment. The symptoms, diagnosis, and development phases of Parkinson's disease were described with specific reference to the Hoehn and Yahr scale. This scale was also used to determine which participants will meet the criteria, specifically referring to the late stage of Parkinson's disease. The management of Parkinson's disease in terms of pharmacological and non-pharmacological treatment was scrutinized. Challenges specifically in the South Africa context were critically discussed and kept in mind while interviewing participants for this study. The final section of the literature review conceptualized the effect and impact Parkinson's disease has on the different systems in a person's life; specifically focusing on the person, family and communities.

The empirical research generated the following themes: Participants' views on the impact of Parkinson's disease on their daily lives, the emotional effects of Parkinson's disease, behavioural effects of Parkinson's disease, physical effects of Parkinson's disease, social effect of Parkinson's disease, participants' views on their support systems, the effect of Parkinson's disease on the family, participants' views on the treatment they receive, participants' views on how Parkinson's is perceived by society, the participants' view on their future and lastly the advice on coping with Parkinson's disease.

### 4.2.3 Research Question

In the context of this study, the following research question was asked:

What are the experiences of people living with Parkinson's disease?

The data collected from the in-depth interviews with the participants, revealed themes and sub-themes relating to the experiences of people living with Parkinson's disease. As the research was qualitative in nature, descriptive data was obtained. These descriptive experiences of people living with Parkinson's disease were discussed in chapter three.

The following themes and sub-themes reflect the experiences of people living with Parkinson's disease. These themes and sub-themes were discussed comprehensively, in the previous chapter.

**Table 4.1: Themes and sub-themes of research**

THEMES	SUB-THEMES
Theme 1: Participants' view on what Parkinson's disease is	Sub-theme 1.1: Participants view on the process of diagnosing the disease Parkinson's.
Theme 2: Participants' view on the impact of Parkinson's disease on their daily lives	Sub-theme 2.1: Participants' view on daily activities. Sub-theme 2.2: Implication on daily life activities.



<b>Theme 3: The emotional effects of Parkinson's disease</b>	<b>Sub-theme 3.1: The effects of Parkinson's disease on self-esteem</b> <b>Sub-theme 3.2: Development of anxiety and fear</b> <b>Sub-theme 3.3: Denial</b>
<b>Theme 4: Physical effects of Parkinson's disease</b>	<b>Sub-theme 4.1: Participants' view on the physical challenges</b>
<b>Theme 5: The social effect of Parkinson's disease</b>	<b>Sub-theme 5.1: Withdrawal from friends</b> <b>Sub-theme 5.2: Loss of quality in friendships</b> <b>Sub-theme 5.3: Loss of interest in activities</b>
<b>Theme 6: Participants' view on their support systems</b>	<b>Sub-theme 6.1: Participants' view on the nature of their support systems</b>
<b>Theme 7: The effect of Parkinson's disease on the family</b>	<b>Sub-theme 7.1: Participants' view on their functioning in their family</b> <b>Sub-theme 7.2: Participants' view on their role in their family</b>
<b>Theme 8: Participants' view on the treatment they receive</b>	
<b>Theme 9: Participants' view on how Parkinson's is perceived by society</b>	
<b>Theme 10: Participants' view on their future</b>	<b>Sub-theme 10.1: Hopes and dreams for the future</b> <b>Sub-theme 10.2: Fear for the future</b>
<b>Theme 11: Advice on coping with Parkinson's disease</b>	<b>Sub-theme 11.1: Accept the diagnosis</b> <b>Sub-theme 11.2: Utilize support systems</b> <b>Sub-theme 11.3: Maintain a positive mind set</b> <b>Sub-theme 11.4: Educate yourself on Parkinson's disease</b>

### 4.3 Conclusions

The conclusions discussed below were drawn from the literature study presented in chapter two and the research methodology contained in chapter three.

### 4.3.1 Conclusions from literature study

The ecosystems perspective, as theoretical foundation for this study, proved to be appropriate as it helped the researcher to cultivate a holistic view of how different systems are both connected and impact on each other; which consequently will affect the nature of the experiences of people living with Parkinson's disease. It highlighted that humans do not develop without the influence of their personal ecosystem and the larger ecosystems, of which they are part. Furthermore, working from this perspective allowed the researcher to consider the nature of different systems and how these systems ultimately influence participants' experiences of Parkinson's disease. The ecosystems perspective therefore enabled the researcher to identify and describe the experiences of participants living with Parkinson's disease.

Parkinson's disease is a chronic, degenerative neuro-degenerative disorder that affects one in 100 people over the age of 60 years. While the average age at onset is 60, it is evident from this study that people have experienced symptoms before reaching the age of 60. Currently there is no objective test, or biomarker, for Parkinson's disease, thus leading to a high rate of misdiagnosis, especially when the diagnosis is made by a non-specialist as indicated by this study. Although there is no cure for Parkinson's disease as yet, there are a variety of treatments that can allow the patients to lead a fulfilling and productive life for many years to come. Many symptoms can be relieved by medications, though over time these can become less effective and can produce undesirable side effects, such as involuntary movements known as dyskinesia. There are also surgical interventions, such as deep brain stimulation (DBS), which involves the implantation of electrodes in the brain. Because of the risks inherent in this type of treatment, most patients normally do not consider it until the medications they have been using no longer provide them with meaningful relief. Individuals with Parkinson's disease have a reduced health-related quality of life and increased psychological and physical morbidity. Individuals with Parkinson's disease may reduce their social contact as a direct result of their symptoms including reduced mobility and a lack of movements needed for everyday activities. It was evident throughout the literature review that Parkinson's disease

does not just affect the person living with it – it affects the entire family and an extended community of friends and loved ones, all the ecosystems.

#### **4.3.2 Conclusions from research methodology**

The qualitative approach, using the case study design and specifically collective case studies proved to be the appropriate approach and research design for this study. The information gathered was personal and rich in nature which gave meaning to the experiences of people living with Parkinson's disease, the collective case study design was appropriate as the researcher was able to broaden her understanding of the experiences of the different participants.

The use of in-depth face-to-face interviews and the semi-structured interview schedule enabled the researcher to obtain first-hand information in the form of words from participants. It further allowed some flexibility to explore certain topics further during the interviews. It can therefore be concluded that the face-to-face interviews and semi-structured interview schedule, as methods of data collection used in interviewing the participants and the recordings, worked effectively in collecting data. The researcher can therefore recommend these methods to future researchers who are planning to explore and describe the experiences of people living with a chronic disease such as Parkinson's disease.

The spiral of data analysis, as proposed by Creswell, Marschall and Rossman (in Schurink et al., 2011:404-419), were used during the research process. The steps in the data analysis process included planning for the recording of data; data collection and preliminary analysis; managing data and reading; generating categories, themes and patterns and coding data; testing emerging inunderstanding, searching for alternative explanations and presenting the data in the form of a mini-dissertation. This method of qualitative data analysis enabled the researcher to convert raw data into meaningful information. Reflexibility was considered to establish trustworthiness of data. The researcher used clarification during the interview to confirm findings with participants to establish the trustworthiness of data and to ensure that findings reflected the meaning described by the participants.

### **4.3.3 Key findings and conclusions from empirical research**

The researcher is of the opinion that the findings of this study cannot be generalised, but that the findings can be transferable to similar settings with similar populations. The following key findings and conclusions are made according to the themes generated from the data.

#### **4.3.3.1 Theme 1: Participants' view on what Parkinson's disease is**

##### **Key findings**

The literature review discussed in Chapter 2 points to the lack of knowledge amongst society regarding what Parkinson's disease entails. The empirical findings supported this fact:

- Participants were usually more familiar with the motor symptoms of Parkinson's disease, as these are the signs of the disease that are noticeable from the outside. These symptoms included slowness of movement, unusual stiffness and uncontrollable movement that affects a limb.
- It was evident that the rate of misdiagnosis was relatively high, especially when the diagnosis was made by a non-specialist.
- Although there is no cure for Parkinson's disease yet, there are a variety of treatments that allow patients to lead a fulfilling and productive life for many years to come.
- Participants shared the belief that Parkinson's will not cause death.
- Most of the participants were not aware that they were suffering from Parkinson's disease and therefore had not received appropriate treatment. Most had sought treatment for the specific symptoms they were experiencing such as the tremor, cognitive impairment and walking difficulties.

##### **Conclusions**

It is evident that Parkinson's disease is mostly perceived as a negative, however as individuals familiarise themselves with Parkinson's disease and consult with specialists, a sense of hope is developed. Different treatment options are available to individuals who suffer from Parkinson's disease which ultimately increases the quality of life of individuals.

#### **4.3.3.2 Theme 2: Participants' view on the impact of Parkinson's disease on their daily lives**

##### **Key findings**

The participants' reported a number of serious negative effects due to their experiences of Parkinson's disease. The reported effects were identified on three levels namely emotional, social and behavioural.

- Participants who live with Parkinson's disease are confronted not only with the physical manifestations of the disorder, but also with the psychosocial issues that impact on quality of life.
- Many expressed frustration with failure to engage in physical activities they were able to do prior to the onset of the illness. Parkinson's disease sufferers said they could no longer: dress themselves, walk without assistance, eat properly or turn in bed. Participants also talked of the way the physical shortcomings had led them to live isolated lives.
- Emotional factors that affect participants with Parkinson's can be seen as both internal and external. Some changes that occur may be the direct cause of the disease process itself, whereas other emotional changes can be seen as influenced by external factors and the participants' reaction to them.
- Denial, a feeling of shock and disbelief and the question of "Why me?" were common reactions, especially at the time of initial diagnosis and early on in the disease process.

- Stress was evident from daily life tasks, events, problems, fatigue, anxiety and frustration with having to deal with the limitations and life adjustments that Parkinson's disease often creates.
- Feelings of anxiety, frustration, embarrassment at not being able to do every day things and often depression, can have a huge effect on Parkinson's patients.
- Behavioural effects of Parkinson's disease manifested as withdrawal from others -on the one side they had the desire to be alone, while on the other side they experienced feeling incredibly lonely.
- Social effects of Parkinson's disease included a loss of interest in activities and social events. Some participants did not have any desire to be socially involved with their friends or families and found that they had withdrawn from social activities.

## **Conclusion**

Parkinson's disease can affect many aspects of a person's daily life. However, with careful planning and activity monitoring, the effects of Parkinson's can become much less stressful and instructive.

### **4.3.3.3 Theme 3-5: The physical, emotional and social effects of Parkinson's disease**

#### **Key findings**

In line with Bronfenbrenner's ecological systems theory, the participants in the study reported that Parkinson's disease did affect different systems in their lives, especially on the family and social groups.

- Participants tended to withdraw from social interaction with their existing social groups and activities involving friends and social events. However, where friends and family were supportive of the participants, a stronger bond between them seemed to emerge.



- The emotional strain and change in behaviour experienced by participants living with Parkinson's disease, resulted in additional stressors placed on the home environment. Participants felt guilty of the dependency they had on their partner and ultimately this affected how they perceived their role in the family.
- In combination with the motor and non-motor symptoms that affect daily living activities, participants living with Parkinson's disease and their families must learn to adjust and re-orient their lives in accordance to the progression of the disease, which often resulted in new roles within the family context, in which responsibilities are delegated between family members and all caregivers involved.

## **Conclusions**

When the phrase "Parkinson's disease" is mentioned the majority of participants automatically thought about the physical symptoms associated with the condition such as the tremors, the loss of mobility and other motor impairments. However throughout this study it became evident that coping with Parkinson's disease also takes a tremendous toll on the emotional well-being of the participants.

### **4.3.3.4 Theme6: Participants' view on their support systems**

#### **Key findings**

- Participants reported that they mainly managed Parkinson's disease through religious belief and faith, purpose and meaning, and the support of family and friends.
- Participants mentioned that maintaining a positive mind-set, ultimately led to a better well-being.
- Interventions, such as seeking support groups, could prove useful in providing social support for people living with Parkinson's disease.

- Involvement of health professionals in such endeavours may be crucial in order to ensure that people who live with Parkinson's disease find answers to some of their questions on possible causes of the illness.
- Participants identified the importance of belonging and having unity with others who had been diagnosed with Parkinson's disease. One reason for this is because they were able to relate to and understand the experiences of one another.
- Participants identified the importance of informational support in gaining access to information relating to Parkinson's disease, medication usage, and information which could aid daily living.

## **Conclusions**

People with Parkinson's disease rely on caregivers for a wide range of support like driving them to doctor's appointments to helping them get dressed. As the disease progresses, dependence on a caregiver increases substantially. It is evident in this study that coping strategies do have a direct impact on quality of life in individuals living with Parkinson's disease. More active strategies, such as maintaining a positive attitude lead to higher ratings of quality of life than those who approach coping through being in denial or having unrealistic hope.

### **4.3.3.5 Theme7: The effect of Parkinson's disease on the family**

#### **Key findings**

- Parkinson's disease takes a toll on patients and their families in terms of physical limitations, financial costs, and emotional fallout
- The financial aspects include medical costs such as those related to diagnosis, medications, surgeries, home care, counselling, physical therapy, and frequent hospitalizations

- While not everyone with Parkinson's will find that their relationships are affected, the condition can affect mood, self-image and communication with others.
- The effect on meaningful activities was essentially linked to the loss of social identities, as seen where participants described activities they used to do as part of their identity, for example, being able to go shopping, to cook, and to provide for the family as a father. Losses in function related to meaningful activities were also seen but also included taken-for-granted activities associated put on makeup
- Many participants stated that coping with Parkinson's and sharing the journey with their partner has made their relationship stronger.

## **Conclusions**

Parkinson's disease is an unwanted intruder and a potentially strong and disruptive force which can upset the emotional and economic relationships in the family. The empirical finding showed that recognizing that Parkinson's disease has an impact far greater than on the participant alone can help marshal the needed resources to help ease the burden for the participant and the family alike, and help foster a sense of cooperation and adaptive behaviour.

### **4.3.3.6 Theme 8: Participants' view on the treatment they receive**

#### **Key findings**

- Participants were generally very satisfied with the medical treatment they received, specifically referring to the prescribed medication.
- The successful resolution of the perceived treatment participants received are based on the utilizing of resources outside the family that may include extended family, friends, church, the neurologist and support groups.

- Participants shared that in utilizing these resources will result in a more informed understanding of the expectations concerning prognosis and rehabilitative efforts.
- The neurologist had a specific relationship, which was more than prescribing medication. Through good rapport and honest communication, participants can convey a realistic expectation regarding their future
- Participants indicated that the support groups they belong to are a tremendous source of information about the disease itself and ways of coping with it.

## **Conclusion**

Although it is clear from literature that there still remains numerous challenges regarding the quality of treatment for Parkinson's disease within South Africa, participants shared that they were satisfied with the treatment they received.

### **4.3.3.7 Theme9: Participants' view on how Parkinson's is perceived by society**

#### **Key findings**

- Participants argued that there are major gaps in the general public's knowledge of Parkinson's disease and this often resulted in the public turning a blind eye towards them. Participants felt that the general public needed to be alerted to the range of symptoms, the age of onset and how common the disease is.
- Participants have found that they tend to avoid public situations due to the fear of negative judgments by others.
- Participants specifically experienced stigmatizing attitudes about their communication style and physical symptoms. These attitudes were demonstrated by perceiving participants as having a mental disability.

## **Conclusion**

Given the nature of some symptoms of Parkinson's disease like tremors and rigidity, it is plausible that individuals with Parkinson's disease may be subjected to stigmatisation and discredited because of negative societal perceptions of bodily movement. The more visible and less “normal” the symptoms of Parkinson's disease are, the more likely they are to be judged as socially unacceptable. In summary, it seems that public attitudes about Parkinson's disease may be stigmatising due to various visible symptoms of Parkinson's disease. It is therefore important to consider the impact of this stigmatisation on a person with Parkinson's disease. Participants expressed that the stigmatisation negatively impacted them in many ways, including contributing to emotional stress, anxiety, reduced self-esteem, social isolation, embarrassment and shame.

#### **4.3.3.8 Theme 10: Participants' view on their future**

##### **Key findings**

- Participants were very aware of the burden they could become on others as Parkinson's disease forced a change of roles and increased their dependency on others.
- Participants shared typical concerns regarding their future, like reaching goals, travelling or completing specific hobbies.

##### **Conclusions**

It was evident that participants had normal concerns regarding their future, excluding their personal concerns regarding Parkinson's disease. Further positive expectations regarding participants view on their future seemed to emerge.

#### **4.3.3.9 Theme 11: Advice on coping with Parkinson's disease**

##### **Key findings**

- Participant shared the journey they had experienced in coming to terms with the disease, primarily not accepting what had happened or being in denial but

also because of the feelings of negativity, pessimism, depression, and chronic sorrow that could be exhibited,

- In order to enhance the ability to move, participants identified the importance of concentrating on movement, using self-talk and the mental rehearsal of movement.
- Participants identified the benefits of bringing the future closer by living one day at a time or engaging in the present and not thinking too far ahead.
- Participants identified the importance of making the best of their current situation which meant doing activities and continuing the best they could within the limitations imposed by the illness. Participants identified the importance of being positive and having a positive outlook which could influence well-being and act against a depressive outlook.
- Participants identified having hope or optimism for the future as an important way to live, because without it, life could be very hard. Individual's hope varied, for instance, some may hope for a "good" outcome from rehabilitation or for achieving goals, whilst others had a more concrete hope for a miracle cure.
- The importance of humour was identified as an important outlet for living with and experiencing Parkinson's disease.

## **Conclusions**

Acknowledgement and acceptance is initially described as the best advice for others. Further advice was given on acknowledging that something was wrong before diagnosis, then acknowledging and accepting the diagnosis, and then further being able to accept the different meaning it had for each person's life.

## **4.4. Recommendations**

Based on research findings, recommendations are made for application in social work practice, and future research.

#### 4.4.1 Recommendation for social workers for practice

Therapeutic intervention with people who live with Parkinson's disease holds unique challenges. There is increasing evidence that the effective care of people living with Parkinson's disease should involve a multi-disciplinary team of health professionals, including the social worker. However, basic intervention steps remain crucial in terms of practice application and these will now be highlighted.

- There is growing evidence for the efficacy of rehabilitation therapies for specific symptoms, necessitating the involvement of the wider multi-disciplinary team. More team members should be included in the treatment plan.
- Social workers are able to provide education and increase awareness to help reduce the stigmas associated with Parkinson's disease, thus they are an essential part of the team and should be included in the team
- Social workers need to address the importance of possible depressive states with individuals and care givers and give advice on and how they can obtain supportive services in their area.
- The participants discussed other strategies to decrease feelings of depression which included activities such as mindfulness, yoga, exercise, and support groups. Social workers can assist individuals and families with finding support groups like PASA and encouraging such activities within their area.
- This study revealed the important role education plays in theme eleven, sub-theme 11.4, in managing Parkinson's disease. The participants discussed that education assists individuals and families with information about the disease. Education will provide families and individuals with a better understanding of the disease and the progression of the symptoms appears less scary and daunting. Education of the individual, families and community would also help reduce misconceptions about the disease.
- Many of the participants share stories about patients who were taunted and treated differently because of members in the community lacking the

understanding of Parkinson's disease. Social workers can increase the education in the community about Parkinson's disease, to lessen stigmatization and misunderstanding of Parkinson's disease.

- The research also revealed that tangible resources are important when working with individuals with Parkinson's disease. Social workers should familiarise themselves with support group in communities and link individuals with these services. Therefore, it is important for social workers to be aware of the steady increase of individuals being diagnosed with Parkinson's disease and how we could provide more resources to patients. Parkinson's is an expensive and progressive disease. Individuals and their families are struggling to pay for medications and services to help reduce caregiver burnout.

#### **4.4.2 Recommendation for future research**

Future research should include a larger target sample in order to compare results and to be representative.

Using this research as a platform, future research can focus on different aspects or population groups in South Africa to determine that the experiences of people living with Parkinson's disease are similar to the findings yielded by this study.

Such research can focus on the factors influencing the experiences of people living with Parkinson's disease from different cultures.

Research on the impact of different cultures, traditional healers and different socio-economic groups can be determined and assessed. Most importantly, the incidence and prevalence of Parkinson's disease in South Africa should be determined conclusively to guide policy development and the provision of health and social work services.

#### **4.5 Concluding remarks**

The study aimed to explore and describe the experiences of people living with Parkinson's disease. Throughout the study it was found that Parkinson's disease



impacts significantly on the physical, psychological and social well-being of people living with this disease in a number of ways.

The research emphasized the need to intervene with persons suffering from Parkinson's disease, to improve their overall psychosocial functioning and well-being. Further research should be done with a more diverse target group to determine if the experiences of Parkinson's disease correlate or differ across cultures.

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## **6. LIST OF APPENDIXES**

### **APPENDIX 1**

ETHICAL APPROVAL LETTER



5 September 2015

Dear Prof Lombard

**Project:** The experience of people living with Parkinson's disease  
**Researcher:** C Bantjes  
**Supervisor:** Dr C Carbonatto  
**Department:** Social Work and Criminology  
**Reference number:** 28222505 (GW20150910HS)

Thank you for the application that was submitted for ethical consideration.

I am pleased to inform you that the above application was **approved** by the **Research Ethics Committee** on 1 October 2015. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

**Prof Karen Harris**  
**Acting Chair: Research Ethics Committee**  
**Faculty of Humanities**  
**UNIVERSITY OF PRETORIA**  
**e-mail: Karen.harris@up.ac.za**

Kindly note that your original signed approval certificate will be sent to your supervisor via the Head of Department. Please liaise with your supervisor.

**Research Ethics Committee Members:** Prof KL Harris (Acting Chair); Dr L Blokland; Dr JEH Grobler; Ms H Klopper; Dr C Panebianco-Warrens; Dr C Puttergill; Prof GM Spies; Dr Y Spies; Prof E Taljard; Ms KT Andrew (Committee Admin); Mr V Sithole (Committee Admin)

## APPENDIX 2

### LETTER OF PERMISSION FROM PASA





THE  
**PARKINSON'S**  
AND RELATED MOVEMENT DISORDERS  
ASSOCIATION OF SOUTH AFRICA  
REG NO. NPO 003-851 PBO: 18/11/13/4478

UNIT A  
126 BRAM FISCHER RD  
RANDBURG  
TEL + 2711 787 8792  
FAX + 2711 787 2047  
PO BOX 3990RANDBURG, 2125  
WWW.PARKINSONS.CO.ZA

**6.7.2015**

Chantelle Bantjes  
cbantjes@icas.co.za

Dear Chantelle

Re: **QUALITY OF LIFE STUDY**

This is to confirm that we are aware of your study on people living with Parkinson's Disease .

We fully support your initiative and give permission to you for conducting this research through PASA SA

Should you require any further assistance, please do not hesitate to contact us.

Kind regards

*Karin*

Karin Willemse  
National Director  
084 650 6500

*Gisela*

Gisela Stanek  
Admin. & Training Manager  
084 707 1153

## APPENDIX 3

### INTERVIEW SCHEDULE

## INTERVIEW SCHEDULE

### 1. BACKGROUND INFORMATION

- What is your date of birth?

### 2. Self-actualization

- How do you understand Parkinson's disease?
- Since being diagnosed with Parkinson's disease how has life been for you?
- How would a typical day in your life entail, please describe?
- Does having Parkinson's create challenges or opportunities every day?

### 3. Relationships and support

- What is your last/current employment?
- Have you noticed anything different in your working environment, work tempo, output after being diagnosed with Parkinson's disease?
- Who became part of your support system since being diagnosed with Parkinson's disease?
- Who do you see as your main support person?
- What is the nature of the relationship?
- Are you married/in a relationship or single?
- Did having Parkinson's disease make a difference in any of your relationships?
- Has having Parkinson's disease changed your role within your family unit (parent/sibling/child/grandparent) in any way?
- Has Parkinson's disease caused you to be more dependent on others, if so in which way?

### 4. Challenges

- Are you taking any medication for Parkinson's disease, if so does the medication have any side effects or affect your daily functioning?
- Any other treatment?
- What physical changes have you noticed living with Parkinson's disease?

- Are there any challenges you experience in your environment – physical, emotional, cognitive?
- Is there any financial constraint due to Parkinson’s disease?
- How do you experience peoples understanding of Parkinson’s disease?
- Do you have a medical aid or how do you pay for treatment
- How do people react to you in public if you have visible shaking or twitches?

## **5. Future hopes and dreams**

- What do you hope to achieve as a goal in life?
- What future challenges do you envisage living with Parkinson’s disease?
- What are your biggest fears living with Parkinson’s disease?
- Any recommendations for needs of people living with Parkinson’s?

## APPENDIX 4

### LETTER OF INFORMED CONSENT



**LETTER OF INFORMED CONSENT**  
**SECTION A: RESEARCH INFORMATION**

**1. Title of the study**

The experiences of people living with Parkinson's disease.

**2. Researcher**

The researcher, Chantelle Bantjes, (28222505) is a Masters student in Social Work at the Department of Social Work and Criminology, University of Pretoria.

**3. Background to study**

Pharmacological and medical interventions can make a positive impact on some of the mood problems associated with Parkinson's disease, but no cure has been found to date. By offering insight into the experience of people living with Parkinson's disease, such perspectives could benefit counselling services, by providing specific data on what the nature of the shared experiences of people living with Parkinson's disease are.

**4. Purpose of the study**

The reason for this study is to gain insight into the experiences of people living with Parkinson's disease. The researcher's interest in this topic was evoked by personal experience where a close family member was diagnosed with Parkinson's disease. Observation of changes in different aspects of this family member's life was noted, but the cause, nature and extent of this change is unknown. This has led to the research question "What are the experiences of people living with Parkinson's disease?"

**5. Procedures**

The National Director of Parkinson's Association of South Africa. PASA will provide the researcher with a list of potential participants interested to participate in the study, who reside in the Pretoria area and who are utilising the services of PASA. A total of 10 participants will be selected to partake in the study. Semi-structured face-to-face interviews will be used to collect data for this study; each interview will take approximately 60 minutes. The researcher will compile an interview schedule with questions which will guide the interview. Each interview will be recorded with your permission, to assist the researcher with the recording of the data. Following this session the researcher will transcribe this recorded session verbatim and use this to analyse the data. Thereafter a research report in the form of a dissertation will be written.

**6. Risks and Discomforts**

Fakulteit Geesteswetenskappe  
Lefapha la Bomotheo

No risks or discomforts are anticipated for you to take part in this study. Discomfort might arise throughout the interview, as it is a sensitive personal matter. Should the interview cause you any emotional harm, the researcher will refer you to a social worker at PASA branch in Pretoria East.

**7. Benefit of research**

You will not benefit directly from this study, however the data collected throughout the study will contribute to an improved understanding by professionals of the phenomenon. This in turn could be used to postulate ways in which to improve the professional services offered.

**8. Participant's rights**

Participation in this research project is voluntary and you can refuse to participate or withdraw at any time without stating a reason and without suffering any consequences. You will only be included in this study if you give consent to participate in the research.

**9. Confidentiality and anonymity**

You will not be identifiable through the research or in the research report. The researcher will achieve this by assigning a number to each participant to ensure anonymity in the data. The researcher will maintain confidentiality by not sharing information with members who are not part of the research process. Due to personal interviews, anonymity cannot be protected like anonymity in data, but confidentiality is ensured. The research data and the signed letters of informed consent will be stored securely in the Department of Social Work and Criminology, University of Pretoria for a period of 15 years, according to the stipulations of the University, after which it will be destroyed. You will receive a copy of this letter of informed consent.

**10. Contact details of researcher**

The researcher, Chantelle Bantjes can be contacted on 079 515 2840 if you have any concerns.

**Please sign the subsequent informed consent section.**

Yours sincerely,

**Chantelle Bantjes**

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**SECTION B: CONSENT TO PARTICIPATE IN RESEARCH**

I, \_\_\_\_\_ (Full name and surname of participant) hereby acknowledge that I have been informed about the research study. I am aware of what is required of me as a participant. I have read and understand how the research procedure will be followed. I have asked the relevant questions I may have had and I am aware of the confidential nature of the study. As a participant, I also understand that my identity will be kept anonymous. Finally, if at any point I choose to withdraw from the study, I understand I will not suffer any negative consequences.

I will receive a signed copy of this informed consent form.

Please complete the form below:

I, \_\_\_\_\_ have read and understood the purpose of this study.

**Participant:**

Name: \_\_\_\_\_ (please print)

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

**Researcher**

I have explained the study to the participant, and provided him/ her with a copy of the letter of informed consent.

Name: Chantelle Bantjes

Signature \_\_\_\_\_

Date \_\_\_\_\_



## APPENDIX 5

### DECLARATION OF LANGUAGE EDITING



**MAURINE FISCHER TRANSLATION AND EDITING SERVICES**  
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**Somerset West**  
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Fax: 0866 381 543  
2016-01-12

**TO WHOM IT MAY CONCERN**

This serves to certify that I have performed the editing services described hereunder, as the editor, on the terms and conditions set out below:

**Client:** Ms Chantelle Bantjes

**Nature of editing work done:** *Layout of document, correct sentence construction, spelling.*

**Title of dissertation edited:** **The Experiences of People living with Parkinson's Disease**

**Academic Institution:** **University of Pretoria: Department of Social Work and Criminology, Faculty of Humanities**

**Supervisor:** Dr CL Carbonatto

**Parameters of editing intervention:** *Layout and flow of the document, sentence construction, numbering, Table of Contents, List of references.*

**Formatting style used:** <sup>1</sup> **Arial 12**

**Referencing style used:** **Harvard Referencing Style**

I hereby declare that I have proof read and edited the above Mini-dissertation.

  
**Maurine Fischer**