

**The Psychosocial and Economic Impact of Parkinson's Disease on People Infected and
Affected by the Disease**

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The Psychosocial and Economic Impact of Parkinson's disease

On People Infected and Affected by the Disease

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Leki my beautiful Grand mom even if you are not with me today but I dedicated this thesis for your remembrance!

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Aged People have the right to live life fully so that adults with PD!

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Acronyms:

CT: Computerized Tomography

DBS: Deep Brain Stimulation

EPDA: European Parkinson's disease Association

EPPA: Ethiopian Parkinson's Patient Association

MRI: Magnetic Resonance Image

NINADS: The American National Institute Neurological Disorder and Stroke

PD: Parkinson's disease or Progressive Disease

PWDs: People with Disabilities

PWPD: People with Parkinson' Disease

Definition of Terms

Parkinson's Disease: is a condition of the nervous system characterized by various symptoms

Akinesia is a complete, or almost complete, loss of movement.

Bradykinesia: is slow movement of body

Tai Chi: a Chinese system of slow meditative physical exercise designed for relaxation and balance and health

Dopamine – one of many chemicals that send messages between nerve cells.

Deep brain stimulation (DBS) – surgical method and devices are implanted in the body

On time: when the medication control symptoms

Off time: when symptom control becomes ineffective/ not appearing to respond

Wear off: it is a period of time between the when the Levodopa drug has been taking for along period of time it will bring ineffective /unresponsive

MRI: Magnetic Resonance Image a scan that uses radio waves to generate an image of body tissue

Abstract

Parkinson's Disease (PD) is one of the life threatening diseases that impede the health condition of people around the world. The disease does not discriminate color, age and sex. According to various studies males are most likely exposed by PD than females. The prevalence rate in Ethiopia is unknown where as many studies conducted worldwide affirmed that one in five hundred people are infected by PD regardless of their age. The exact cause of PD is unknown but the loss of dopamine in the brain is the primary contributing factor for a person to experience Parkinson's Disease. Many studies agree that being at the age of sixty and living in toxic environment are the contributing factors for PD. The disease is characterized by tremors, slow voice, wriggling movement, communication difficulties. PD patients are suffering with multifaceted challenges. This study 'the psychosocial and economic impact of Parkinson's on people infected and affected by the disease' is the first of its kind in the field of social work as well for the social science. The author relied on qualitative study with exploratory nature and Addis Ababa is the center of this study that engaged dwellers from ten sub-cities. This study involved eighteen adults living with PD, four careers and three Neurologists. The modus of operandi applied to collect the data are Key Informant Interviews (KII) and Focus Group Discussions (FGD) and case studies. The finding of this study indicated that PD has brought multilayered psycho-social and economic impact on patients, family members as well as their close relatives. It was observed that the majority of the patients living with PD either experiencing early retirement, self-stigmatization, introvert behaviors, subjective experience of time, lonesomeness, depression, social anxiety and etc., divorce, frequent quarrel with family members, refrain oneself from social gathering, unable to deliver the social and communal commitments, wrong interpretation of PD, unable to make love and give birth are some of the daily challenges of the people with PD. The author also found out that PD information among family members, careers and the community members are still at infant stage; the public and private Medias are silent about the subject.

Key Words: PD/Psychosocial economic impact/Addis Ababa/

CHAPTER ONE

INTRODUCTION

1.1 Background of the Study

Parkinson Disease (PD) is a degenerative disorder of the central nervous system that affects individuals who are at the age categories of 60 and above. The exact cause of PD is unknown but various studies indicate that the cause is likely to fall into different categories. In the primary classification the cause of PD is due to the destruction of cells that produce dopamine chemical in the part of the brain. The poor living conditions of individuals accompanied with life stressor events such as carrying heavy materials, working in very stressful conditions, and the traumatic experience associated with accidents—all these can be categorized as secondary causes. Whereas the existence of PD in the family history, the exposures of people to chemicals, pesticides, toxic environments and other health conditions are also other exacerbating conditions that must be considered while working in the field of movement disorder.

Various studies have shown that Parkinson's disease affects one in every 500 people (<http://www.parkinson.org>) and according to this prevalence rate one can estimate that out of the total estimated population of 80 million people in Ethiopia the number of population living with PD is expected to reach 160,000. Of the total of 4.5 million adults above the age of 60 the number of adults living with PD is expected to reach 9,000 in the country.

PD as life threatening disease brings many impacts on the lives of individuals and the psychosocial and economic effects of the disease are immense. According to this study, the psychological impacts of PD can be classified as emotional, behavioral and cognitive impairments.

The social and economic impacts towards individuals, family members and communities are also huge. Majority of the participants dislike engaging in the social gathering like 'iddir', 'sergbet' and other communal events once they have started living with PD. Many studies have

shown that these isolation and refrain from communal participation was due to their postural instability, mask face, drooling and slow voice. The economic burden at all level is acute and infected and affected family members are facing extra health related costs due the progressive nature of the disease.

1.2 Statement of the Problem:

People living with Parkinson's disease face multifaceted challenges and problems in their day to day life. The challenges of PD vary from country to country depending on the availability of quality of services, and the efforts of individuals, families, institution towards mitigating the impact of the disease. In many developed countries– the organizations like EPDA in Europe and NINAD in America are supporting individuals with their comprehensive health service packages. The organizations in these two countries are doing extraordinary jobs and benefiting many people from the provisions of health updates, ongoing researches and assistive technologies. But in the case of Ethiopia many PD patients and their affected family members are suffering due to the unavailability of comprehensive service packages.

There are a number of institutional, environmental and attitudinal barriers which are contributing to the poor quality of life of PD and their caregivers in the country. The Ethiopian Parkinson's Patients Association is the only hope for individuals living with Parkinson's disease and their family members. The Association currently provides non-comprehensive service packages to its three hundred active members and these are due to lack of appropriate supports from concerned bodies including government and funding agencies.

According to this study many PD patients were found to be misdiagnosed and mistreated due to the inept experience of health professionals, lack of a standardized pathological test, and the lack of details in the PD course in the undergraduate programs.

Misconceptions and attitudinal barrier are also other contributing factors for many PD patients not to live their life fully and completely. Environment is also another factors to their challenges and in some part of urban and rural parts of Ethiopia people wrongly conclude that PD and/ or nerve related physical deformities are due to punishment from God. This study has shown that majority of participants do not accept the fact of the disease and denial is also one of the very common experienced due to information gaps and the non-existence of various organizations and support groups in the city.

The cyclical nature of PD as cause and consequences of psycho-social and economic impacts are said to be among the considerable challenges towards people. The physical deformity due to movement disorder and the existence of tremors, slowness of movement and creepy face have led participants of this study to experience self-stigmatization, the feeling of emptiness inside and mood irritability. In addition to these the acute economic burden and weak interpersonal relationships have led them to live hazy lives.

The existence of unsatisfactory support from families, communities, non-governmental organizations and the passive involvement of government in the areas of PD are among the major exacerbating factors for PD patient to live in the cycle of dependency.

Statistically speaking the number of PD patients in Ethiopia seems meager compared to other life threatening disease and from the social work point of view a single individual has equal value with the huge number of people. Thus being small in number does not necessary require lesser attentions from government, local, financial and care giving institutions. It is evident that the Ethiopian State has legal frameworks that stipulate institutions to take necessary action to fulfill constitutional requirements. Article 41/5 of the FDRE Constitution states 'The State shall, within available means, allocate resources to provide rehabilitation and assistance to the physically and mentally disabled, the aged, and to children who are left without parents or guardian.'

Due to the existence of multi-layered challenges experienced by infected and affected people with PD in Ethiopia, and by reaching to a conclusion that as there are no studies conducted in relation to the social, psychological and economical impacts of the disease in the country the author conducted this study and has come back with versatile lived experiences of infected and affected people.

1.3 Objective of the study

The study is aimed to explain the facts of Parkinson's disease and its impact on psychosocial and economic condition of individuals and affected members of PD in Addis Ababa.

Particularly the focuses of study were:

1. To identify the nature of psychosocial and economic impact of Parkinson's disease on the life of people living with PD and their affected family members
2. To enhance people's coping abilities, improve the operation of social systems, initiate social workers to engage in the development of a social policy
3. To highlight social work implication in terms of knowledge building, research practice, policy or advocacy in the area of Parkinson's Disease and identify the role of social workers
4. To demonstrate practical challenges regarding PD and come up with practical intervention strategies that would likely help family members and service provider organizations mitigate the risk and the consequences of the disease.

1.4 Research questions

This study answered the following questions:

1. What are the psychosocial and economic impacts of Parkinson's disease on infected and affected people?

2. How do participants react to the effects and consequences of the disease?
3. What are the impediments that PD failed to gain limelight at various levels?
4. What are the coping mechanisms that PD patients applying to mitigate their challenges?
5. What new approaches and service provision techniques shall be taken by institutions?

1.5 Significance of the Study

This study is aimed to look into the psychosocial and economic impacts of Parkinson's disease on infected and affected members. This study has come back with detailed findings and discussion accompanied with social work implications at three tiers and it is believed to help researchers, and practitioners and implementing agencies to understand the reality and interwoven effects of Parkinson's on individuals, family members, communities and the country. In addition, the study result which is pointed as social work implications are believed to contribute for students and researchers to use it as a knowledge building document and help them to do further investigation on the area. In addition the alternative intervention strategies proposed under the recommendation part of this study will allow development agencies to use them as a user guide for addressing life threatening disease.

1.6 Limitation of the Study

This research as the new study concerning the psychosocial and economic impact of PD, the researcher during document reviews has faced difficulties in terms of getting comprehensive information on the impact of PD on the health, economy and psychosocial aspect of patients in the country. The researcher during the data collection had also faced difficulties in applying many open ended questions by posing extra questions because the participants living with PD have speech problems and they are usually active for a short period of time which is between 8am-11am. When the researcher started conducting the KII and many of the participants were found to be experiencing lower voice at the middle of the session. Hence the researcher was forced

to conduct one interview at different sessions. This actually limited the number of participants as well the quality of information that has to be collected from the field.

In addition to the above stated reasons after the pretest the researcher was able to readjust the KII into a mix of close and opened ended questioner and this was done to collect appropriate information from the field without enforcing participants to be in a state of lethargy.

CHAPTER TWO

Literature Review

2.1. A Brief Overview of Parkinson's disease:

Parkinson's disease (PD) is a chronic, progressive, and neurodegenerative process that affects between 1 and 2% of individuals and mostly older than 65 years of age (Rodrigues et al, 2006: 1073). The average age of onset of the disease is 60 and this progress significantly and about 5 to 10 percent of people have "early-onset (Medicines in development, 2014,p.5).

The disease is named after the English physician James Parkinson, who first described the illness in 1817. Another name for this illness is paralysis agitans, which is simply the Latin translation of "shaking palsy." (Calne, Lidstone & Kumar, 2008, p143).

Parkinson is a degenerative neurologic disease. Degenerative means "declining in quality;" thus, the disease increases its severity over time and neurologic refers to the nervous system as a result of this the nervous system that gets worse over time. (Calne et al, 2008, p143). With progression of the disease, there are more physical implications, such as decreases in muscular strength and physical fitness along with mental, social, and economic implications for the individuals and their families (Rodrigues et al, 2006: 1073).

During the first half of century researchers began writing about emotional concomitants of PD and some researchers viewed PD as psychological and physical manifestations of intra psychic conflict and researchers' believed that emotional symptoms of PD were a reaction to the disabling nature of PD (James, 2010, p.1). In the nineteenth century PD was almost never seen before the age of fifty and it was seen as a degenerative process or defect of nutrition in certain weak or vulnerable cells.

According to European Parkinson's Disease Association, it is estimated that 6.3 million people have Parkinson's disease worldwide, affecting all races and cultures. According to the available

statistics, 1.2 million people in Europe have the disease (Basic Information about Parkinson's disease, www.parkinson.org). Approximately 50,000 Americans are diagnosed with Parkinson's disease every year. 95% of those diagnosed are over 50 years old. At any given time, about 500,000 people, or 1% of those over age 50 in the US are struggling with this condition (American NINDS, 2013).

Many studies have shown that PD affects about 50 percent more men than women, and the reasons for this discrepancy are unclear. Other studies have found an increased risk in people who live in rural areas and in those who work in certain professions, although apparent risks are not fully characterized (American NINDS, 2013).

Researches related to PD are lacking in Africa. However, because Africa is experiencing a demographic transition, the population will become much older by 2015 (increase in the percentage of persons aged 65 and over) and since PD predominantly affecting older persons, such disease are expected to become more common. To date, in Africa there have been no case– control or cohort studies of PD and there is no information regarding environmental or genetic risk factors (James, 2010).

Data on several aspects of PD, including drug responsiveness, quality of life, survival, and other socioeconomic effects of PD are also lacking in Ethiopia. Statistically speaking in Ethiopia there is no specific research that indicates the fact of the PD at national level but the Ethiopia Parkinson's Patient Association has suggested that the number of people living with PD in Addis Ababa will make up to ten thousand.

2.2. Major Causes and Symptoms of PD

The cause of PD is essentially unknown and many risk factors have been proposed, however, scientific evidence has not been found to support a large effect. The Possible causes identified include, accelerated ageing, oxidative damage, environmental toxins and genetic predisposition (The British Psychological Society, 2009, P.6). Though, the cause of pathological change in PD is unknown but many researchers have agreed that main pathological change of PD is the death of dopamine-generating cells in the substantianigra, a region of the midbrain (Parkinson Primer available at: www.parkinson.org).

People with PD classically present with the symptoms and signs associated with Parkinsonism, namely bradykinesia, rigidity and rest tremor. There is no consistently reliable test that can distinguish PD from other conditions that have similar clinical presentations (Royal College of Physicians of London,2006, P.3).Studies conducted by Menza, Robertson, Hoffman &Bonapace (1993) suggest that the symptoms of PD often appear gradually, and it usually begins on one side of the body first, and slowly progress over time. The symptoms of Parkinson's disease can be categorized as motor and non-motor symptoms include tremors, rigidity, and slowness of movement, postural instability and gait dysfunctions) and the non-motors can be categorized cognitive impairment, pathological face, anxiety and depression.

For some people with PD, cognitive impairment can develop and may cause significant disability and some studies suggest that as many as 36 per cent of newly diagnosed people with PD have one or more areas of cognitive impairment evident on formal neuropsychological assessment. Early cognitive difficulties associated with PD include working memory problems, slowed information processing speed, impoverished learning and recall, and subtle executive dysfunction (The British Psychological Society, 2009, p.5).

Quality life of individuals with PD is very important because of its characteristics, symptoms, and secondary complications (Kyle, 2010, p. 33). With progression of the disease, there are more physical implications, such as decreases in muscular strength and physical fitness, along with mental, social, and economic implications for the individuals and their families (Rodrigues et al, 2006, P.1073).

2.3 The Physical and Psychosocial Impact of Parkinson's disease

The quality of life of people with PD has been shown in some studies to be more influenced by a person's psychological adjustment to their illness and disability than by the severity of the disease itself (The British Psychological Society, 2009, P.6). Each year thousands of people incur traumatic injuries or illness that disrupts their manner of living. The experience and response of an individual who incurs traumatic physical loss is influenced by his/her unique characterological, cultural and biological self. It is not the severity or nature of the injury alone that determines the psychological response of victims rather it is their person in environment (meaning the social, physical, and biological environment and ecological fit between them that determines behavior (Kay&Sylvia, 1990, p.83).

According to Shindler& Brown(1993) the diversity of symptoms associated with Parkinson's disease and its management affect individuals' usual or expected physical, social and mental wellbeing, referred to here as health-related quality of life (HQL). For example, problems with movement can lead to difficulties with self-care activities, embarrassment, social isolation and depression.

Although PD is predominantly a movement disorder, other impairments frequently develop, including psychiatric problems such as depression and dementia. Autonomic disturbances and pain may later ensue, and the condition progresses to cause significant disability and handicap with

impaired quality of life for the affected person. Family and carers may also be affected indirectly. (Royal College of Physicians of London,2006, p.3).

The American National Institute Neurological Disorder and Stroke (NINDS publication, 2013) stated that cognitive impairment, mood swinging, psychosis, sleep disturbance, fatigue, neurobehavioral muddle are among psychological symptoms associated with PD. Fatigue is one of the most common, distressing and disabling non-motor symptoms of PD and there is currently no pharmacological treatment and modafinil is ineffective. (The British Psychological Society,2009, p.8).

A positive living Guide produced by H.Lundbeck and Tevaphrmatical industries in collaboration with EPDA stated that Parkinson's can cause considerable difficulties in a person's ability to communicate with others—speech can be affected in volume, tone, inflection and pace. Facial expression may become mask-like and limb movement restricted; handwriting can become smaller and smaller until it is indiscernible. Over 40% of patients with PD experience depression and evidence is emerging that depression can be considered an intrinsic part of PD rather than a reaction to disability. Dementia is an extreme manifestation of the non-motor symptoms representing severely compromised cognitive abilities, emotionality and personality (Hutton,Knoller&Ahlskog, 1996, p.46).

According to Kay & Sylvia (1990, p.83) there are four independent clusters of affective response that may occur when a person experience a catastrophic and sudden physical loss of functioning.

2.3.1 Disruption of Body Image and Body ego:

The body image refers to the mental representation of one's own body at any moment and it emanates from the visual perception and tactical exploration of the surface of one's body, sensation from the inner organs, skeleton muscular system, and skin. The physical self feels less

familiar in ways that may be physically painful, frightening or anxiety producing; while such example of disrupted body image as the phantom pain of the amputee are the familiar to the health care professional, they are usually an unexpected and unaccountable phenomena to the patient. The same is true for individuals with Parkinson's disease; they experience restless, sleepless and reality distortions (Keus et al, 2007, p.451).

2.3.2 Subjective Experiences of Time

The study conducted by Kay and Sylvia the subjective experience of time is the way time feels to an individual; whether there is a sense of past, present and future. Personality and mood greatly affect the subjective experience of time and time moves very slowly for depressed person because many patients including persons with Parkinson's disease experience time as moving painfully, slowly, and they become bored, restless, and unhappy. Suicidal individuals, for example, are found to be more present than past; the patient's subject experience of time is significant because of its usual incompatibility with the temporal orientation of family and staff (Kay&Sylvia, 1990, p.87).

2.3.3 Grief and Depression:

The undisputed present of loss encourages one to assume that grief or depression automatically follows severe injury. Depression is a characterized by a sense of a low mood, variance in appetite resulting in weight loss or weight gain, insomnia, physical agitation, loss of energy and fatigue, and diminished ability to think fully. The study of Kay&Sylvia(1990,p.87) suggest that one of the more significant factors affecting the likelihood of depression response is the sense of locus of control perceived by the individuals; a degree of believe that one's behavior controls the reward of the world. During the injury people with an external locus of control will be highly depressed following the injury than those of with an internal locus of control.

2.3.4 Social Isolation:

There are a number of factors in relation to Parkinson's disease which can contribute to the social withdrawal of the sufferer. As Parkinson's disease is a chronic illness, the potential for these factors influencing the individual become greater over a very long period. The greatest factor at present which contributes to the social isolation of people with Parkinson's is their preconceived ideas or myths about the condition. Studies indicate that many people worry that Parkinson's disease will either kill them, be inherited by their children, make them totally physically incapacitated, or directly result in dementia (www.thirdage.com).

2.4 The Social and Economic Impacts of PD

The incidence and prevalence of Parkinson's disease (PD) increase with age; with disease duration, both direct and indirect annual costs associated with this disorder will likewise continue to escalate. Given that the population of those 65 years and older is expected to increase from 35 to 80 million by 2040(www.ajmc.com/publications/supplement/2012)

A study posted online by *Am J Manag Care*(2012) stated that Parkinson's disease (PD) imposes a significant economic burden on the healthcare system. As the population continues to age and shifts to include a larger proportion of persons 65 years and older, the economic burden related to PD will continue to escalate. The majority of treatment costs in PD are associated with advancing disease; specifically, the costs related to increasing need for care (www.ajmc.com/publications/supplement/2012).

According to the American Journal of Managed Care, the annual economic impact occurred as a result of both direct medical expenses and indirect costs, such as lost income, disability payments and medical costs.(www.parkinsoninfo.org/about-parkinsons-disease/economic-impact).

The mental and emotional cost of PD on patients, families and friends cannot be quantified As with most chronic illnesses, the major burden of informal care is most often borne by the spouse and family members of the person with PD. Care responsibilities including physical demands can

be very significant and the personal, emotional, social and financial impact of PD on carers and family members can be huge. The change in relationships between people with PD and their spouses can be very distressing for all concerned, and it is, therefore, not surprising that care-giving can adversely affect the physical and psychological health of the carer (The British Psychological Society , February 2009:9)

2.5 Psychological Therapy and Social Interventions for Parkinson's disease

Many researchers have a limited understanding of the cause of Parkinson's disease and there are currently no definite ways to reduce the risk of this condition. Some studies have suggested that certain factors can lower the risk of Parkinson's disease for example higher caffeine intake, higher intake of vitamin E and nuts, higher intake of unsaturated fatty acids and regular use of nonsteroidal anti-inflammatory drugs. There are also practical intervention strategies that could improve the physical, psychological, socio-economic challenges related to the consequences of PD. These intervention strategies have been used by many health practitioners, associations to address the challenges faced by their clients.

2.5.1 Comprehensive and Community-Based Rehabilitation

According to Christofel Blindedn Missionary, in supporting services, institutions are encouraged and strive for a comprehensive approach. If the full impact of poverty on the lives of persons with disabilities, their families, and their environment is to be addressed, then a comprehensive community-based approach is necessary, including health care interventions, education, rehabilitation and sustainable livelihood development.

2.5.2 Palliative Care/PC/

The PC must be part of health institutions as well in associations working closely with PD and this care system along with case team is appropriate at any stage from diagnosis of an illness through to the end of life. Palliative care package consists of 1) key information; (2) Care Preferences; (3)

Legal Matters; (4) Financial Matters; (5) When I Die; and (6) Sharing Information (www.getpalliativecare.org, 2012).

2.5.3 Twin track Approach:

A Twin Track is a combination of approach focusing on disability specific(empowerment) supporting and empowering people with PD, their families and representing organizations through increasing their access to support services, health care, education, livelihood and social activities as well as through political empowerment and societal (mainstreaming disability) that are working to identify and overcome the barriers in society that persons with disabilities face, e.g. physical accessibility, communication, attitude, legislation, and including persons with disabilities into all aspects of development.(www.cbm.org/i/promoting-inclusion)

2.5.4 Regular Exercise

Regular practice of physical activity has well defined benefits for emotional health, because it is a recommended effective non pharmacological therapy for stress, anxiety, and depression (Rodrigues et al, 2006, p.1076). For instance, Bill Douglas claimed that, Tai Chi is one of rhythmic martial art exercises, reported to have beneficial effects for individuals living with PD, based on the study conducted at Florida University which concluded, “patients that attended Tai Chi classes for one hour/week for 12 weeks were less likely than a group of control patients to experience an increase in the severity of their condition and a decrease in motor function,” (www.worldwidehealth.com)

2.5.5 Support groups

Support group can be very useful for both the Parkinson's patients and their relatives and isolation can play a big part in depression and so encounters with others facing the same condition allows

people to share thoughts and feelings, to feel supported and to give meaning to their illness (www.thirdage.com).

Speech and language therapy: Patients with Parkinson's commonly develop dysarthria, which is characterized by poor articulation. Speech therapy is sometimes used to treat Parkinson-related dysarthria. Particular consideration is given to improving vocal loudness and pitch range, as in the speech therapy programme "Lee Silverman Voice Treatment" (LSVT). Teaching strategies optimise speech intelligibility, ensuring that an effective means of communication is maintained throughout the course of the disease and helpful technologies are also used. (London National Institute for Health and Clinical Excellence 2006).

Conceptual Frame work

The researcher during this study considered essential sociology and psychology related theories like system, structural functionalism and psychological as substantial inputs. As it is stated earlier 'grounded theory' was developed during the data collection process.

A system is essentially any set of objects, with their attributes, which relate to each other in a way that creates a new super entity. The family is a social system (Winton, 1995, n.p) and it is a boundary-maintained unit composed of interrelated and interdependent parts such that an alteration in one part affects all components of the system. Family systems are typically composed of one or more subsystems, smaller units (e.g., parental, spousal) which serve various functions within the family system.

Fig 1: The Short term and long term impact of PD (Source: this thesis Author)

Psychosocial impact:

- emotional
- behavioural
- memory problem, Stigma and Discrimination
- Loose social ties

Biological impact:

- Postural instability
- facing difficulties while rasing from chair and when movong across room

Economical Impet:

- inadequate income
- dependency rate
- medical cost expense
- Low pension funds

Lack of Institutional capacity:

- mis dignosis
- mistreatment
- lack of health insurance
- lack of accessing DBS, Speech therapy,

CHAPTER THREE

Research Methodology:

3. Methods

3.1 Research Design

This study used a qualitative design with a great purpose to explore a deeper understanding of the facts, causes, consequences of the unfamiliar disease and coping mechanisms of the sufferers and their affected members. By applying this approach the researcher was able to formulate a grounded theory and explore the psychosocial and economic impact of Parkinson's in the study area.

This study was in fact passed through exploratory research design as there is no single study conducted in the areas of psychosocial and economic impact of the disease. The researcher in addition to the KII and FGD data collection tools had also used case studies and home observations as pertinent approaches to dig out sensitive information that our society silent about the matters . Hence the researcher has found out new insights, finding and results that can be used for direct interventions as well as for further studies in the area.

3.2 Scope of the Study

The scope of study was confined in the capital city of Addis Ababa with a special focus on the Ethiopian Parkinson's Patients' Association (EPPA). The Association's office is located in Kera, which is 7 kms from Piazza. The Association due to encompassing members from ten sub-cities of Addis Ababa the researcher was able to collect information in connection with person in environment, which is one of the causing factors for Parkinson's disease. In addition to this, those PD patients who use holy water as treatments and PD outpatients in Zewditu and Tikur Anbessa government hospitals were also incorporated as part of the study.

3.3 Population of the Study

The study involved different categories of participants with the purpose to complete information from various angles. Individuals, groups, organizations, and programs were the key categories of unit of analysis in the study. In this study a minimum of thirty two participants were engaged and based on the EPPA membership fact sheet twenty nine participants were selected to be part of KII, FGD, Case study and home observation. Out of twenty nine participants ten of the participants living with PD were engaged in the KII; eight of participants living with PD were engaged in focus group discussion; seven of patients with PD engaged in case study and home observation, and the rest four participants were care givers and friend of patients. In addition to this three neurologists were also part of the study.

3.4 Inclusion criteria

The researcher had set various preconditions to select study participants. In the application of KII the health status of individuals living with PD, the age brackets of 31-70, years of vulnerability with PD (from one year to twenty years) were considered to be part of the selection process. In the case of focus group discussion, the participants' selection was carried out on the basis of patients living with Pd and those who have experience on care provisions for patients with PD. In the application of case studies and home observations, all participants were set to be patients living with PD. In addition to the direct participants of the study neurologists were selected on the basis of work experience with PD.

3.5 Sampling Techniques

The researcher had applied purposive sampling technique as all the necessary information was acquired directly from people infected and affected by Parkinson's disease. According to Padgett

(2008) this is one of the sampling techniques in qualitative research that is deliberately made to select respondents based on their natural ability to give the required information. Hence the researcher had managed to collect valuable findings due to the application of purposive sampling technique. The study participants were thirty two (female=44% and male=56%) and of the total twenty five of the participants were adults living with PD and the rest four participants were care givers. In order to validate the data three Neurologists were also participated in the key informant interview questioner.

3.6 Sources of Data

Primary and secondary sources of information were used as part of this study. The primary data was collected through the application of in-depth interviews, Focus Group Discussion/FGD/, case studies and home visits.

Even though there are available studies in the areas of Parkinson's diseases globally as well clinical studies in the study areas but finding social researches and documented files in developing countries especially in Ethiopia were a rare case. Hence, the researcher reviewed electronic and published materials such as books, magazines, and journal articles as part of secondary sources.

3.7 Data Collection Procedures

All the necessary information from each unit of analysis was collected from the field without hesitation as there was supportive letter written by the School of Social Work. The researcher had also prepared the consent form to be signed by the study participants. During the data collection process the Executive Director of EPPA had officially suggested the study participants to cooperate and be able to provide true information for the researcher. In every step of the data collection process the researcher had introduced herself as well as the objective of the study to the participants. During the group discussion the seats were arranged in circle style by which

discussants were able to share their experiences and coping mechanisms. The study participants were also allowed to freely enter and exit and this is due to the nature and effects of the disease; and it was observed that majority of them were taking dopamine stimulants freely in the middle of the session.

The researcher during the key informant interviews, Focus Group Discussion and case studies had had a face to face conversation to grasp the verbal and non-verbal communication of the study participants. The researcher during case studies had used the tape recorder to prevent emotional as well as information disconnection between the participants and the researcher. During home visits the researcher did not go with guidelines where as she went there as a visitor. The researcher from home visits was able to construct ideas and could have a better understanding on the relationship between patients and family members. In one of the home visits the researcher was able to see very comfortable chair used by the PD patient and also the house lady was really cooperative for the patient.

3.8 Data Collection Tools

3.8.1 Interview: there were two kind of key informant interviews guides prepared for patients and Neurologists. The interview questioner which was initially prepared for the patients had been readjusted three times. During the pre-test session the researcher was found out that the open ended question alone is never enough to get appropriate information hence a mix of open and close ended questions were prepared. The key interviews were more of unstructured type and hence the researcher used probing questions apart from the KII guidelines.

3.8.2 FGD guides: the focus group discussion guide was prepared by considering the research question, the patients and the participants experience to the disease. In the preparation of the guide very sensitive concerns like taboo words and sensitive issues were avoided as the groups were a combination of both gender and discussants have different knowledge and culture exposures.

3.8.3 Case study and observation: The case study and home observation were conducted to gather the feeling, emotions, perception of an individual's, family members and the community towards PD and the effects of the disease. These applications were actually helped the researcher to gather the untold stories of Parkinson's disease and has found out hidden concerns. The concerns are – the use of Viagra for alleviating erection problem by Pd patients are now becoming common practice and the other issue is the discordant couples are living a pretending life and these are basically the cause for family disintegration.

3.9 Research Procedures

This study was conducted by applying different procedures. With this regard the researcher primarily had developed the thesis proposal by visiting Ethiopian Parkinson's Association and reviewing documents from the secondary resources. Up on the approval of research topic, objective and statement of the problem the researchers had passed through the development and pretest of key informant interview and focus group discussion guidelines.

The support letter from the Addis Ababa School of Social work was collected and this support letter was showed up for the concerned bodies such as Ethiopian Parkinson's Association and Neurologists who are working in Zewditu and Tikur Anbessa hospitals. The consent from was also prepared and applied by the researcher to keep the confidentiality and the anonymity of the data.

This study had passed through all the required research procedures from the data collection to interpretation and reporting the study. Hence, the researcher had organized the report in to five section by which the American Psychological Association/APA/report format was applied and different secondary sources like journals, books, websites and periodic were properly sighted in the study document.

3.10 Data Analysis Techniques:

All the data from the field were organized in thematic areas and translated from local language to English. The researcher had also entered the data in the excel sheet and all the coded information and transcribed data were rechecked and they were free of errors. The excel data supported by pivotal tables were able to produce pertinent qualitative information and this helped researcher to easily filter socio-demographic variables, coping mechanisms and other suggestions forwarded by the study participants. The finding and discussion parts were written by referring both the research question and objective.

3.11 Ethical Consideration

All the confidential information which was collected from the field was handled properly to minimize the risks of publicizing personal information. In the case of reporting or case studies the researcher has used pseudo names and codes throughout this document.

The Amharic consent form was also signed by the study participants to keep their confidential information, and for those who were unable to read and write the researcher had read the consent form and assisted them to put their signatures on the paper. The consent form basically incorporated the 'to do or not to do concerns' which have to be protected during the data collection process as well as at reporting stage.

3.12 Validity of the Study

The data collection tools such as FGD and in-depth interview, case studies and home observations were the deliberate mechanisms employed by the researcher to enhance the response rate of unit of analysis as well the validity of the data. In this study PD patients had been frequently contacted at various data collection processes and this helped the researcher to deeply understand the impact of the disease. Supplementary to this, the researcher assured the quality of the data by triangulating

information from concerned bodies such as family members, neurologists and service providers working on the areas of PD. The researcher prior the development of guidelines process had also reviewed various literatures which could be pertinent to the study. Thus, the analysis part was done by integrating findings with some facts; researcher's opinion and by integrating theories and the lived experience of patients and their care providers.

CHAPTER FOUR

5. Findings

This section encompasses the cocktail of findings which were collected from the application of primary sources such as KII, FGD and case studies. The raw data collected from the field were entered in to excel sheet and the important variables associated with psychosocial and economic impact were extracted due to the application of pivotal table. The finding reports are presented in three thematic areas: the socio-demographic profile of the participants, nature and the fact of the disease in Addis Ababa and the effects of PD on health, economy, psychology and social aspects of infected and affected people.

Table1: Socio-demographic information: KII with adults with PD

Name	Age category	Gender	Education	Marital	Job	Birth place	Sub city	Religion	Categories Years of living with PD
PwP D01	57-69	Female	Primary	Divorced	Self employed	Rural	Kolfek eranyo	Orthodox	sixteen to twenty
PwP D02	57-69	Male	college diploma	Married	Government	Rural	Akaki	Orthodox	eleven to fifteen
PwP D03	44-56	Female	Primary	Married	jobless	Urban	Lideta	Orthodox	one to five
PwP D04	57-69	Male	college diploma	Divorced	jobless	Urban	Kolfek eranyo	Orthodox	one to five
PwP D05	44-56	Male	Primary	Single	jobless	Rural	Bole	Orthodox	six to ten
PwP D06	31-43	Female	BA	Married	Government	Urban	Gulele	Orthodox	one to five
PwP D07	above 70	Male	Primary	Married	jobless	Rural	Lideta	Orthodox	one to five
PwP D08	57-69	Female	Secondary	Married	jobless	Rural	Kirkos	Orthodox	one to five
wPD 09	57-69	Male	Vocational	Married	private sector	Rural	Arada	Orthodox	six to ten
PwP D10	above 70	Male	Primary	Married	private sector	Rural	Kirkos	Orthodox	eleven to fifteen

Table2: Socio-demographic information: FGD with adults with PD

Name	Gender	Age	Years of living with PD	Caregivers	Children	Heard about PD before your diagnosis	Risk factor for PD	How do you know your PD status
Lishan	F	73	3	Daughter	4f; 4m	No	Blood pressure	Doctor
Assessfa	M	78	8	Daughter	3f; 3m	No	Accident	Doctor
Genetu	M	65	11	Family	2f; 1m	No	Carrying heavy wood; muscle sliding	Doctor
Felke	M	58	4	Family	6f; 1m	No	Accident	Doctor
Asgele	M	62	4	Family	1f; 3m	No	Don't know	Doctor
Amsale	F	55	1	Child	Children	No	On job accident	Doctor
Yebrehu	F	75	>10	no one is constantly providing her care;	No	No	Stress	Doctor
The founder of E-PPA	F	48	16	Spouse+ children	2f; 1m		Exposures to chemicals	Doctor

Table 3: Profile of Care Providers

Name	Gender	Age	to whom you are providing Care
Caregiver 01	F	51	Mom
Caregiver 02	F	55	Husband
Caregiver 03	M	69	Friend
Caregiver 04	M	23	Mom

Table 4: The Socio Demographic Profile of Study participants in case studies and home observation

Name	Sex	Age
Case 01	Female	58
Case 02	Female	55
Case 03	Male	64
Case 04	Male	60
Case 05	Male	89
Case 06	Female	50
Case 07	Male	57

Table5: Socio-demographic information: KII with Neurologists:

Sr. No	Code	Position	Name of Hospital	Years of Experience on PD and other nerve disease	Do you think the cause of PD varies from country to country	What do you think the cause of PD	What are the most likely cause of PD in Ethiopia	The most cause of Juvenile Parkinson an (Person at the Age 20)
1	Male Neurologist I	Professor Emeritus, Faculty of Medicine AU	Girabet Tehade so, Butajera	>30 years	Yes	Aging, vascular, toxic environment	Unknown	It is a rare case in the case of Juvenile; it is believed that toxic factor than hereditary
2	Female Neurologist II	Resident RC Neurology	TikurAnbessa and Zewditu	6years	No	Genetic; hereditary	genetic	Hereditary
3	Male Neurologist III	Resident RC Neurology	TikurAnbessa and Zewditu	3 years	No	Neurodegeneration	genetic	Genetic/Hereditary

4.1 Socio-demographic profile of participants in Key Informant Interview

The total population of this study was thirty two participants and of which twenty five were people living with PD, four were caregivers and the rest of three were neurologists.

Facts on the above Table 1 has shown that there were ten adults living with PD (four female and six male) who were fully participated in the key informant interview processes and all of them were in the age brackets of 31 and 70. As education status concerned fifty percent of the respondents have either completed their education at primary level or dropped out and twenty percent of them had college diploma and the rest thirty percent had certificate and BA. Marriage was also another important variable which was considered to be part of the study and this study was found out that ten percent of them were single, twenty percent of them were separated after the appearance of PD and the rest seventy percent were married and of which 10 percent of them were

PD couples. Concerning the person in environment seventy percent of the participants were born and raised in rural part of Ethiopia and the remaining thirty percent of participants—their origins were from Addis Ababa. In connection with the types of job ninety of the participants had lost government or private jobs prematurely due to their physical impairments, as a matter of fact PD is affecting people who are at the productive ages and on average 50 percent of the PD patients, ranging from a minimum of one year to a maximum of twenty years, were found to be suffering with the life threatening disease.

4.2 Focus Group Discussion with People living Parkinson's disease:

It was on April 26 at ten in the morning that the researcher had started the FGD with eleven people living with PD (eight patients with PD and three care givers). The discussion was held at Ethiopia Parkinson's Patients Association's office and the seats were arranged in a circular form with the purpose all participants to see each other as well for the researcher to able to record their verbal and non-verbal communication. The objective of mixing PWPD and care givers was actually done deliberately because the existence of such an arrangement can be used as a platform for experience sharing.

4.3 Socio-demographic profile of Neurologists:

The three neurologists were invited to participate in KII with the twenty eight questions. The researcher had deliberately invited medical practitioners by engaging people from middle to senior level. During the KII with Neurologists it was observed that there is a knowledge gaps as well capacity difference among neurologists in the application of clinical diagnosis and the work experience in the area are among the reasons stated by Neurologist I. The Neurologists engaged in the study had a work experience from minimum of three to maximum of thirty years.

4.4 The Nature, Facts and Myths of the Disease in Study Area

The researcher asked the participants to respond the facts and figures of the disease in the areas where they are living and majority of participants refused to guess the number of patients in Addis Ababa. It is a shock finding that all of the participants in KII and FGD have never heard about PD disease in any communication tool including the national media before they went to hospitals for checkups. Even a lady living with PD has never heard about the disease though her husband is suffering with PD for many years earlier on her status. It was found that some patients prior their examination had noticed symptoms such as tremor in one hand, wriggling movement, dizziness, soft voice, masked face and rigidity.

The founder of E-PPA in this regard also responded that it is difficult to forecast the number of patients living in the city this is due to the fact that there are no clear information announced by the government and as a matter of the fact that majority of PD patients believe that they are the only person who are infected by PD in the world and that is why the number of PD patients is still unclear in the case of Ethiopia. The founder of E-PPA in her response stated that though the patients know their status very clearly either they confined their secret within one self and/or family member. Some even if they disclose about their disease they do not know about where to go or even they have no clue where our association is located. She added, even if there are a number of rich, elites and influential PD patients living in Addis Ababa but they do not want to join the Ethiopian Parkinson's patient's associations.

Even though the exact cause of PD in Ethiopia is still unknown but majority of the participants clearly stated that they have either family members or neighbors who are suffering with PD. Lishan in this case told to the researcher that her forty-year old daughter is now suffering with PD and in the case of Genetu his aunt and uncle had a PD history, and Feleke's younger brother is

also suffering with PD and in the case of PD couples Amsale and her husband is living with PD; even if there is no PD history in Assefa's family but he mentioned that he has one neighbor living with PD.

The researcher also asked the participants about the perception and thinking of the disease. The name Parkinson's disease or progressive disease in Ethiopia is unknown and still a contentious issue unlike other life threatening disease. Pd has various local names in Addis Ababa and according to KII and FGD participants: nerve, 'Yayergitchet'/draft/ likift', yeseytanbeshita/ evil spirit / demetgeday/ cat killer/are some of the local names given for PD. In a very traditional judgment that the context of life threatening disease and the people living with AIDS and PD are usually connected with estrangement from God and the wage of sin is either a long suffering 'yekumsekaye' or death.

All FGD participants believe that the cause of their disease is somehow connected with God and the community has seen them as sinners, and sinners are believed to receive their punishments from the supreme power 'God'. In the same way sixty percent of the KII participants associate their susceptibility with God or an evil spirit in the form of 'lekift', 'metet' /wizard and/ or with some job related accidents, workloads and stress. W/ro Lishan suggested that "my prior health condition with blood pressure is the causing factor for me to live with PD"; whereas four patients (Asseffa, Geletu, Yibreha and Amsal) had stated that their susceptibility is due to various accidents either they were engaged in risky job, or had a car accident and for some the cause was due to workload and life stressors and traumatic experience. For the case of Feleke draft air was the cause for his susceptibility and in the case of Assegele the cause for his susceptibility is unknown; whereas the founder of E-PPA, suspicious about toxic environment because she used to work in an industry where she had exposures with chemicals.

In the case of very experienced Neurologist I who worked for over 30 years stated that the cause of PD in Ethiopia is unknown though various factors like aging, hereditary and toxic environment are recognized in Europe and other Asian countries. In contrary Neurologists II and III the cause of Pd in Ethiopia is hereditary and especially for juvenile Parkinsonism, who are infected at the early age of 20; whereas Neurologist I refused that the cause of PD for person who are infected at the early is due to toxic environment than hereditary influences.

Concerning the concept of PD vis-à-vis nerve the researcher had found out that professionals including health practitioners and service providers have been interchangeably using the name PD with nerve disease and many of the KII participants living with PD have also proved that the name Parkinson's is new term to them and out of the total participants sixty percent of them call their health status as nerve than Pd. Similarly During the focus group discussion all participants agreed that there is a strong similarity between nerve diseases and PD— in the case of w/roYibrhu when she went to the hospital for the first time the Doctor diagnosed and told her it is a nerve disease from that time onwards she calls her disease a nerve rather than PD.

4.5 Reactions towards PD

The researcher asked the participants how did they know their Pd status and how their first reaction looked towards the disease and almost all of the FGD and KII participants responded as they all went to hospital for diagnosis and it was their Doctors who told their PD status for the first time and none of them were acquainted with the name PD in earlier times and let alone recognizing the extra information—the cause, symptoms and the consequences of the disease— in which any of electronic and print medias are silent about the subject. In the case of reaction towards the subject of Pd seventy percent of the participants responded as they did not react badly when they hear their status for the first time. W/ro Lishanin her statement stated that I wrongly perceived PD as a normal disease at first and thought that it is curable after I complete the prescribed drug and later

in time I understood PD is a progressive and incurable as well a life threatening disease. She added even though the implications of PD is much sever than cancer and HIV and AIDS but it is not a niche area for various funding institutions including government, international and local NGOs. The reaction of the people towards PD has now changed due to the increasing knowledge on the area and understanding of the disease is a progressive and in this case majority of them have now developed depressions, self stigmatization, anxiety, and even in the case like PwPD 10 he sold his house because his wrong thoughts were emanated from a despair feeling inside associated with the effects of dwindling quality of life.

In the case of Ato Asseffa he used to hide his hand if people were around with him because he had seen many people were scared on his trembling hand and gave him a lip service and he added people who have trembling hands are usually associated and interpreted as if they have killed cat. Whereas W/ro Lishan refused the association of killing a cat with a hand tremor and she argued that if that was the case I killed more than ten cats but my hand is still free of tremors.

4.6 Service Providers and the Implication of Service Packages in the Study Area

Ethiopian Parkinson's Patients' Association is the pioneer and the only institution working on the areas of PD and has members living in the ten sub-cities of Addis Ababa. In addition to this the association provides trainings, peer to peer education, and financial support for members. The founder of E-PPA says "I am lucky because I was able to establish this association with the unwavering support from family members". The association is now a pioneer umbrella organization in Ethiopia and supporting those who are in need. My association with the financial support receiving from German and other international funding agencies, is now supporting members with limited care and support services like training for members, pocket money of up

to 300 Birr per month which will be used for medical costs, and celebrate world Parkinson's disease every year on April 11.

During the discussion and document review the researcher has come to understand that there are also a number of private and government hospitals that are providing services to Parkinson's patients in Addis Ababa. To name a few Zewiditu and Tikuranbessa are the government hospitals that are providing outpatient services to people living with Parkinson's disease. For the patients who have low income the hospitals provide free diagnosis and dopaminestimulants such as levodopa and carbidopa and seventy percent of them are benefiting from the services. As majority of the participants explained the supply of free drugs lack consistency and they are usually forced to buy medicines at a very expensive cost ranging from 55-65 for 10 tablets. Eighty percent of participants rated that the services packages that are providing in health institutions are poor and the rest twenty percent rated it is so-so 'menimaylem' though the services are still an incomplete package.

According to the Neurologist I the services available in the hospital are not providing dopamine stimulant, counseling, DBS, or support group rather they use a referral system in the case of general practitioners who diagnose the patients.

Whereas, Neurologist II&III responded that there is not as such a comprehensive service packages available in the areas where they are working except prescribing drugs which are very few for patients with minimum income. In this case almost all neurologist participated in the KII rated that the services available in the private and government hospitals are still in a phony state, in which various packages like physiotherapy, counseling, support group and DBS service are not even available in the giant hospitals.

As respondents stated that the dopamine drugs prescribe for PD patients vary from person to person depending on the levels of mild, medium and the chronic appearance to the person. Levodopa, carbidopa, bisacody are the dopamine stimulants prescribe for PD patient to improve one's body movement, tremors as well for some to serves as nutritional complementary. According to Neurologist II stated in the case of few downs and erection problems as part of other drugs sildenafil/Viagra/is also prescribed for PD patients.

The drugs have also side effects that appear on to the lives of PwPD as the time flies the drugs that are taken to reduce the negative effect of the disease become wear-off. PD patients who are at the medium and chronic stages experience their drugs may be wear off/non-responsive; for some who are at mild stage may continuously experience the yo-yo disorder, by which the person will be active shortly after the drug is taken or being passive once the effects of the drug is deteriorated.

if the drugs are taken at the mild stage the dopamine stimulant will be very effective even and one can use the same drug for more than 25 years and for those who started the drugs at the medium stages the effectiveness of the stimulants will be more likely to be 12 years and for those who started at chronic or advanced stage the same medicine will likely to be effective from 8 to 10 years, if it is regularly taken Neurologist III said.

The other pertinent factors that threaten the quality life of PD are the high cost of the medicine and the inaccessibility of the drugs and as a stroke of luck the drugs is somewhat available in Addis Ababa. Whereas, for patients living in rural cites of Ethiopia such the dopamine stimulants are not available even there are no hospitals which are ready to give services for residents.

The patients explain that the drugs have their own pros and cons and for all patients except PwPD 4 and 9 the dopamine stimulants are helping them to reduce their rigidity and communication difficulties. For majority of the patients those who have taken medicine for more than 6 years are now facing difficulties and experiencing yo-yo disorder by which their health mood meter is one

time on and the other time off. And for the patients like PwPD 4 and 9 the medicines have reached to the wear-off stage, and for the rest of patients the side effects of the medicines are sweat, gastric, bad smell, constipation and nausea.

The researcher put a question what the diagnosis and treatment look like in the health institutions and the Neurologist I in this regard responded that clinical diagnosis is the dominant and the primary technique that is applied for suspected PD patients. The Neurologist uses his judgment, refers medical history of PD as well asks the patients to move around the room. In addition to this clinical diagnosis he also uses other supportive techniques that will be applied like the use of MRI and CAT to scan the brain in the case of calcification. In the same way Neurologist II is also applying Clinical diagnosis and rarely uses CAT and MRI, and in the case of Neurologist III, he only applies clinical diagnosis for suspected PD patients.

In connection with the diagnosis techniques all Neurologists (I, II, III) responded that

PD patients may be wrongly misdiagnosed due to the predominate application of clinical technique by which the Neurologist uses the medical history and personal judgment of Patients that resonate from unilateral resting, postural instability, or by just looking tremor in one hand.

The other factors that contribute to the misdiagnosis and mistreatment are the neurologists less experience in the area as well as stated by Neurologists even in undergraduate program the course of Parkinson's disease is not given in detail as this is the case practitioners could have little knowledge in various levels of PD from mild to the advanced stage. The existences of incomplete cycle during clinical diagnosis as well when patients are being diagnosed by general practitioners are also the other contributing factor for misdiagnosis and mistreatment as stated by Neurologists.

Table 6: Advantages vs. Disadvantages of Clinical diagnosis For PD patients:

Neurologist	Advantage of Clinical Diagnosis/personal judgment	Disadvantage
Neurologist I	Simple, not time taking; diagnosis can be done in the absence of diagnostic procedures especially in rural settings;	It is the only means for diagnosing patients with Pd
Neurologist II	Simple, can be diagnosed by seeing the physical movement	Pd has similarities with other nerve disease
Neurologist III	Limits the diagnosis expenses of patients, saves time that is going to be taken for unnecessary investigations,	Misdiagnosis/ treatment for unable to identify Pd with other nerve disease

4.7 Effects of PD on Health and Economy of patients with PD

Health and economy are essential elements in measuring the wellbeing and the quality life of a person. Parkinson's among the life threatening diseases in the country causes all multi-faceted challenges on the daily lives of the people and the disease source is oftentimes religiously associated with curse and punishment from God, or associated with 'metet' evil spirit. In light of these multilayered problems majority of PD patients are suffering with impact of the disease that brought to their lives with lack of dopamine drug and they usually lead a traumatic life helplessly.

The researcher had found that the impact of PD on the health status of the patients and family members are so immense and majority of the patients who are suffering with the disease either they totally or partially physically impaired as result of these they are forced to quit their jobs

Whereas patients who used to work as self-employed would have now no chances except completely losing their sources of incomes and being able to economically dependent on family members.

The negative impacts are too many and prolonged throughout their lifetimes, it is noted that seventy percent of the participants experience mobility, communication and functional difficulties, and also face weight loss, frequent urination, insomnia, sexual dysfunctional, lethargy and cognitive disorder. Of the total twenty percent faces only functional mobility like unable to dress, hold cup, unable to drive etc., the rest ten percent belongs to those who have mobility and communication difficulties.

Sixteen years ago, the founder of E-PPA with a master's degree, had a work experience in a factory and also engaged herself in the consultancy firm businesses. She was one of the bread winners in supporting her family's source of income. She had done a lot of consultancy works for various institutions but now suffering with the PD and unable to continue with the sophisticated and network demanding businesses.

The effect of the disease has completely transformed my physical capability to a disability, the founder of E-PPA said, I have now difficulties to move from place to place and my speech is also affected though I do not have a hearing impairment and dressing problem. But majority of the association members are facing difficulties and they are either totally and/or partially unable to read and write, and feed and dress by themselves.

Dependency and living every day with the prolonging progressive impacts of the disease are really painful especially for patients who have no sources of income. PD is also severely affecting the livelihood of the patients and due to their physical immobility, communication and functional difficulties ninety percent of them quit their job prematurely meaning before they reach to the

retirement age of sixty. All participants are expected to frequently visit hospitals one time in three months; costs related to drug, checkups along with the transportations are the very expensive concerns that infected and affected family members are experiencing on their lifetimes. According to neurologists, disability, an early retirement, minimum pension funds, their dependency on their family members, the high cost of living, high cost of medicine and transportation cost are among the factors that could be categorized under the impact of economy in association with PD. As repetitively reported PD patients do not come to hospital due to the ranges of difficulties from knowledge gaps to the high cost of transportation and medication. Majority of the PD patients in this regard acknowledged that they are unable to afford the costs associated with medicines because they are expected to spend a minimum of one thousand Birr per month for medicines, taxi contract and referral service associated costs. As majority of affected family members are unable to pay costs associated with PD they usually take them to religious institutions, traditional healer places' tenquaye bet' than hospitals the severity of disease will be more exacerbated and complicated especially in the case of people who have low or no source of incomes; most often times the poor people usually appear to hospital when their disease appeared to either medium or chronic stage and that worsen the diagnosis as well the reaction of medicine towards the health of the person as reported by Neurologists. The researcher has also found out that even if there are special privileges in government hospital that are providing for person with low/ no source of income, the supply of such a free dopamine stimulants in the drug store in often times do not match with the number and demands person with PD.

Ato Wondyrirad Habtiyemer, 73, a college graduate and a father of three children. He used to work as a teacher in government school for considerable years. As he stated the symptoms of PD revealed on him two years ago and it is becoming progressive through time. Because of the disease he could not write, speak, and now struggling to move from place to place and these unavoidable challenges forced him to

lose his job. When he left his job pension was the ultimate source of his income, however, due to his mobility difficulties he could not follow the retirement process. Moreover, the treatment he took was not as such helpful to reduce his suffering because the physicians were not able to clearly identify the cause of his symptoms. This strongly hurts him psychologically more than that of losing his job.

4.8 Effects of PD on psychosocial Aspect of patients with PD

Apart from economy and health, psychosocial is also the very essential indicator for people to live a quality life. In the country like Ethiopia the human health and well-being depends on the ability to communicate effectively with others and to maintain social relationships. But the ability to function successfully in social situations and to live up to the expectation of others is highly complex and depends on the preservation of different mental abilities, such as the ability to infer the emotions of others, to determine their perspectives and intentions, and to appropriately use this knowledge to guide behavior and interpersonal communication. In adults with Parkinson's disease, degeneration of the brain leads to progressive difficulties that affect movement, but also specific mental abilities that are critical for social functioning.

In this case all the participants were asked to explain how their emotional, behavioral and social lives have looked like after they start living with PD. Many of the study participants agreed that they are frequently quarreling with spouse, children and family members and these are mainly due to the conscious and unconscious discrimination acts and self stigmatization nature of the infected and affected person. As stated by all neurologists—avoidance of communal participation, speech problem, economically being parasitic towards others, stigmatization and discriminatory acts are the major psychological influences as well causes for the Patients to live with anxiety, depression, experiencing gauche behavior. As stated by the founder of E-PPA majority of PD patients are immensely suffering with the impact of the disease. The impact that PD brought to the infected and

affected family lives have multi-layered effects on their social and psychological aspects. The social implication of the disease has adverse effect on patients and their family members. A decade and five years ago the founder of E-PPA used to actively participate in the community works 'iddir', marriage ceremony and/or attend coffee ceremony but now due to her physical disability she failed to engage in physical demanding communal works .

In majority of the cases the PD patients are supposed to have a close follow up from their at least one adult family member because they usually suffer with throat block 'tineta' which resulting from drinking water; need the help of family members while walking or need support while dressing and bathing. The two family members the patient and caregiver in this regard are forced to quit their jobs. Losing jobs to the patient as well to the care givers will bring a socio-psychological problem. Most of the time infected and affected members expressed their anger feeling either through venting their spleen to the care givers or bragging to the person closely associated with.

a sense of rejection, a feeling of burden to the family, feeling empty inside, loneliness, stressed out, depression , anxiety are the common psychological pain of PwPD, said neurologists. Majority of PD patients come to hospital for check-ups and they frequently explain that their behavior is somehow changed from their previous; it is evident that almost all have developed introverted behavior whose feelings and thoughts are suppressed inwards. The majority of participants stated that they are not willing to share their inner feelings and as a result of this self-stigmatization and discrimination are the manifestation for dwindling relationship among family members as well neighbor and communities.

Insomnia, hallucination manifested due to the negative consequences of the disease and the drugs are essential characterizations of psychological impacts to the study participants. The depression is not apparently caused by self thinking alone but in fact that the negative consequences brought by

the overlapping of social and economic divergence. It is obvious that majority of PD patients associate their disability as one of the reasons for their pathetic life, anxiety as well the subjective experience of time, by which they are only focusing on the present time than noticing their futures.

The impact of PD is diverse in its nature and very complicated—a single dysfunctional disrupts the whole system; the person, family, community and country at large. And due to job loss or erection problems or movement disorder many PD patients have lost their beloved family members, and it is worth mentioning that they are leaving a desperate life the Neurologists said.

Though divorce is an inevitable fact of human experience but for the majority of the study participants divorce is becoming a reality one should accept when he/she lives with PD. The types of divorce can be categorized in various forms for some it could be legal and separating once and forever; whereas for some the divorce may not be happened legally and the society may unlikely recognize the wife and husband are leaving together when it is not in actual conditions. In this artificially created divorce the husband and wife live like a cohabitant life styles that do not make love, do not share happiness, and sadness just living in one room in different beds. In both divorce cases the PD patients are the more severely vulnerable group in the family as well in the community.

Many people living with PD patients do not want to participate in the social gatherings these could be either due to that fact that tremors, postural instability, soft voices and frequent urination are the major barriers that prohibited them not to engage in communal works. Lip services 'mtse', rejection, stigmatization, discrimination— consciously and unconsciously that arise from the family members and community are the considerable impediments for socialization, as repeatedly stated by neurologists.

The frequent quarrels among Pd patients have also significant contribution towards the disintegration of family members including children. In regards to social anxiety majority of the patients have flagged their concerns as their spouses are very careless about them in the case of PwPD 02 his relatives sarcastically telling him that he is useless and weak and for the participants like PwPD 03, 05 & 08 self stigmatization and avoidance of social gatherings are becoming part of their lives and when majority of these people explained the reason is due the wrong interpretations they have to themselves. For instance, in the case of Asseffa he used to hide his hand for many years thinking that people may mock at his trembling hand. In the case of Amarech— she totally avoided communal participations due to her soft voice and wriggling movement. For PwPD 06, 7, 9&10 the consequences of Pd are a hurt breaking to them because they are physically disabled at their productive age and a feeling of being burdened to the family members.

Most importantly however for almost all participants' economical and physical dependability, the non-existence of communal based supportive system and knowing the disease is a lifelong are the critical factors that cause quarrel, social isolation and divorce among infected and affected members of the society. The PD patients and care givers repeatedly explained that the supportive social system for PD is still at infant stage for various reasons. For PD participants 02 & 04 state that 'I easily irritated 'wuhaqetene' whether it is or not my concern and I frequently quarrels with my family because they do not understand me what I am struggling with.

The tragedy of life...

Asseffa , 57, a father of two sons, was born and educated in Nazrit. He had versatile teaching experience in government and private schools. He likes teaching as he loves his families because that passion started early childhood. It was six years ago Asseffa has started experiencing tremor in his right hand and begun walking slowly; his sound

became very soft and his students could not hear him very clearly. That was the time he started questioning himself what is going to happen when I lost my livelihood.

When his illness is becoming serious he went to a doctor for checkups; that was the time Asseffa lost his courage and began looking inward. The rigidity of his hands, the wince feeling together with masked face make his life very complicated. He lost his faith because he thought that he was the only man suffering from the progressive disorder. As the time goes by the progression of tremor, wriggling movement accompanied with his cognitive disorder the administration of the school gave him a retirement paper. That was the worst time for Asseffa and his wife.

When Asseffa begun sitting at home; the multifaceted challenges such as the depression, dizzy feeling along with frequent anger are becoming his routine experience. As his wife is not wellaware of Parkinson's disease and its symptoms; she did not understand his physical as well psychological suffering. Asseffa could not find another job and his family's livelihood was totally dependent of his pension fund, a meager fund that could not even cover his transport cost for health check. In every day the two sons got board of hearing the everyday quarrels of their parents.

When the bright day turned out to darkness Asseffa and his wife got divorced. Asseffa is now forced to live a lonely life; he hates himself as well approaching his friends. No one is on his side except the Ethiopian Parkinson's Patient Associations. He hates talking with neighbors, he hates going to iddir, serg because he does not want to see other people mocking on his speech. His soft voice is the reason for his self stigmatization as well lack of courage for socializations.

Asseffa got registered as being fifty five members in the Ethiopian Parkinson's patient's associations. It is since then he continues receiving various supports

including financial, psychological and information. With the peer to peer education providing by EPPA Asseffa changed his attitude from feeling the only PD patient in the world.

4.9 The Impediments of PD to get a limelight

As indicated in the above sections PD is a prolonged disease that severely affecting the whole system of the individual, family, community as well the country. In the case of Ethiopia PD is the most neglected disease and did not get a public eye particular from development and funding agencies. Whereas the EPPA is the only hope for the patients in Ethiopia with its all challenges including the financial, work premise as well human resources. The association has now three hundred active members who are benefiting from peer to peer education, health education, pocket money. The founder and the Executive Director of E-PPA repeatedly state that our members have very serious problems and almost all of them are economically dependent, and the service providers including health institutions and family members must give extra attention to the patients. Though there are many professional, influential and renowned people living with PD in Ethiopia yet they do not want to come to us and join the association and this could be one of the reasons for our voices could not be heard as much as we want and could not influence the policy makers, funding agencies at large etc.,

During the discussion the study participants have repeatedly stated that the influential institutions are not playing active roles in the prevention of PD in the country. In this regard public and private medias working in the country are not as such playing active role in changing people's mind and it is known that there are radio and television program working on disability area in the country but none of them herd while talking about PD. The ministry of health on the other hand is one of the most influential institution concerning prevention, controlling, care and support provisions for life threatening diseases in the country but in the case of movement disorder the ministry has been a

passive player on the areas of prevention, care and support system. The researcher has also found out that there are no assistive technologies like deep brain stimulation, neuron rehabilitation center and palliative care approach that are available in the country for server patients with Pd.

4.10 Family support system and coping mechanism for/of PD patients

Caregiver 01, Lishan's daughter continuously stated that for a person to be a care provider one has to have a soft heart and enduring personality. Caregiver 01 from her practical experience stated that I hold my mom's hands to support her arise from chair and bed, and be able to move from place to place.

Even though my mom stays at home but every morning I change her clothe for she is able to feel free, and I put her medicine and water at a nearby on the table, care giver 3 said.

The study participants have agreed that a jar of water should be put in very accessible places for patients because they are highly susceptible to throat blocking and difficulties inhaling and exhaling. According to Bekele one of the closest friends of PD patient suggested that family members should closely support their family members either by telling them fun stories, or through spiritual support.

My children and husband are serving me like militaries; if they hear a sound around my place where I usually move around and work they come very quickly and see me whether I am okay or not. They tell me a bundle jokes every day and that makes me feel good and release stress, the founder of E-PPA said.

Caregiver 01, 51, is a daughter of Lishan. Lishan is suffering with PD for the last three years. Those years were very difficult moments for Caregiver 01 and her families. W/roLishan, 73, was physically and economically independent woman before PD was detected in her body. She was a

bread winner for her families—cooking, washing and baking 'enjera' were among her favorites and daily routine chores. Now she is facing a different scenario.

My mom is struggling with rigidity, tremors, frequent urination as well as communication difficulties and I always change the care provision approaches that I am doing to my mom, Caregiver 01 said.

A year ago Caregiver 01 and her other family members hired a homemade to serve Lishan; but the lady could not play her role as a care giver instead she became a source of anger. The homemade instead of becoming a helper and a source of happiness she locked the room and left Lishan alone throughout the day. That was the time Caregiver 01 got mad of the homemade and gave her a red card.

Caregiver 01 always worries about her mother suffering; she always gives priority for her mom than anything. Every morning she always changes her pajamas to an office dress so as her mother to feel she is on job. Before Caregiver 01 lives her mom alone; she always supplies medicine and water at a nearby on the table.

I am optimistic that new day comes and things will change for PD patients but until that darkness turn out to sparkling event, we, care providers, are responsible to give unconditional love to the patients because the PD patients must feel complete personality, live longer life and free from depression and anxiety.

Hence, the beginning of love should start from home and grow towards relative, neighbors and the communities. If the family members do not care and worry about them; nobody will give a glimpse of attention, Caregiver 01 said.

Caregiver 01, who has an infectious smile, always suggests her mom to take a small meal in every hour. Lishan also accepted her daughter idea and she always takes 5 / 6 'Guresha (small portion of food) to avoid her body rigidity and muscles cramp, and as well 'Lihatch/Drooling/.

W/o Lishan urged that it is always good to chew 'tiratere' like beans, roasted barely and chewing gum is helpful to improve speech problems. Before taking 'Data, shimbera, beans etc., PD patients must consult their doctors because all these would have side effects and contrary to dopamine drugs Lishan said.

During the field visit and the information collected from Parkinson's Patients Association the researcher noted that as there are a number of patients who are homeless and they are counting days to die. Street is now becoming a death bed for many.

For those who are homeless and helpless patients there should be a strong communal support system and national volunteer must be trained and engage in home to home care provisions Bekel said.

According to Letay, my husband has symptoms of frequent urination, in every hour I have to take care of him whether it is during the day or at night.

Using diaper for frequent urination and body discharges are very important especially for care providers not to have an awkward sleep at night, Letay suggested.

Fight back'swith PD

Caregiver 04, 23, a 4th year university student, is a son of Executive Director of E-PPA. Parkinson's day was celebrated colorfully in Ethiopia for the 3rd time on April 11, 2014 in Jupiter Hotel. The motto of the day was 'fight back'. During this commemoration Caregiver 04 got a chance to share his mom's fight back experience to the audience. The hall was filled by

neurologists, PD-patients, family members, medical students and the media. On his bilingual presentations he emphasized various scintillating words on how his mom is fighting the consequence of PD on her own as well with the family support. His mom has now counted her 16th since she knew her PD status. Caregiver 04 told to the audience that when he was six years old; his friends asked him whether his mother drunk an alcohol, when they see her wriggling movement. He in return asked his mom whether she was drunk; his mom was not upset in return rather she told him that she is suffering with the unknown disease.

He continued his speech— his mother and all family members were wandering about the unknown disease for many years. The medicine she was taking that time was not helpful because she was misdiagnosed, said Caregiver 04. As my mom's family members have been living in USA, my mom had gotten a chance to go there and knew her health condition. That was the moment that every family member had mixed feelings: happiness visa-a-vise sadness.

For about sixteen years my mom has never forgotten her wishes, needs and passion for a moment; she is a hard worker—One time she opened a private business in our compound. My mom is very courageous, hard worker and never gave up the things she like the most though she is suffering with the progressive disease. As she assumed there are a number of patients living in Ethiopia and she established the Ethiopian Parkinson's patients Association in 2011- has now 300 active members and it is the second association in Africa next to South Africa.

He emphasized that support system is very important for PWPD—it could be moral or physical or spiritual.

The physical support that I am always offering to my mom include: I hold her hands and support her waist to keep her moving place to place, helping her to walk on stairs, and raising from chairs, beds. My mother supported me a lot more than I did support

her. If my mom was not supportive to me and my sister and if she let herself to sleep all the day I could not be successful in my carrier caregiver 04 said.

As my parents are followers of Orthodox religion, my mom always participates in social gathering though she has a balancing and speech problems. She is doing this for good reason; even if she is not doing communal chores but she at least attends the ceremony. My mom always uses social gathering events as a communicative strategy to change the mind sets of her relative and neighbors concerning PD.

Caregiver 04 gave an opinion that family members or close associate are important players in the lives of patients with PD caregivers should be there for them; give them the courage and shall contribute to strengthen the supportive system at family, community and government level.

CHAPTER FIVE

DISCUSSION

The researcher prepared this section with the great aim to strengthen and compares the findings along with various theories, practical facts and real life examples of PD. The researcher used various modus of operandi to triangulate the validity of primary sources from the various angles including: facts and myths, quality service provisions, quality of life

5.1 Facts and Myths

The study has found out that there are knowledge gaps among health practitioners and it is evident that when the patients went to hospitals for the first time they were told that their disease is nerve though it is Parkinson's disease. It is true that practice makes improvement but at least there should be consensus on the usage of words among practitioners and patients– unless otherwise the diagnoses were and always will be continued being conducted wrongly and this brings about complexity and challenges for care providers, and other professional. According to the NINADS (e-news released, 2000) Parkinson's – a neurological disorder is more than a brain disorder that is caused by the dysfunctionality of a neuron cells that produce domain.

The other misconception that adult with PD dealing with is the cause of the disease is still mysterious in the case of Ethiopia. The study has found out that thirty three percent of Neurologists says the cause of PD in Ethiopia is unknown; and whereas sixty percent of neurologist responded the cause is vivid and associate with age, toxic environment, hereditary pesticide, polluted water. As the years of suffering starts from early age the burden is too high in terms of contributing to dysfunctional family as well to the economy of the country.

The cause of PD in the other part of the world is somehow vivid and stating that aging, toxic environment, hereditary are among the factors for PD whereas, the cause of PD in Ethiopia is still

contentious in this regard the very experienced Neurologist state that the cause of PD and Juvenile Parkinson is unknown and toxic environment or exposure to chemicals are the cause for early onset; whereas the general practitioners and those who have little experience argued that the cause of PD in Ethiopia is known and the cause for Juvenile is hereditary than toxicity.

According to Dr. Massey (*ALT-MED Medical and Physical Therapy news released April 2014*) although the exact cause of cell death is unknown...some have theorized that chronic exposure to environmental toxins may increase the risk of Parkinson's disease. Exposure to certain pesticides and herbicides can double the risk of developing Parkinson's disease.

In this study majority of the PD patients (seventy percent) their origins are from rural places and this reminded me one study people living in rural areas are highly affected than those who are living in Urban areas –living in a rural area (increased farm use of pesticides and herbicides) also increases the risk of Parkinson's disease. Another toxic may be an accumulation of heavy metals in the substantia nigra. Exposure to heavy metals is common in urban communities, said Dr. Massey.

In this study the researcher found out that for more than considerable decades the information concerning the name of PD, its causes, symptoms and the prevention skills and so forth was totally a mysterious issue for both the individuals living with PD as well for the caregivers. This could be one case that much attention still not given to the disease at national level. In addition to this, the international funding agencies that are investing millions of donation for HIV, emergency etc., are less likely interested to intervene in this life threatening disease; the Media which are also said to have the capacity to mobilize and familiarize the public are totally soundless about the issue. Whether the electronic and print media are conscious or unconscious about the issue for the past decades the severity of PD have been talked a lot worldwide, this research could be an eye opener and serve as a call for attention be it for government influential bodies or funding agencies, or

media owners, professionals, amateurs, PWPD and caregivers this is the moment to wake and save thousands of people who are suffering with PD at their productive ages.

5.2 Quality of Health Service:

Before dealing with the quality of health services it is worth mentioning to define health and a quality of life. It is a naked truth that health is a very crucial and non-negotiable element and even it is not a preference of various choices for one person to live a complete life. Many organizations define health in many ways. According to the constitution of the World Health Organization, (1948, no. 2, p. 100 April 7) health is defined as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

As briefly indicated in the finding section the qualities of services as rated by the respondents are poor. The doctor patient relationship, the service packages that are being provided, the frequency of visit to hospital, the supply of the medicines are some of the evaluation criteria that set to rate the quality of health services in the health institutions. The Neurologists who have worked for six and thirty years argued that the services packages that are providing to the outpatients are still in the infant stage in both government and private health institutions. When they support their arguments let alone the government hospitals, which have high burdens and demands from the public at large the giant private hospitals which are said to be very fame on public eye are not able to provide a diagnosis and outpatient services for PwPD let alone providing a full-fledged services encompassing Deep Brain Stimulation surgery services, Neuron rehabilitation center. In many cases the researcher has observed and come to understand that the service packages available to the HIV patients/ cancer is more likely comprehensive than what it does available for people with PD. For instance in the case of other life threatening disease the service packages follows a palliative care approaches.

Many studies conducted worldwide including this study affirmed that the numbers of patients living with PD in rural areas are more than the people living in urban –this could be due to their exposure to farm pesticides, water pollution. This study confirmed that even though there are hospitals available in Addis Ababa but there is no single hospital outside of Addis which opens the door for adults living with PD. This concern flags the questions of unable to fulfill the Millennium Development Goals; quality services, demand vs. supplies of medicine as well accessibility in terms of cost and geographical proximity and the right of individuals to get what they want when they want.

The examination and the treatment processes of the disease are only carried out by Neurologists alone without engaging a professional mix from dieticians, social workers, psychologist etc., who are very important to improve the quality life of patients apart from the medical examination. Jankovic in 1988 stated the management of Parkinson's disease requires multiple professionals to address not only the patient's needs, but also those of the family and care- giver. Pharmacologic interventions are important and the mainstays of treatment, but appropriate interventions from other disciplines are also necessary throughout the stages of the disease.

4.3 Quality of life Of Individuals with PD:

World Health Organization defines Quality of Life as individuals the perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment (WHOQOL, 1997).

Many studies conducted by professional and health practioners confirmed that the clinical examination and application of laboratory tests are very critical assessment to determine the heath status of the person. As a result, and also because anxiety and depression frequently go

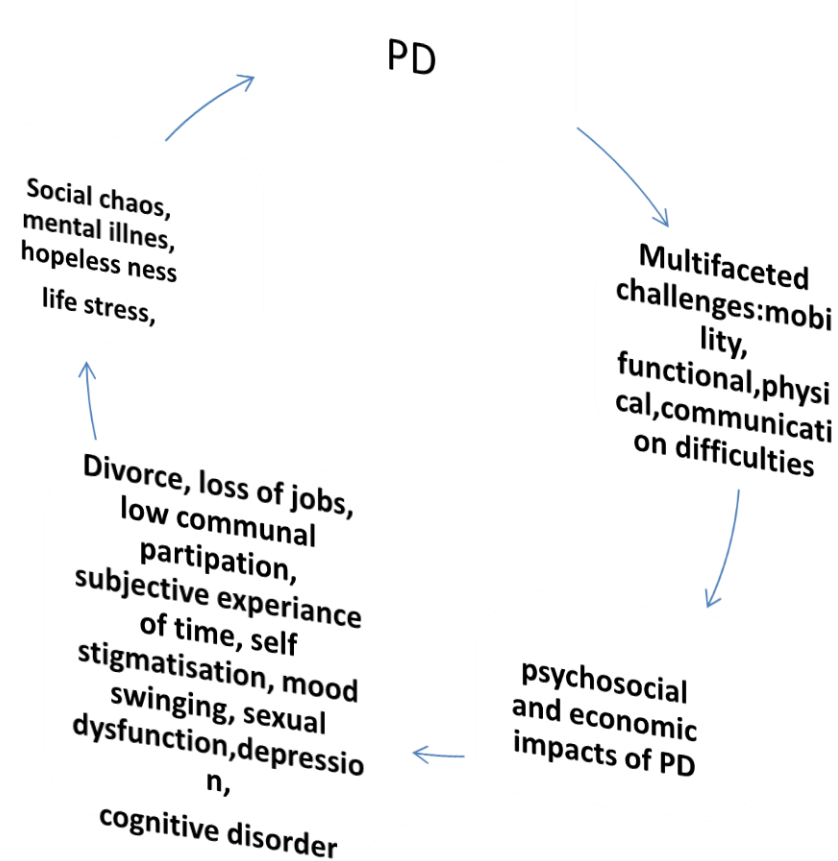
unrecognized by clinicians treating PD (Shulman, Taback, Rabinstein & Weiner, 2002,n.p), mood disorders such as depression are under-treated in PD (Weintraub, Moberg, Duda, Katz & Stern, 2003, 178–183).

In Ethiopia a clinical study concerning PD was conducted thirty years ago and one study was also conducted last year and four studies are now at some stages. But majority of these studies are conducted based on medical ethics guided by measuring and observing the clinical diagnosis principles and the issues of quality of life from individuals perception is forgotten in this regard. But this study most importantly however greatly varied from the laboratory test and medical history because it includes the perception, remedial opinions of individuals with PD and their families towards PD, the drug implication and its effects towards their social, economic and psychological wellbeing of individuals.

The researcher to determine whether a quality of life help to improve the social, psychological economical and physical wellbeing of adults with Parkinson's disease incorporated general open ended question in both key informant interviews with Patients and their care givers. Accordingly the social aspects were studied from the social functioning, social bond, the perception of PwPD towards the socialization vis-à-vis the perception of the society towards PD, PD patients and care givers and the awareness level was also considered. Under the psychological part, the human behavior before and after their health status, the effects of the diagnosis and domain stimulants towards their mental thinking, the cognitive issues were considered.

As a matter of fact the economy aspect was also studied from various angles including pension amount, the cost related to health checks, transport, and loss of job with premature age.

Source: this author -Cyclical relationship between PD and Psychosocial and economic impact of PD



The researcher during the data collection period observed that the cause of PD in Ethiopia is majorly the secondary causes. Hence the above chart indicates the grounded theory or a concept of this study. Parkinson's disease in many countries is caused by the loss of dopamine chemical in the brain and mainly triggered by a condition of toxicity and chemical exposures. Whereas in the case of this thesis participants majority of them are exposed to PD for the first time due to the life stressors accompanied with carrying heavy loads, working in every hectic environment, car accidents or physical damage etc., hence in the case of Ethiopia the cause of PD in addition to being at the age of sixty the life stressors are among the factors that expose individuals to be in such health conditions.

So, this researcher concludes life stressors cause PD and PD causes life stressors and this is an open area where it requires further investigation by imminent researchers because it is clearly observed in this thesis that the secondary causes are more dominant than the primary causes.

5.4 The Effects of PD on Social life of Individuals

Government, communities, individuals and professionals in Ethiopia have neither clues about how to prevent the disease nor detectable efforts towards mitigating the impact of the disease.

This study indentified that none of the participants heard about the disease either on radio, TV or print media before they went to hospitals, this causes the low attention towards PD patients from family members, and neighbors because the patients are labeled as sinners and sinner must accept punishment from God. In addition the society since they are not well aware about the disease and its impact they mostly take infected family members to religious institutions. The follow up towards patients, who are staying in the religious institutions, might not be given enough care. The impact progress towards the neglected patients might be faster than the persons who are cared by family members. Most patients in light of these effects are dying prematurely with no care and support providing by family members and support associations.

When the person infected with the PD, he or she can only reduce the pains by taking a combination of three to four prescribed tablets per day depending on the diagnosis. Many studies suggest doing physical and vocal exercises, attending laughter therapy, taking tablets on consistent basis, and attending religious prayers are the most stress relievers for PD patients. But such mitigation strategies are known orally by some of the respondents but none of them are practicing and this is due to the unavailability of speech therapists, physical exercise like tai-chi trainers, and or the cost is too high and the inaccessibility of physical environment toward individuals living with pd.

As with most chronic illnesses, the major burden falls to the family members. The family members including spouse, children and relatives are the ones to care for the sufferers. According to the participants caring on consistent bases require patience and one adult must be jobless. The frequent urination call from the patients, feeding, supporting, following up the medicine are among the demanding tasks that must be done by the children and spouse.

Care responsibilities including physical demands can be very significant and the personal, emotional, social and financial impact of PD on careers and family members can be huge. The change in relationships between people with PD and their spouses can be very distressing for all concerned, and it is, therefore, not surprising that care-giving can adversely affect the physical and psychological health of the career (The British Psychology society February 2009, p.15)

According to the family system theory– a theory introduced by Dr. Murray Bowen suggests that individuals cannot be understood in isolation from one another, but rather as a part of their family, as the family is an emotional unit and each member has a role to play and rules to respect. Maintaining the same pattern of behaviors within a system may lead to balance in the family system, but also to dysfunctional. For example, in the case a spouse with PD one family members and caregivers must take full responsibilities (www.genopro.com/genogram/family-systems-theory)

According to the FGD and KII participants twenty percents of family members are disconnected emotionally or divorced due to the fact that the consequences of the disease brought to them. PwPD01 for example was exclusively a source of income for her spouse and children before she got ill. After the passages of time the symptoms of the disease are becoming very complicated and make her unable to do the job she did before. When the time flies, she found herself abandoned by her husband. When the family members are not supportive the fate of the patients is to suffer with anxiety, depression, and thinking that life is all about death; children are also burdened by reality

distortion and the family bond become weaker and it become very difficult who is actually in the family genogram.

5.5 The Effects of PD on the Livelihood of Individuals

According to Addis Standard magazine published on May 2014, currently Ethiopia has more than 4.5 million people who have reached the retirement age of 60. But as the majority of them had not been listed on state payroll, they are not entitled for 'old age benefit' of any sort should they succumb, as they often do, to age related vulnerabilities including poverty.

The onset year for the majority of PD patients in this study confirmed that individuals are suffering at a very premature age meaning at their productive age so the burden of the economy is too high. various studies indicates that aging is one of the top factors for PD and the onset is 60, but this study indicates that in the case of PwPD in Addis Ababa in between 40-45 percent have symptoms of the disease at the early stage of their lives(early 40s) and the rest of respondents relay on fifty and above sixty.

The medical cost towards PD treatment is very expensive which is in between 251 Birr closer to 1000Birr on monthly basis in Ethiopia, and majority of them are dependent on their family incomes. Thus majority of PD patients who are affected by fifty percent rising of inflation are unable to go to hospitals and in fact they spend their day at churches- as followers give them salvation.

Government in partnership with the international institutions, funding agencies and research institutions should do either a research on the PD medicine to enable them to be produced on local capacity or should strongly bargain international suppliers for the medicines to be supplied at a low cost in fairly manner.

One of the roles of social workers, in addition to their advocacy works, is to deal with most vulnerable and stigmatized people to initiate them to be part of the society by preventing dysfunctions that hinder their active participation in the service usages as well in the communal works.

The PD patients like any human being have capacity to deal with life challenges-Majority of the studies indicate that the elder people are being treated as recipients of salivation, pension funds etc., but one thing that must be considered with the capacity they possess we should engage them in economic empowerment schemes. Otherwise with the meager monthly pension ranging 294 ETB (readjusted by the government of Ethiopia in 2009), life will be very complicated and the oneness attitude and practice among family members “emotional units” will be a day dream and structural change may be happened due to acute economic call.

According to the FDRE constitution Art 90(1) the state “shall aim at providing social security for all its citizens”. And the universal social benefits that are available to everyone, financed from the general state revenue, as a form of social assistance are non existence though Ethiopia as one of the signatory countries of the United Nations’ Declaration Human Rights, which identifies social security as a basic human right.

5.6 The Effect of PD On the Psychology of Individuals

The quality of life of people with PD has been shown in some studies to be more influenced by individuals' psychological adjustment to the illness and disability than by the severity of the disease itself (Suzukamo, Ohbu, Kondo, Kohmoto&Fukuhara, 2006, p. 761–766).

One of the touchiest stories of PD patients, indicated by the founder of E-PPA, as they are unable to express their emotional and psychological pain through facial expression meaning they have a mask face meaning lack wince expression yet uncommon symptoms revealed in other diseases. Having masked face in PD patients’ implies care givers do not to understand them easily and

unable to provide them the necessary care and support provisions. A PD patient stated that his family members are stigmatizing him and do not offer him any communication except giving him meals, said the founder of E-PPA.

The government and E-PPA and other social development organization must work hard to alter the wrong attitude and perception towards PD patients by providing health education for careers, relatives and family members.

Six participants boldly stated that because they have a lower voice, tremors in their hands and have wriggling movements, frequent urination and masked face they hate engaging themselves in social occasions fearing that people could stare and pointed at them. These letting them to be depressed, feel angry, live alone, talk alone without expressing their inner feelings. The prevalence of depression in PD is estimated at between 30 and 40 percent. According to a recent review, generalized anxiety, agitation, panic attacks and phobic disorders are common in PD, occurring in up to 40 per cent of people with the condition (Hanagasi&Emre, 2005, p.146).

Cognitive problem, depression and anxiety are the most common characteristics appear in PD patients' and caregivers hence these groups must give attention towards their health and do some physical exercise, use counseling and cognitive behavioral therapy services, and mental rehearsal exercising, and patients should regularly take a memory note; do alarm art that reminds them their activities.

Majority of the participants stated that they are unable to do what they have to do by their own. Lishanfor example was used to suffer with hallucination that arose from anger and stress—during the day the home made always left Lishanalone in a locked house. Prevalence estimates indicate that up to two-thirds of people with PD have sleep disturbance (Tandberg, Larsen &Karlsen, 1998, n.p), with approximately one-third of people with PD reporting moderate to severe sleep problems.

Specific sleep disorders associated with PD include insomnia, hypersomnia, parasomnia, and rapid eye movement (REM) sleep behaviour disorder (Truong et al., 2008, p. 62).

AtoAsseffa stated my behavior is somehow recently changed and become ticklish whether it was or not my issue I have started entering in to people's conversation as well work to change their stand. All these interferences are bringing me quarrel and ending up with fighting with my children.

Troster and Fields (2008) highlight the problems inherent in diagnosing mood disorders in PD due to the overlap of symptoms between PD and disorders such as depression and anxiety. Within the main psychiatric diagnostic criteria (American Psychiatric Association, 2000), there are separate classifications for mood disorders attributable to medical conditions, including PD. One danger inherent in this approach is that it might be erroneously assumed that treatment of PD will also successfully ameliorate any mood symptoms.

The psychological influence of PD can be disabling for an individual's as their motors symptoms, and in particular the fluctuations of non-motor symptoms such as anxiety and slowed thinking can be particularly disabling (Witjas et al.,, 2002). This study has found that people with PD experience diverse psychological behavior. The anxiety, swing mood, sleeps disorder; masked face and cognitive disorder are experienced by the KII and FGD participants. For some people with PD, cognitive impairment can develop and may cause significant disability (Lieberman, 1998).

CHAPTER SIX

Conclusion and Implication

6.1 Conclusion

Parkinson's disease affects everyone around the world with no exception of age, sex and color. The causes may vary from country to country. Every person with Parkinson's Disease (PD) 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 disease should focus not just on the disease but also on the patient's needs and preferences.

Many studies conducted by professional and health practitioners have confirmed that the clinical examination and application of laboratory tests are very critical assessment to determine the health status of the person. As a result, and also because anxiety and depression frequently go unrecognized by clinicians treating PD (Shulman, Taback, Rabinstein & Weiner, 2002), mood disorders such as depression are under-treated in PD (Weintraub, Moberg, Duda, Katz & Stern, 2003).

In Ethiopia a clinical study concerning PD was conducted thirty years ago and one study was also conducted last year and four studies are now at some stages of development. But the majority of these studies have been conducted based on medical ethics guided by measuring and observing the clinical diagnosis principles, and the issues of quality of life from individuals perception is forgotten in this regard. But this study most importantly however greatly varied from the laboratory tests and medical history because it includes the perception, remedial opinions of individuals with PD and their families, the drug implication and its effects towards their social, economic and psychological wellbeing of individuals.

Parkinson's is a degenerative disease that suffers thousands of people in Addis Ababa. The cause of the disease in Ethiopia is still contentious among health practitioners— toxic environment; hereditary and aging are exacerbation factors that electrify the situation of PD in to severity. This study confirmed that the rural people are highly exposed to the PD than people in urban cities. The exposures in rural areas are due to pesticides, water pollution, and herbicides and for those urban dwellers heavy metal accompanied with various life stressors are the major ones. The secondary cause of PD in the study population is more dominant than the primary cause i.e. loss of dopamine.

There is no single hospital or health post available for diagnosing and treating rural dwellers with PD outside of Addis. Those who are economically good come to Addis Ababa and get the diagnosis and treatment; and those who are economically do not have the means to come to Addis Ababa otherwise they spend their whole life in bed or will use holy water or other traditional healers.

This study has confirmed that the application of clinical diagnosis techniques lack standards among practitioners this is due to the fact that under the graduate program the course of PD at medical education institution are not given as such attention and this in fact contributes to the misdiagnosis and mistreatment of many PD patients. The medication that is providing cost free lack consistency and very poor families are susceptible to extra costs. The dopamine stimulants have pros and cons towards individuals with PD- some are able to move from place to place, able to speak, and soon; sweating, nauseas, gastric, constipation, yo-yo disorder and / or wear off are among the side effects pointed out by the study participants.

The use of comprehensive packages and multidisciplinary professionals towards mitigating the impact of the disease are uncommon to the patients as well to the associations working in these areas. In contrast the challenges towards the patients and their affected family members are uncountable—social turmoil , frequent quarrels, weak social bondage, family breakdowns in

association with meager income and or sexual dysfunctional, divorce, the psychosocial impacts and the acute economic burden accompanied with high peaking cost of living are among the very few consequences of PD

In many studies various researchers have suggested that the prevalence of males with PD is higher than females. This figure variance is also clearly shown in this specify study. The scope of this study is limited in Addis Ababa with a special attention to the Ethiopian Parkinson's Patients Association. The Association has higher number of male with PD than female PD. In this study 44.4 percent are female participants and the rest 55.6 percents are male participants.

The awareness level of PD both in rural and urban part of the country is very low. The Ministry of Health and the media which are believed to have a capacity to change the mindset of the people are silent about the subject. This study has shown clearly that female participants have a little knowledge and understanding about PD than male PD and care givers.

The society should be well aware of the disease through various means like media campaign, street campaign and other pertinent workshops and mass gathering events. In addition the higher institutions should carry out a research which can help the society to fully aware of the disease and to provide appropriate care and supports by family members, health institutions and social service providers for the people living with PD.

This study has found out that even though female PD to male PD ratio is small but the social and economic burdens towards female are higher than male because in the country like Ethiopia, community role is one of the very pertinent roles that woman should play in her life times and participating in iddir, weddings and other communal holidays like commemorating Saints' days. These communal works are very critical and every woman should do in her lifetimes— females with PD as they are unable to perform the family and community duties they face lots of challenges from being mocked by their neighbors to divorcing their spouse.

Many studies have confirmed that all Parkinson's patients suffer severely with a complex cause and cause of the disease. However young onset Parkinson's holds more challenges in terms of psychosocial issues compared with Parkinson's in older patients. Younger sufferers live longer with their disease and experience it during the most productive years of their lives. They are at increased risk of suffering from non-motor symptoms such as anxiety, depression, cognitive issues, breakdown of relationships and employment issues etc. These problems require as much attention as the medical problems involved, as they too have a great impact on the patient and his/her family life. The person with Parkinson's needs all the support possible.

After several years of living with Parkinson's, challenges to quality of life may increase in such areas as movement, mood, communication and socialization deteriorate. The psychosocial and economic impacts of PD towards PD carrier and their families are immense and according to findings the PD certainly causes the psychosocial and economic turmoil towards the quality of life but in reverse the various life stressors accompanied with exposure are also the cause for PD. Thus the relationship that exists between PD and psychological impacts are a cyclical in nature rather than linear; one causes the other and vice versa.

Early retirements, divorce, stigmatizing oneself from social gathering, depression, anxiety, mask face, toxic relationship among spouse and children; frequent urination, hallucination, feeling loneliness, tremor accompanied with physical immobility, functional difficulties like reading, writing, holding cups, dressing, driving are the major challenges towards the patients.

Having seen these life stressors majorities of the participants in addition to the medicine prescribed by their doctors they apply home remedial techniques to reduce their pain, stress and their difficulties. AtoAssegle for instance usually use a plastic plate/cup, soft/handkerchief to avoid his drooling and he also chews gums to reduce his communication difficulties; likewise w/roLishansuggested that she mostly eats chick beans, roasted barely helps to improve soft voice.

The founder of E-PPA is also added, in Ethiopia we do not have speech therapist that could guide us to improve our communication difficulties but majority of us are mitigating our soft voice problem through singing, chewing gums and by talking loudly with our family members.

For wriggling movement and postural instability PD patients should do a physical exercises and they should do walk. W/oLishan stated that she frequently eats a small portion of food to prevent muscle cramping and rigidity; even if she has difficulties in walking but she does stretch her hands, legs as well walk around at home.

For those frequently being depressed; creative arts like listening music, drawing pictures, watching comedy films/drama, physical exercise, talking with people, reading books could be taken as major stress relievers; and for those who live home alone Caregiver 03, a friend of E-PPA's founder, suggested that it would be more wise if the government/E-PPA is giving a health attention, this could be done by deploying volunteers that could serve as a home based care providers, who are providing cleaning services as well relaxing and sharing PD patients.

The conscious and unconscious discrimination and stigmatizations towards PD and their family members are common but most of the time PD patients stigmatize themselves due to their physical, psychological, economical and social impacts what the symptoms brought to them. Alleviating these multilayered issues are the top agenda for all but most importantly however patients with PD themselves should develop a firm pattern of meaningful life and should live positively by accepting fact and the naked truth of the consequences of the disease.

6.2 Social work Implication

In this study the findings confirmed that there is no social support group established by either PD or their care givers. Hence, the Ethiopia Parkinson's patients association is the only hope for infected and affected people with PD. During interview and focus group discussion the participants

emphasized that the only intervention given by them is from Neurologists and the involvement of Social workers, dieticians, counselors, physiotherapist, speech therapists are nil though the area requires multidisciplinary interventions and comprehensive approach.

According to Diane Breslow, social work intervention is not a “one size fits all” approach. Social workers aim to understand each person or family’s unique situation and goals. Therefore, every case is approached individually, and their roles are very important to improve the quality of PD and their care givers. Social workers are trained in the bio-psycho-social model of assessment and care, i.e. the theory that individuals and families are a composite of complex physical (biological), emotional (psychological) and socio-cultural and family aspects, all of which combine to play a role in one’s behavior and relationships. Because problems impact people on any and all of the three levels, social workers and other allied healthcare professions intervene at all the levels. The goal is to offer patients and families a comprehensive, holistic approach to care..

The very objective of this study was to understand the nature of the psychosocial and economic impact of the disease in the study area of Addis Ababa and aimed at identifying areas that need improvement as well as to point out concerns that require public attention. Hence the researcher has come up with three big areas that have direct implication to Social Work fields.

6.2.1 Research

It is observed that there are misconceptions and knowledge gaps among PD patients and neurologists— the wrong name of PD as nerve, unavailability of standard clinical diagnosis techniques have caused many PD patients to be wrongly diagnosed and treated. The higher health education institutions in this regard need to improve their curriculum and provide a special attention towards PD. Private and government hospitals need to improve and upgrade their service provisions to the internationally acceptable standard – universal clinical diagnosis techniques along with advanced examination instruments are non-negotiable facts that institutions need to possess.

The researcher has suggested that the medical practitioners along with social workers must do further studies on the areas and come up with practical intervention scheme.

Even though the exact cause of the disease is unknown and contentious issues in Ethiopia various researchers need to further explore on the area that helps to inform the society. Majority of the medical researchers give emphasis only the medical and clinical aspects of the disease and overlooked the social, psychological, economical aspect of the disease including the adverse effects of the drug on to the lives of individuals and caregivers. Hence the researcher in addition to the clinical diagnosis techniques and symptoms, they need to consider and apply the non- clinical aspects of the disease. This could be done by involving multidisciplinary professionals in the clinicalresearch

Majority of life threatening diseases in the country have a national facts and figures but in the case of this study the researcher has found out nothing to refer in relation to PD. Hence responsible government office along with various professional mix are encouraged to do a national study that clearly shows the status of PD in the country

6.2.2 Policy

The researcher during her document review has confirmed that there is no single international and national policy document that specifically addresses Pd issues and this impacted the giant financing institution not to plunk budget on prevention, care and support provisions. Social workers in this regard need to convince policy makers by taking a lead in physical and virtual meeting platforms that help to draw public attention and resource mobilizations.

The issues of quality of services in various private and government hospitals have been rated as poor due to inconsistency in the supply of drug, limitations on the knowledge of health practitioners and unavailability of hospitals other than Addis Ababa. Thus social workers along

with health institutions need to work hard and advocate to the improvement of service provisions and availability of stimulants on regular basis.

The role of health institutions must not only provide a diagnosis and free supply of drugs they rather need to provide a comprehensive services that consists of case team by which counseling services, support systems and peer to peer experience sharing need to be part of the daily operational systems. Thus the roles of social work in making the comprehensive package happen at various institutions and branching out hospitals in rural places of the country would be immense.

6.2.3 Practice

As defined by World Health Organization, health is a state of complete physical, social, mental wellbeing not merely the absence of the disease. PD brings diverse health complications among which physical impairment, cognitive disorder and mask face. Many studies have also indicated that people affected by disability are more likely to experience poverty and this increases their chances of living in a non-supportive environment. Thus, concerned institutions along with humanitarian development organizations need to give due attention by applying a Twin- Track” approach which emphasis on mainstreaming empowerment and social specific program.

Individuals living with PD and care givers have multiple burdens from losing job to losing patience. Thus, a positive living in particular life style adjustment, medication follow ups, physical exercises, persistent participations in social support systems may need to be considered by the individuals themselves and family members. The intervention process to improve the quality of life of individuals should not be a onetime event rather a process that requires consistent updates and multidisciplinary engagements.

The study has found out the majority of patients living with PD have been experiencing self-stigmatization, lonesomeness, depression and social anxieties. Thus the active engagements of

social workers in facilitating a family therapy, establishing social support group, carrying out media popularization can have a great contribution to mitigate the social turmoil's.

The awareness level of individuals and caregivers at all level towards PD is extremely low and majority of them do not know the cause and consequence of the disease; stigma and discrimination towards PD patients and their care givers are common. With this regard, various concerned bodies including: media, EPPA, social workers, local and International NGOs, private and non-governmental hospital need to play a key role in changing the misconception through a continuous community mobilization and awareness campaigns.

The functional and communicational difficulties that are faced by patients need to be addressed through palliative care and community based rehabilitation program. To reduce mobility and dizzy feelings—the use of Physiotherapy, tai-chi meditation program and watching comedy films are essential intervention areas that all patients with PD, care givers and institutions working on the area need to consider.

Patients with PD experience job loss due to their early retirement and have been ostracized from the benefits that life offering. With this regard institution are advised to apply occupational therapy which emphasis on easy job with flexible hours of working.

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Annex 1

Consent form for Patients with PD

Introduction

I am Helen Asfaw, a student at Addis Ababa University School of Social Work, and I am conducting interviews for my Thesis entitled 'The Psychosocial and economic impact of Parkinson's on the people infected and affected by the disease in the case of Addis Ababa.

During this study, you will be asked to answer various questions as how you are initially vulnerable by the disease and how the disease is impacting your life and family members. This interview is designed to take approximately an hour in length. However, please feel free to expand on the topic or talk about related ideas. Also, if there are any questions you would rather not answer or that you do not feel comfortable answering, please say so and I will stop the interview or move on to the next question, whichever you prefer.

All the information will be kept confidential. I will keep the data in a secure place. Only I and the faculty supervisor Dr. Mohammed Hassen will have access to this information. Upon completion of this project, all data will be destroyed or stored in a secure location.

Consent form

I am aware that my participation in this interview is voluntary. I understand the intent and purpose of this research. If, for any reason, at any time, I wish to stop the interview, I may do so without having to give an

The primary purpose of this study is to fulfill the academic requirements School of Social Work, but it has also the aim to understand the real cause, Psychological, economic and social impacts of

the PD in the Ethiopian context, and to make relevant recommendations based on gathered facts for those interested parties who needs to make intervention in this major societal problem

One to one interview type of questionnaire has been designed to gather the opinions of peoples who are living with PD.

I have been offered a copy of this consent form that I may keep for my own reference.

I have read the above form and, with the understanding that I can withdraw at any time and for whatever reason, I consent to participate in today's interview.

Interviewer's Signature

Participant's Signature

Date

Date

Again, thank you for giving me your valuable time and opinion.

Annex 2**Key Informant Interview Questionnaire****Section One: Personal Data**

1. Name please [Optional] -----
2. Gender? F M
3. Age range? A) Below 18 B) 18 - 30
C) 31 – 43 D) 44- 56 E) 57 -69, F. Above 70
4. Marital status?
 - a) Single
 - b) Married
 - c) Separated
 - d) Divorced
5. Education status?
 - a) Primary school
 - b) Secondary school/high school
 - c) Vocational or technical school
 - d) Some college, no degree
 - e) Bachelor's Degree
 - f) Advanced Degree (Masters, PhD)
6. In which sub city /Area of city are you living? _____
7. PIE(What is your birth place a. Rural b. Urban
8. Do you know the local name of PD? _____

Section Two: Cause, symptoms and Effects of PD(Health and Economy)

9. Did you observe some symptoms of Parkinson's disease before you get diagnosed?

a. Tremor b. Feeling depression, c. soft voice d. unclear handwriting e. masked face f. Other specify.....

10. Have you ever heard about PD before you got infected by the disease? Yes.....No

If yes, from: a. Radio, b.TV, c. Newspaper d. Word of mouth

11. Years of living with PD _____

12. Who told you for the first time that you have PD?

a) Doctor b Friend c. Family member d. Traditional healers

e. By associating with some PD patients' f. Other, please specify _____

13. What was your feeling and reaction when you knew for the first time that you have PD?

14. Do you know the cause for your susceptibility/ vulnerability to PD?

A. Hereditary (Mother, father) B. Age. C. Poisoned environment

D. by caring others infected by PD E. Drug complication F. Any other _____

15. What are the effects of the PD on your daily life? (multiple answers are possible for this question)

a) Decreased mobility:Partial/total inability to move from place to place

b) Communication difficulties: Partial/total inability to communication orally

c) Partial/total hearing impairment

d) Constipation, frequent urination, weight loss

e) Partial/total inability to read and write

f) Functional mobility: Partial/total inability to feed & dress by myself, to use transport, g.

Depression h. Cognitive difficulties and behavior

g) Lethargy/tiredness; Insomnia

h) Physical symptoms; abnormal fall, wriggling movement

i) Sexual dysfunctional j. Other/s [Please specify] _____

16. What are your coping strategies to mitigate the above impacts?

17. Are you employed?

- a. Yes b. No

18. If "Yes", please state the sector in which you are working?

- a. Government b. Private Sector c. NGOs
 d. Self-employed e. Other [Please specify] _____

19. What type of job are you working?

- A) Office work c. . .Industry/factory
 B) Service giving/that has customers d. Other [Please specify] _____

20. Does the PD affect your daily/monthly income? And if your answer is "yes" how? Do you think that your current income level is less than what you had been earning prior to the PD's appearance? _____

21. How often do you go to hospital?

-
- A. One time per month B. One in three months C. Once in Six D. Once in a year

22. How much money do you spend monthly on average in relation to the PD for medical related issues (to see doctor, medication, and therapy, taxi, etc)?

23. Can you tell me in brief the service packages that you are using in hospitals?

、

24. What are the pros and cons of PD drug in your daily life?

25. What are the factors that exacerbating your conditions of PD to be more dependent depressed and socially isolated?(please explain with practical examples)

26. Do you think the impact of PD has the following effect on your life?(support with examples)

a. Subjective experience of time b. disruption of body image c. social isolation d. depression

Section Three: Effects on Social and Psychological Aspects

27. Who are on your side as caregivers in dealing with your PD associated problems?

- a) Spouse (if you are married)
- b) Children
- c) Friends
- d) Relatives
- e) institutions
- f) Others (please specify) _____

28. From which organizations or institutions are you getting the necessary care and support?

- A) Religious institutions
- B) Health facilities
- C) NGOs
- D) Iddirs
- E) Self-help groups
- F) Others (please specify) _____

29. What type of care (s) and support are you receiving (have you received) from those organizations or institutions?

- A) Financial support
- B) Health care (medical treatment/provision of medicines, etc)

C) Psychological support

D) Emotional/moral support

E) Other services(please specify) _____

30. What benefits do you get as a result of the service provisions

Financial _____

Health care _____

Psychological support _____

Other services _____

31. How do you rate the services that you are receiving from these institutions and individuals?

A) Excellent b. Very good C. Good, D. Poor

32. Does the PD affect your day-to-day social relationships? If "Yes" how?

a) Relation with Spouse (if you are married) _____

b) Relation with Family member _____

c) Relations with the neighborhood community _____

d) Relation with the Colleagues or co-workers _____

33. Has your social relationship changed due to the PD? (It could be positively and negatively),

please

elaborate? _____

34. Have you ever faced any psychological influences a result of PD? If “yes” what are these influences? From whom?

Personal _____

Family members _____

35. Which faith/religion are you following?

- a) Orthodox D. Catholic
- b) Muslim E. Pagan/Atheist
- c) Protestant F. Other [Please specify] _____

36. Do you personally believe that the PD has some supernatural origin (Do you attribute it to a curse or other religious sin)

- a) Yes b. No

37. If your answer is “Yes”, have you ever resorted to the following religious/cultural interventions?

- a. Going to holy water/”Tsebel”/ C. Traditional healer /”Awaki” /”Tenkuway”/
- b. Praying in church/mosque with the help of priest/pastor/sheik
- d. other [Please specify] _____

Section Four: Remedial Opinions

38. What are the coping strategies applying to mitigate the psychosocial economic impacts at individual _____

at family _____

At institution _____

39. What should be done to prevent this disease from the beginning from your own life experience? _____

40. What should be done to alleviate the social, economic, spiritual and psychological effects of the PD at each of the following listed levels

a) At individual level (from the patient himself/herself)

b) At Family level

c) At community level (school, churches, NGOs/CSO, etc)

d) Government level_____

41. Do you know any social support group established by /for PWP_____

42. If yes, what benefits do you get from social support group?_____

43. Do you have any comments that you would like to give in relation to the PD?

For PWP_____

For care givers/family members_____

For government/ Institutions_____

For media_____

Annex 3

Focus Group Discussion Guidelines:

I am Helen Asfaw , aSocial work student in Addis Ababa University. The purpose of our today's meeting is to discuss issues concerning PD, it causes, the risk factors, consequences of PD at individual, family, community level. Having said this I would like to thank all of you for giving me your precious time and willing to provide your honest and valuable points on the issues that I am going to raise:The FGDs will be taking place in two categories. The first Group will consist of infected PD andtheir affected familymembers; this group basically keeps the gender balance. The second group I only deal with Women living with PD.

The researcher will open the discussion by telling attendants an ice breaker and /or by talking or showing them scintillating stories of Pd patients who are living with PD. Such an approach will help both participants and a researcher to make ease of the conversation and create user friendly dialogue.

FGD with PD and their affected family members:

1. Have you ever heard about PD before? (If yes or noask them where do they get it and what that information was (N.B: Verbal and non-verbal communication is very important)
2. Do you believe PD and Nerve diseases are one and the same? (Probe, are they same?)
3. What is the local name of PD?(What symptoms providing by the communities)
4. What are the risk factors for one person to be susceptible for PD? Explain with cases
5. Can you say there are many PD patients in Addis Ababa? How many people do u guess
6. Do you have relatives infected by PD? (Mother, father, grandma, son, daughter, uncle, aunt)
7. Do you have neighbors infected by PD

8. What are the INITIAL and MEDIUM symptoms of PD
9. How do you know your PD status(Prob Doctor, Church.....?)
10. What was your first reaction when you heard that you have PD?
11. Do you know any of your family members that you have PD?
12. How do your family members support you (Prob, finance, care)
13. What are the consequences of PD (Prob at individual, family, community and country level)
14. What are the psychosocial impacts of PD (Probe at PWP, affected family members)
15. What are the economic impacts of PD(Probe at PWP, affected family members)
16. Do you know any organization working on Parkinson's(Prob what are the services providing by these organization)
17. Which private and government organizations working on PD(Prob What are their services)
18. Do you think the service providing by private and government institutions are enough to fulfill the demands of PD in Addis(Probe why is not enough
19. What are the home remedies and /or the coping mechanisms that you are using while feeling pain, depressed, unable to speak, unable to raise from chair/bed,
20. What kind of supports are you getting from: family members b. health practioners (Ask Infected PD)
21. What kind of supports are you providing for family members(Ask care givers)
22. Why PD did not take public attention unlike other diseases like HIV, TB,Cancer(Probe the facts VS challenges)
23. Do you believe PD is a punishment from GOD (Probe the debate)
24. Do you use healers like 'Tsebel, tenkuaye bet', etc to get rid of PD?
25. Why many family members prefer to take PD patients to go to traditional healers than hospitals?

26. What factors do you think exacerbate the condition of PD(Probe From simple, medium to critical illness)
27. Have you/your family members lost job due to PD status? (Probe what was the reason?)
28. Did you get compensation by the time you left your job? (What was your compensation look like?)
29. Do you use hospitals for check up (How often, why not hospital? Why traditional healers)
30. How much money do you spend for Medical check -ups and medicine, Transport)
31. Who provides you care at home(Daughter, son, relative) What their supports do look like
32. What intervention shall the care giving institution provide for PD and Care givers to improve their quality lives?
33. Do you know any person/ individuals/ Institution that provide Speech therapy, DBS, Physical exercise(IF YES/ NO probe).

Annex 4

KII with Neurologists and Health Practitioners

I am Helen Asfaw, a Social work student in Addis Ababa University. For the partial fulfillment of MA in the School of Social work I am conducting this research entitled ‘the psychosocial and economic impact of Parkinson’s disease on people infected and affected by the disease’. The primary purpose of this study is to fulfill the academic requirements School of Social Work, but it has also the aim to understand the real cause, psychological, economic and social impacts of the PD in the Ethiopian context, and to make relevant recommendations based on gathered facts for those interested parties who needs to make intervention in this major societal problem.

I. Personal Data

1. Name _____
2. Position _____
3. Name of the hospital _____
4. Year of experience as Neurologist/ working on the areas of PD _____

PD Cause, symptoms:

5. What do you think the cause for PD? _____
6. Do you think the cause for PD varies from country to country(if yes please explain the reason
 - a. Yes b. No.....
7. What are the most likely causes of PD in Ethiopia _____
8. What are the main cause for Juvenile parkinsonian (person at the age of 20)

Diagnosis, Treatment:

9. As a Neurologist, what diagnosis techniques do you apply for PWPDP?
 - Use MRI and CAT to scan of the brain
 - Use laboratory to test blood;

19. Do you personally believe/ professionally accept that a frequent use of drug will bring negative impact on the lives of PD patients. a. Yes b. No

if yes, explain _____

20. How do you rate the availability/ quality of services in the institution you are working

a. Excellent b. Very Good c. good D poor E. can't tell

If you choose poor, explain the reasons _____

21. How do you rate the cost of medicine for Dopamine drug?

a. Very expensive b. expensive c. fair d.cheap e. can access at free

22. Do you think the drug is accessible for PwPD in the country _____

Psychological and economic impact of PD on PwPD:

23. What do you think the impact of the disease on the quality life of the PwPD? towards:

a. Social _____

b. Psychological _____

c. Economical _____

d. Biological _____

24. As a neurologist/ health practioners what do you suggest to the PwPD to live positively with the consequence of the disease _____

25. What do you think the most challenges living PD?

26. What challenges have you faced while working on the areas of Parkinson's disease? _____

27. What do you suggest for institutions/associations working on the areas of PD _____

28. Any feedback that you would like to comment?

Thank you for your valuable time!

Annex 5

Consent form for Patients with PD(Amharic version)

የስምምነት ቅፅ

እኔ ሔለን አስፋውበአዲስ አበባ ዩኒቨርሲቲ የሶሻል ወርክ ተማሪ የድህረ ምረቃ ፕሮግራም ተማሪ ስሆን ለ2ኛ ድግሪ መመረቂያ የሚሆን የሚሟያ ጥናት በማድረግ ላይ እገኛለሁ። የምርምር ጥናቱ አርእስት የፓርኪንሰን ህመም በታማሚዎቹ ላይ የሚያስከትለውን የስነ ልቦና፣ ማህበራዊና የኢኮኖሚ ጉዳት በአዲስ አበባ ከተማ ውስጥ የሚለውን ለማጥናት የተዘጋጀ ቃለመጠይቅ ነው።

በዚህ ጥናት ወቅት እንዴት የህመሙ ተጋላጭ እንደሆነና በምን ህይወትዎንና የቤተሰብዎን አባላት እንደጎዳ ለመመልከት ይሞከራል። መጠይቁ አንድ ሰዓት አካባቢ እንደሚወስድ ይገመታል። በመጠይቁ ጊዜ የሚመስልዎትንና ከበሽታው ጋር ተይይዞ ጠቃሚ ነው የሚሉትን እንዲገልፁ ይበረታታሉ። ለመመለስ ፍላጎት ከሌለዎት ጥያቄ ቢኖር ሳይመልሱት ሊያልፉት ይችላሉ።

ሁሉም የሚመልሷቸው ጥያቄዎች መልሶች ከኔና ከሚያማክረኝ መምህር በስተቀር ለሌላ ግለሰብ የማይገለጽ ሲሆን ሚስጥራዊነቱ ይጠበቃል።

ስምምነት

የምሰጠው ቃለ መጠይቅ በፍቃደኝነት ላይ የተመሰረተ እንደሆነና ለምን አገልግሎት እንደሚውል ጠንቅቄ የማውቅ ሲሆን በማንኛውም ጊዜ ቃለ መጠይቅን ለማድረግ ካልራኩ ማቋረጥ እንደምችል አውቃለሁ።

የዚህ መጠይቅ ዋነኛ አላማ የሶሻል ወርክ ትምህርት ክፍል መመረቂያ ጽሁፍን ለማሟላት ሲሆን ነገር ግን በተጨማሪ የዚህ የፓርኪንሰን ህመምን መነሻ ምክንያቶች፣ ማህበራዊ፣ ስነልቦናዊና ኢኮኖሚያዊ ጉዳት በማወቅ በኢትዮጵያ ውስጥ ያለውን ገጽታ በመገንዘብ የተሰበሰበውን መረጃ መሰረት በማድረግ የተለያዩ ጉዳዮችን በቅርበት የሚከታተሉና መፍትሄ ለማፈላለግ ለሚሰሩ ሁሉ ሊያግዝ የሚችል የመፍትሄ ሀሳብ መጠቀም ሌላኛው አላማ ነው።

የአንድ ለአንድ የቃለ ምልልስ በማድረግ የፓርኪንሰን ህመም ተጋላጮች የሚሰጡትን መረጃና አስተያየት ለመሰብሰብ በሚችል መልኩ ጥያቄዎቹ ተዘጋጅተዋል።

ለመረጃ ይሆነኝ ዘንድ የዚህ ቃለ መጠይቅ ግልባጭ ማግኘት እንደምችል የተገለጸልኝ ሲሆን ከላይ የተገለጸውን ፎርም ያነባብኩትና የተስማማሁበት ሲሆን በማንኛውም ምክንያት መጠይቁን ማድረግ ካልፈለግኩ አለማድረግ በመገንዘብ ለዛሬው ቃለ መጠይቅ መልካም ትብብራን ለማድረግ ፈቃደኛነትን እገልጻለሁ።

የተሳታፊው ፊርማ

ቀን

የጠያቂው ፊርማ

ቀን

በድጋሚ ለዛሬ ቃለመጠይቅ ጊዜ ስለሰጡን እያመሠገንኩኝ ስላደረጉልን ትብብር ከልብ እናመሰግናለን።

Annex 6

Key Informant Interview Guide for Patients with PD(Amharic version)

ክፍል አንድ፡ የተጠያቂው የግል መረጃ

1. ሙሉ ስም (ፊቃደኛ ከሆኑ ብቻ) -----

2. ያታ ሴ ወን

3. የእድሜ ክልል ሀ/ ከ18 በ ለB-30

ሐ/ 31-43 መ/ 46 ሠ/ 57-69 ረ/

ከ70 በላይ

4. የጋብቻ ሆኔታ

ሀ/ ያላገባ

ለ/ ያገባ

ሐ/ የተለያየ

መ/ የተፋታ

5. የትምህርት ደረጃ

ሀ/ የመጀመሪያ ደረጃ

ለ/ ሁለተኛ ደረጃ የደረሰ

ሐ/ የቴክኒክና ሙያ ትምህርት የተማረ

መ/ የኮሌጅ ትምህርት የወሰደ

ሠ/ የመጀመሪያ ድግሪ

ረ/ ድህረ ምረቃ (ማስተርስ ወይም ፒኤችዲ)

6. በየትኛው ክፍለ ከተማ ይኖራል? -----

7. የትውልድዎ አካባቢ ሀ/ በገጠር ለ/ በከተማ

8. ፓርክንሲስ በተለምዶ በሀገራችን ምን ተብሎ እንደሚጠራ ያውቃሉ? -----

ክፍል ሁለት፡ የፓርክንሲስ ህመም መነሻ፣ ምልክቶችና ጉዳቶች (የጤናና የኢኮኖሚ)

9. ህክምና ከመጀመርዎ በፊት የፓርክንሲስ ህመም ምልክቶች የቱ ይታይብዎ ነበር?

ሀ/ መንቀጥቀጥ ለ/ ድብርት ሐ/ የድምጽ መስለል

መ/የእጅ ጽሁፍ ግልጽ አለመሆን

10. በህመሙ ከመጋለጥዎ በፊት ስለፓርኪንሰን ስምተው ያውቃሉ? አዎ/አልሰማሁም መልስዎ አዎ ከሆነ ከየት? ሀ/ ከሬዲዮ ለ/ ከቲቪ ስርጭት ሐ/ ከጋዜጣ መ/ ከሌሎች ሰዎች

11. በፓርኪንሰን በሽታ ለምን ያህል ጊዜ ተጋላጭ ሆነዋል? -----

12. ለመጀመሪያ ጊዜ ለፓርኪንሰን ህመም እንዳልብዎ ያሳወቅዎ ማነው?

ሀ/ ሀኪም ለ/ ጓደኛ ሐ/ ቤተሰብ አባል መ/ ባህል ሀኪሞች

ሠ/ ከሌላ የፓርኪንሰን ታማሚዎች ረ/ ሌላ ካለ ይግለጹ -----

13. የፓርኪንሰን በሽታ እንዳልብዎ ሲያወቁ ምን አይነት ስሜት ተሰማዎ? ምን አይነት እርምጃስ ወሰዱ? -----

14. ለፓርኪንሰን በሽታ የተጋለጡበት መንስኤ ያውቃሉ?

ሀ/ ከዘር የተወረሰ ለ/ በእድሜ መግፋት ሐ/ ከተበከለ አካባቢ /በኬሚካል

መ/ ሌሎች የበሽታውን ታማሚዎች በመንከባከብ ሠ/ በመድኃኒት አወሳሰድ ችግር ረ/ ሌላ ካለ ይግለጹ

15. በፓርኪንሰን ህመምተኝነትዎ የተነሳ በየቀኑ የሚያጋጥሞትን ችግሮች ቢገልጹ? (ብዙ ዝርዝሮች ሊኖሩ ይችላሉ)

ሀ/ በከፊልም ሆነ በሙሉ ከቦታ ቦታ መንቀሳቀስ አለመቻል

ለ/ በከፊልም ሆነ በሙሉ ከሌሎች ጋር መነጋገርና መግባባት አለመቻል

ሐ/ በከፊልም ሆነ ሙሉ በሙሉ ማዳመጥ ችግር

መ/ ቶሎ ቶሎ መሸናጎት ክብደት መቀነስ

ሠ/ በከፊል ሆነ ሙሉ በሙሉ ለማንበብና ለመጻፍ አለመቻል

ረ/ በከፊልም ሆነ ሙሉ በሙሉ ራስን ችሎ መመገብ መልበስና ትራንስፖርት መጠቀም አለመቻል

ሰ/ ድብርት

ሸ/ ማስተዋልና የመለየት ችግር

ቀ/ መዳከምና በመሳጨት

በ/ አካላዊ የሆኑ (ድንገተኛ የመውደቅና የመወለጋገድ አካሄድ)

ተ/ የግብረ ስጋ ግንኙነት ማድረግ አለመቻል

ቸ/ ሌላ ካለ ይግለጹ

16. ከላይ የተጠቀሱትን ችግሮች ለመቋቋም የተጠቀሙበት ዘዴ ምንድነው? -----

17. ስራ አለዎት? ሀ/ አዎን ለ/ የለኝም

18. መልስዎ አዎን ከሆነ ተቀጥረው የሚሰሩበት ከሚከተሉት ውስጥ የትኛው ቀጣሪ ነው?

ሀ/ የመንግስት ለ/ የግል ድርጅት ሐ/ በጎ አድራጎት ድርጅት መ/ የግሌን ስራ ሀ/ ሌላ ካለ ይግለጹ -----

19. ምን አይነት ስራ ይሰራሉ?

ሀ/ ቢሮ ስራ ለ/ አገልግሎት መስጠት /ከደንበኛ ጋር የሚያገናኝ ሐ/ ኢንዱስትሪ ውስጥ መ/ ሌላ ከሆነ ይግለጹ

20. የፓርኪንሰን ተጋላጭ በመሆንዎ በሚያገኙት ገቢ ላይ ተጽዕኖ ፈጥሯል? መልስዎ አዎ ከሆነ እንዴት ይገልጹታል? አሁን የሚያገኙት ገቢ የፓርኪንሰን ታማሚ ከመሆንዎ በፊት ያነሰ ነው? -----

21. ሆስፒታል በምን አይነት ጊዜ ልዩነት ይሄዳሉ?

ሀ/ በወር አንድ ጊዜ ለ/ በሶስት ወር አንድ ጊዜ ሐ/ በስድስት ወር አንድ ጊዜ መ/ በዓመት አንድ ጊዜ

22. ከፓርኪንሰን ህክምና ጋር በተያያዘ በወር በአማካኝ ምን ያህል ወጪ ይኖርብዎታል? (የሃኪም ክፍያ፣ የመዳኒት፣ የህክምና፣ የትራንስፖርት ወዘተ) ይጨምራል።

23. ምን ምን አገልግሎቶችን ከህክምና ሆስፒታሉ እንደሚጠቀሙ ቢገልጹ? -----

24. የፓርኪንሰን በሽታ መዳኒቶችን በመጠቀም ያገኙትን ጥቅምና ጉዳት ቢገልጹልኝ? -----

25. የፓርኪንሰን ህመም ተጠቂ እንደመሆኖ ምን ምን አይነት ሁኔታዎች የበለጠ ጥገኛ ለመሆን፣ ለመደበር፣ ከሰዎች ለመነጠል ወዘተ የሚዳርግዎ ወይም የሚያባብስብዎ መንስኤዎች ናቸው። (በተግባር ከደረሰብዎ በመነሳት ይግለጹ) -----

26. የፓርኪንሰን ህመም የሚከተሉትን ጉዳቶች በህይወትዎ ላይ እንዲደርስ አድርጓል ብለው ያስባሉ? (በምሳሌ በማስደገፍ ይግለጹ)

ሀ/ ጊዜን በአግባ አለመለየት ለ/ የአካል ቅርጽ መበላሸት ሐ/ ከማህበረሰብ መነጠል መ/ ድብርት ወይም መደበት

ክፍል ሶስት: በማህበራዊና በስነ ልቦና ላይ ሚያደርሰው ተጽዕኖ

27. ያለብዎትን የፓርኪንሰን ህመም በማስታመም የሚረዳዎ ማነው?

ሀ/ ባለቤትዎ (ያገቡ ከሆነ) ለ/ ልጆችዎ ሐ/ ጓደኞች መ/ ዘመዶች ሀ/ ድርጅቶች ረ/ ሌላ ካለ ይግለጹ -----

28. ከየትኞቹ ድርጅቶች /ተቋማት አስፈላጊውን ድጋፍና እንክብካቤ ያገኛሉ?

ሀ/ ከሀይማኖት ተቋማት ለ/ ከህክምና ተቋማት ሐ/ ከበጎ አድራጎት ድርጅቶች መ/ ከመረዳጃ አደሮች ረ/ የቡድን የእርስ በርስ መረዳዳት
 ሠ/ ሌላ ካለ ይግለፁ -----

29. ምን አይነት ድጋፍና እንክብካቤ ከጠቀሱአቸው ድርጅቶችና ተቋማት ያገኛሉ?

ሀ/ የገንዘብ ድጋፍ ለ/ የህክምና እርዳታ (መዳኒት ድጋፍና እርዳታ) ሐ የስነ ልቦና መጽናናት/ማማከር መ/ የሞራልና የሀሳብ ድጋፍ ሠ/ ሌላ አገልግሎት ካለ ይግለፁ ----

30. ከሚያገኙት የድጋፍ አገልግሎት ምን ጥቅም ያገኛሉ? የገንዘብ -----
 የጤና እንክብካቤ ----- የስነ ልቦናዊ ድጋፍ ----- ሌላ አገልግሎት -----

31. ከድርጅቶቹ ወይም ከተቋማቱ የሚያገኙትን የድጋፍ መጠን በምን ደረጃ ይገልፁታል?

ሀ/ እጅግ በጣም ጥሩ ለ/ በጣም ጥሩ ሐ/ መጠነኛ መ/ ደካማ

32. የፓርኪንሰን ህመምተኝነቱ በእለት ተዕለት የማህበራዊ ግንኙነቶች ላይ ጉዳት አስከትሏል? አዎ የሚሉ ከሆነ በምን መልኩ?

ሀ/ ከባለቤትዎ ጋር (ያገቡ ከሆነ) ለ/ ከቤተሰብ አባላት ጋር ሐ/ ከጎረቤትና ከማህበረሰቡ ጋር መ/ ከጓደኞችዎና አብረዎቸው ከሚሰሯቸው ሰዎች ጋር

33. በፓርኪንሰን ህመም የተነሳ ማህበራዊ ኑሮዎ ተለውጧል? (በመልካምም ሆነ በጎጂ ሁኔታ) እባክዎ ይግለጹ/ያብራራሉ -----

34. በፓርኪንሰን ህመም የተነሳ የስነ ልቦና ተጽንኖ ደርሶቦታል? መልሶ አዎ ከሆነ ተጽኖው ምንድነው? ያደረሰብዎ ማነው? ከራስዎ ጭንቀት ----- ከቤተሰብ አባላት -----

35. የምን ሀይማኖት ተከታይ ናት?

ሀ ኦርቶዶክስ ተዋህዶ ለ/ እስልምና ሐ/ ፕሮቴስታንት መ/ ካቶሊክ ሠ እምነት የሌለው ረ/ ሌላ ካለ ይግለፁ -----

36. የፓርኪንሰን በሽታ መንስኤ መለኮታዊ ነው ብለው ያምናሉ? (ከእርግማን ወይም ከሀጥያት ጋር ይያያዛል ብለው ያስባሉ) ሀ/ አዎ ለ/ አላሳብም

37. መልስዎ አዎ ከሆነ ከሚከተሉት ውስጥ መፍትሔ ለማግኘት ተጠቅመው ያውቃሉ?

ሀ/ ጠበል መጠመቅ ለ/ በሀይማኖት አባቶች በመደገፍ በእምነት ቦታዎች መጸለይ ሐ/ በባህል አዋቂዎች ወይም በጠንቋይ ለመዳን መሞከር መ/ ሌላ ካለ ይግለፁ -----

ክፍል አራት : የህክምና መንገዶችን በተመለከተ

38. የስነ ልቦናዊና የኢኮኖሚያዊ ጉዳዮችን ለመቋቋም የሚጠቅሙ ዘዴዎች ምንድናቸው?

በግለሰብ ደረጃ -----

በቤተሰብ ደረጃ -----

በተቋም ደረጃ -----

39. ከራስዎ ልምድ /ሁኔታ በመነሳት በሽታውን ለመከላከል ምን መደረግ አለበት ይላሉ? -----

40. የፓርኪንሰን ህመምን ማህበራዊ፣ ኢኮኖሚያዊ፣ መንፈሳዊና ስነልቦናዊ ጉዳዮችን ለመቋቋምና ለመቀነስ ቀጥሎ በተጠቀሱት ደረጃዎች መጠን ምን መደረግ አለበት?

ሀ/ በግለሰብ ደረጃ / ታማሚው ማድረግ ያለበት -----

ለ/ በቤተሰብ ደረጃ -----

ሐ/ በማህበረሰብ ደረጃ (በት/ቤት፣ በቤተ ክምልኮዎች ፣ በእርዳታ ድርጅቶች ወዘተ) -----

መ/ በመንግስት ደረጃ -----

41. በፓርኪንሰን ህመም ተጋላጮች የተቋቋመ የእርስ በእርስ መደጋገፊያ ቡድን ያውቃሉ?

42. አዎ የሚሉ ከሆነ እርስ በእርስ መደጋገፊያ ቡድን ምን ጥቅም አግኝተዋል? -----

43. የፓርኪንሰን በሽታን በተመለከተ ማለት የሚፈልጉት ነገር ካለ ቢገልፁልን?

ለፓርኪንሰን ታማሚዎች -----

ለተንከባካቢዎች/ ለቤሰብ አባላት -----

ለመንግስት/ለተቋማት -----

ለመገናኛ ብዙሃን -----

Focus Group Discussion for people living with PD
and Care providers(Amharic version)

በቡድን ለሚደረግ ውይይት የሚያገለግል

ስሜ ሔለን አስፋው ይባላል በአዲስ አበባ ዩኒቨርሲቲ የሶሻል ወርክ ትምህርት ክፍል ተማሪ ነኝ። ለዛሬው ለመገናኘታችን ምክንያት የሆነን መንስኤ በፓርኪንሰን ህመም ላይ ስለ መንስኤው፣ ስለሚያጋልጡ ሁኔታዎች፣ በበሽታው የሚያስከትለው ጉዳዮች በቤተሰብ፣ በግለሰብና በማህበረሰብ ደረጃ ምን እንደሚመስል ለመወያየት ነው። በቅድሚያ ጊዜያችሁን ስለሰጣችሁኝና በቅንነት ጠቃሚ የሆኑ መረጃዎችን ከምጠይቀው ጥያቄ ጋር በማያያዝ ልትሰጡኝ በመፍቀዳችሁ ላመሰግናችሁ እወዳለሁ።

የቡድን ውይይት የሚካሄደው የፓርኪንሰን ተጠቂዎችንና የቤተሰብ አባሎቻቸውን በአንድነት የሚያሳትፍ ሲሆን የፆታ ተዋዕኔ የተመጣጠነ እንዲሆን ይጠበቃል።

የምርምሩ አጥኚ ለመወያየት የሚሆኑ ነጥቦችን በማንሳት ውይይቱን ያስጀምራል ወይም ከፓርኪንሰን ህመም ጋር የሚኖሩና ከስኬታማነታቸው የሚታወቁ ሰዎችን በመግለጽ ያስጀምራል። ይህ አይነቱ ጀምሮ በመቀራረብና በንዳኝነት መንፈስ አጥኚውና ተሳታፊዎቹ ውይይት እንዲያደርጉ መንገዱን ያመቻቻል።

ከፓርኪንሰን ህመምተኞችና ከቤተሰቦቻቸው ጋር የሚደረግ ቡድን ውይይት

1. ስለፓርኪንሰን ህመም በፊት ስምተው ያውቁ ነበር? (አዎ ካሉ ወይም ካለሉ በመጠየቅ ከየት መረጃውን እንደሰሙ/እንዳገኙ መጠየቅ) (ማስታወሻ፣ በድምጽም ሆነ በተለያዩ እንቅስቃሴ የሚንፀባረቁ መልሶች ጠቃሚነታቸው የጎላ ነው።)
2. የፓርኪንሰን ህመምና የነርቭ በሽታ አንድነው ብለው ያስባሉ? (ማስታወሻ፣ መመሳሰላቸውን መመርምር)
3. ፓርኪንሰን የሚታወቅበት የሃገር ውስጥ መጠሪያ ምንድነው? (በማህበረሰቡ የሚገለጹበት ምክንያቶች ምን ይመስላል)
4. ለፓርኪንሰን ግለሰቦችን ተጋላጭ የሚያደርጓቸው ምን ምን ናቸው? ምክንያቱ ይጠቀሱ
5. ብዙ የፓርኪንሰን ህመምተኞች አዲስ አበባ ውስጥ አሉ ብለው ያስባሉ? በግምት ምን ያህል ይሆናሉ ብለው ያስባሉ?
6. ከቤተሰብዎ መካከል በፓርኪንሰን ህመም የተጋለጠ አለ? (እናት፣ አባት፣ አያት፣ ልጅ)

7. ከጎረቤትዎ መካከል በፓርኪንሰን የተጋለጠ ሰው አለ?
8. የፓርኪንሰን ህመም መጀመሪያ እና እየባሰ ሲመጣ ምን ምልክት ያሳያል?
9. በፓርኪንሰን መያዝዎን እንዴት አወቁ ? (ዶክተር፣ ቤተክርስቲያን . . .)
10. ለመጀመሪያ ጊዜ ፓርኪንሰን እንዳለብዎ ሲያውቁ ምንድን ነበር ያደረጉት?
11. ከቤተሰብዎ መካከል በፓርኪንሰን ህመም የተጋለጠ አለ?
12. የቤተሰብዎ አባላት በምን መልኩ ድጋፍ ያረጉልዎታል?(በገንዘብ፣ በእንክብካቤ)
13. ፓርኪንሰን ያስከተለብዎ ጉዳት ምንድነው? (በግለሰቡ፣ በቤተሰብ፣ በማህበረሰብ)
14. ፓርኪንሰን በስነ ልቦናና በማህበራዊ ላይ የሚያደርሰው ጉዳት ምንድነው? (በግለሰብ፣ በቤተሰብ ላይ)
15. ፓርኪንሰን በኢኮኖሚ ላይ የሚያደርሰው ጉዳት (በታማሚው ላይ፣ በቤተሰብ ላይ)
16. በፓርኪንሰን ህመም ዙሪያ የሚሰሩ ድርጅቶችን ያውቃሉ (በነዚህ ድርጅቶች ምን አገልግሎት ይሰጣል)
17. የትኞቹ የግልና የመንግስት ተቋማት በፓርኪንሰን ዙሪያ ይሰራሉ (ምን አገልግሎትስ ይሰጣሉ)
18. በግልና በመንግስት ድርጅቶች አዲስ አበባ ውስጥ ላሉት ለፓርኪንሰን ህመምተኞቹ የሚሰጡት አገልግሎት በቂ ናቸው ብለው ያስባሉ? (ማስታወሻ: በቂ ካልሆነ በመጠየቅ ይዘርዘር)
19. ህመም በሚሰማዎ፣ በሚደብሮ፣ መናገር በሚያቅትዎ፣ ከአልጋ መነሳት በሚያቅትዎ ጊዜ ወዘተ . . . ምን አይነት የተለምዶ መዳኒቶችን በመጠቀም እርስዎን ከሁኔታው አንፃር ለመደገፍ ይሞክራሉ?
20. ምን አይነት እርዳታ ያገኛሉ?
 ሀ/ ከቤተሰብ አባላት ለ/ ከህክምና ባለሙያዎች (ህመምተኞቹን መጠየቅ)
21. ምን አይነት ድጋፍ ለህመምተኞቹ ያደርጋሉ (ተንከባካቢዎቹን መጠየቅ)
22. ፓርኪንሰንን ልክ እንደ ኤች.አይ.ቪ ፣ ቲቪና ካንሰር ለምን የህዝቡን በቂ ትኩረት ለምን አላገኘም? (ማስታወሻ: ያሉትን ሁኔታዎች ከተግዳሮቶቹ አንፃር ማየት)
23. የፓርኪንሰን በሽታ የፈጣሪ ቁጣ ነው ብለው ያስባሉ (ማስታወሻ: ክርክር እንዲደረግበት ማድረግ)
24. ካለብዎት የፓርኪንሰን በሽታ ለመፈወስ ፀበል ወይም ጠንቋይ /የባህል ሀኪሞች የመሳሰለውን መፍትሔ ለመጠቀም ሞክረው ያውቃሉ?
25. ለምን አብዛኞቹ የፓርኪንሰን ህመማን ቤተሰቦች ታማሚዎቹን ወደ ህክምና ከመውሰድ ይልቅ ወደ ልማዳዊ ፈውስ አማራጮች መውሰድ ይመርጣሉ?
26. ምን አይነት ሁኔታዎች ፓርኪንሰን በሽታ እንዲባባስ ያደርጋሉ? (ከቀላሉ ወደ መካከለኛ በመቀጠልም ከፍ ወዳለው ደረጃ ሊያደርሱ ይችላሉ)

- 27. ለፓርኪንሰን በመጠቃት የተነሳ በስራ ላይ የደረሰው ሁኔታ ምን ይመስላል? (ወይም በታማሚ ቤተሰብ ላይ የደረሰውን ይግለጹ)
- 28. ስራዎትን በለቀቁ ጊዜ በቂ ማካካሻ አግኝተዋል? (የማካካሻው ሁኔታ ምን ይመስላል?)
- 29. ያሉበትን ሁኔታ ለማረጋገጥ ሆስፒታሎችን ይጠቀማሉ? (በምን ያህል ጊዜ ልዩነት? ለምን ሆስፒታል አልሆነም? ለምን ባህል ህክምና አዋቂዎችን መረጡ)
- 30. ለህክምና ምርመራ፣ ለመድሃኒት ለትራስፖርት ወዘተ በወር ምን ያህል ወጪ ያወጣሉ?
- 31. እቤትዎ ውስጥ እንክብካቤ የሚያደርግልዎ ማነው? ድጋፍ ምን ይመስላል ወይም በምን መልኩ ያደረጋል
- 32. ድጋፍ የሚያደርገው ተቋም ለፓርኪንሰን በሽተኞቹና ለደጋፊ ቤተሰቦቻቸው ምን አይነት ድጋፍ ያደርጋሉ?
- 33. የንግግር ችግር ለመፍታት፣ DBS፣ የአካል ማፍታቻ እንቅስቃሴ ድጋፍ የሚያደርጉ ግለሰቦችን ወይም ተቋማትን ያውቃሉ? (አዎ ወይም አላውቅም የሚሉ ከሆነ እንዲያስረዱ መጠየቅ?)

Declaration

I declare that the study entitled “The Psycho-Social and Economic Impact of Parkinson’s disease on People Infected and affected by the Disease” is my own work and that all the sources I have used or quoted have been indicated and acknowledged by means of complete reference.

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This thesis has been submitted for examination with my approval as an advisor for the candidate.

Name: _____

Signature: _____

Date: _____

Organization: _____