



**COLLEGE OF EDUCATION AND BEHAVIORAL STUDIES
DEPARTMENT OF SPECIAL NEEDS AND INCLUSIVE
EDUCATION**

**The lived experience of individuals with communication disorders
associated with Parkinson's disease: The case of Parkinson Patients
Support Organization-Ethiopia**

By: Eyerusalem Tesfaye

July, 2024

Addis Ababa, Ethiopia



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A thesis submitted to Addis Ababa University College of Education, Department of Special Needs and Inclusive Education in partial fulfillment of the MSc in Speech Language and Therapy

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DECLARATION

I the under signed, declared that this thesis entitled “The Lived Experience of individuals with communication disorders associated with Parkinson’s disease: The case of Parkinson Patients Support Organization-Ethiopia” is my original work and has not been presented the award of the degree in any other university and that all sources of materials used for this thesis have been duly acknowledged.

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ABSTRACT

This qualitative study explores the experiences of individuals in Ethiopia who have communication disorders associated with Parkinson's disease (PD). The study aims to gain insights into the specific communication challenges they face, the psychosocial impacts they encounter, additional difficulties they experience, and the coping mechanisms they employ. The research methodology employed was qualitative, with a particular emphasis on a descriptive phenomenological research design. Data was collected through semi-structured interviews with nine participants who were purposively selected from PPSO-E. The data analysis was conducted manually, focusing on thematic areas derived from the interview guides and participants' responses. The findings reveal a range of difficulties related to communication disorders in PD, including reduced voice volume and quality, articulation issues, changes in speech rate, and cognitive-linguistic impairments. The study also uncovers negative implications for emotional well-being, psychological well-being, and economic stability, including misconceptions and stigma. Additionally, physical symptoms are identified, which can exacerbate psychosocial and economic hardships. Participants employed coping mechanisms such as speech and language therapy, social support, and compensatory strategies to enhance their communication abilities. Based on the study's findings, it is recommended that the relevant federal ministries and organization become involved in promoting and coordinating interventions for individuals with PD. Implementing comprehensive strategies to address communication disorders in PD can significantly improve individuals' quality of life, facilitating social connections and active participation.

TABLE OF CONTENTS

CONTENTS	PAGE
ACKNOWLEDGMENT	I
ABSTRACT	II
LIST OF ACRONYMS	VI
CHAPTER ONE.....	1
INTRODUCTION.....	1
1.1. Background of the Study.....	1
1.2. Statement of the Problem	4
1.3. Objective	7
1.3.1. General Objective	7
1.3.2. Specific Objectives	7
1.4. Significance of the Study	7
1.5. Scope of the Study.....	9
1.6. Definition of Operational Terminologies	9
CHAPTER TWO.....	10
LITERATURE REVIEW.....	10
2.1. Communication Disorders.....	10
2.2. Prevalence	10
2.3. Communication Disorders In Parkinson's Disease.....	10
2.4. Treatment.....	11
2.5. Impact of Communication Disorders	12
2.5.1. Emotional and psychological impact	12
2.5.2. Impaired Social Interactions	13
2.6. Coping strategies	13
2.7. Speech and language therapy interventions	14
CHAPTER THREE.....	15
RESEARCH METHODS.....	15
3.1. Research Approach and Design	15
3.2. Study Site	16
3.3. Study Participants.....	16

3.3.1. Sampling Technique	17
3.3.2. Sample size	18
3.4. Data Collection Tool	18
3.4.1. Interview Guide.....	19
3.5. Data Collection Procedure.....	19
3.6. Data Analysis	20
3.7. Ethical Considerations.....	21
3.8. Trustworthiness and Credibility	21
3.9. Dissemination of the Study	22
CHAPTER FOUR	23
RESULTS.....	23
4.1. Experienced Communication disorders.....	25
4.2. The Psychosocial Experience	27
4.3. Economic Experience.....	31
4.4. Coping Strategies	32
4.5. SLT services Experiences	34
4.6. Physical experience	35
4.7. Desired Support.....	35
CHAPTER FIVE	37
DISCUSSION	37
5.1. Communication disorders.....	38
5.2. Psychosocial experience.....	38
5.3. Physical experience	39
5.4. Economical experience.....	39
5.5. Coping Strategies	40
5.6. Speech and Language Therapy experience	41
5.7. Support	41
5.8. Limitation	42
5.9. Implications	42

CHAPTER SIX 44

CONCLUSION AND RECOMMENDATION 44

6.1. Conclusion..... 44

6.2. Recommendations 45

REFERENCES 46

APPENDIX 1 52

APPENDIX 2 53

APPENDIX 3 55

APPENDIX 4 57

LIST OF TABLE

PAGE

Table 1: Profile of the informant-----22

LIST OF FIGURE

PAGE

Figure 134

LIST OF ACRONYMS

PD- Parkinson's disease

PPSO-E- Parkinson's patients support organization-Ethiopia

SLT- Speech and language therapy

SLTs- Speech and language therapists

HKD- Hypokinetic dysarthria

SSA- Sub Saharan Africa

WHO- World health organization

ASHA- American speech and language association

CHAPTER ONE

INTRODUCTION

1.1. Background of the Study

Parkinson's disease is a progressive neurological condition characterized by the early loss of dopaminergic neurons in a specific area of the brain known as the substantia nigra pars compacta. This leads to a deficiency of dopamine in the basal ganglia, resulting in a movement disorder (Kalia et al., 2015). It is a slowly developing chronic neurodegenerative condition marked by primarily motor symptoms such as bradykinesia, resting tremor, rigidity, and postural disturbances (WHO, 2023).

In addition to these symptoms, Parkinson's disease is also associated with various other non-motor symptoms, some of which can appear years before the onset of movement issues. These symptoms include difficulties with speech and swallowing such as word retrieval issues, slower information recall, and excessive saliva production, changes in sense of smell, fatigue, autonomic dysfunction, sleep disturbances, mood disorders, and cognitive decline (Prakash et al., 2016; Wolter, 2008).

Motor speech abnormalities are also highly prevalent and have a profound impact on individuals with PD. These abnormalities collectively referred to as hypokinetic dysarthria, have traditionally been attributed to muscle rigidity and dopamine deficits, resulting in reduced movement (hypokinesia) and slowness (bradykinesia) (Sapir, 2014).

According to Bloem et al (2021), Parkinson's disease is distinct in that its duration can extend over several decades. The usual course involves a gradual advancement leading to increasing disability in those affected. Recognizing the initial stages of Parkinson's disease can be challenging, as evidenced by the significant delay (averaging 10 years) between the onset of noticeable symptoms and the formal diagnosis. In clinical settings, the diagnosis of Parkinson's disease relies on a thorough assessment of medical history and neurological examination.

PD is prevalent, global estimates in 2019 showed over 8.5 million individuals with PD, with recent estimates suggesting that, in 2019, PD resulted in 5.8 million disability adjusted life years. (WHO,2023) Parkinson's disease (PD) ranks as the second most prevalent neurodegenerative disorder

globally, following Alzheimer's disease (Kalia et al., 2015; Dorsey et al., 2018; Alzheimer's Association, 2014).

The aging population is considered a significant factor driving the observed rise in both prevalence and incidence of Parkinson's disease in Sub-Saharan Africa (Parkinson's disease in Sub-Saharan Africa, 2020). Tracking universal health coverage in the WHO African region (2022) reported that healthy life expectancy increased in Africa to 56 years in 2019 compared with 46 in 2000. Prevalence and incidence of PD increasing significantly with age peaking after 80 years (Driver et al., 2009). A recent review indicated the prevalence of PD ranging from 7/100,000 in Ethiopia to 67/100,000 in Nigeria (Parkinson's disease in Sub-Saharan Africa, 2020).

Due to its limited research, the current prevalence and incidence rates of Parkinson's disease in Ethiopia are not known. However, a previous door-to-door study found seven cases per 100,000 individuals (Tekle-Haimanot et al., 1990). A study completed in a university based neurology clinic in Addis Ababa, Ethiopia revealed that among a total of 15.1% neurological patients seen for movement disorder, 47.7% were diagnosed with Parkinsonism (Bower et al., 2005).

Parkinson's disease exercises a negative influence on communication, irrespective of age and gender (Miller, 2008). More than 90% of people with Parkinson's disease will experience at least one symptom associated with speech and communication difficulties over the course of their illness with symptoms such as a weak, harsh voice, imprecise articulation, and dysprosody, which has been considered the main cause of communication problems in people with PD (Schalling et al., 2018). Generally, the occurrence of voice impairment is very frequent across all categories of severity. However, fluency and articulatory impairment gradually increase in frequency as speech is more severely affected (Ho AK et al., 1998). These symptoms collectively make up hypokinetic dysarthria (HKD) and stem from impairments in the systems responsible for respiration, phonation, articulation, resonance, and prosody (Schulz and Grant, 2000).

Furthermore, cognitive-linguistic impairment is a common issue faced by individuals with PD manifests as a short attention span, poor working memory, reduced recent and short-term memory, and difficulties with planning and reasoning play a coordinated role in language comprehension and over all communication (Hancock AD et al., 2011). Symptoms such as problems with slurred speech, word-finding difficulties, challenges staying on topic during conversations, and reduced speed of

information processing may be masked by the motor problems in PD and therefore overlooked (Schalling, 2018; Ho AK, 1998).

Communication is central not just to functioning successfully on a day-to-day basis, it is intimately tied up with feelings about ourselves and how others react to us. It is unsurprising, therefore, that changes to communication profoundly affect people with Parkinson's disease and those with whom they communicate (Miller, 2017).

Individuals who sense they have lost control in communicating are less confident, find it difficult to get their message across, and experience consequent frustration, feelings of inadequacy, and a sense of loss of independence. Precisely these feelings may lead to withdrawal from communicating (Miller et al., 2008).

The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) has shed light on the psychosocial impacts of Parkinson's disease. The ICF has helped to highlight the broader effects of the condition beyond its physical symptoms (Yorkston et al., 2016).

Individuals with PD experience a number of psychological changes in themselves which occur as a consequence of communication difficulties. Loss of confidence and low self-esteem are a common experiences as often other people can misperceive and evaluate them on account of their condition and jump to the wrong conclusion about them. They may be perceived as miserable, drunk, and mocked for their speech (Altahr et al., 2020).

According to Hammarlund et al (2018), the loss of identity and dignity resulting from Parkinson's disease led to shifts in family dynamics, feelings of worthlessness due to limitations in participating in social activities, and reduced interactions with loved ones and acquaintances. Caregivers often experience excessive strain, contributing to the mounting socioeconomic burden associated with the disease (Walga, 2019).

Whitehead (2010) states the strategies used by individuals to cope with the increasing difficulties of communication as a result of their condition. These have been subdivided into extrinsic strategies such as speech and language therapy (SLT), opportunities for social interaction, and support from family members when struggling with communication difficulties. Intrinsic strategies include adapting to the communication changes, concentrating to avoid conversational decline, keeping the

brain active, making a social comparison with others with the disease to reflect on their own positive qualities, and maintaining a positive outlook. PD patients who have effective social interactions experience lower levels of depression and an enhanced sense of personal value (Gupta and Bhatia, 2000).

Whitehead (2010) suggested that patients should be encouraged to engage in activities that can enhance their social networks and self-esteem. Activities promoting social support could be integrated as a cognitive restructuring component of cognitive-behavioral programs. The researcher emphasized the importance of involving speech and language therapy services in such programs, incorporating elements of counseling, group therapy, and social support. Additionally, including family members in consultations and support program delivery was recommended.

While Parkinson's disease has no cure, multidisciplinary intervention is important. A combination of pharmacological and surgical treatments with behavioral, physical, and speech therapy has been shown to be effective in managing the condition (Dotchin and Walker, 2012). The lived experience of individuals with Parkinson's disease is significantly impacted by the complex clinical manifestations of the disease, gradual decline in self-care, increasing disability, and demanding therapy (Bonner et al., 2020; Eatough and Shaw, 2019). Lived experience refers to how individuals reflect on the significance of their experiences and how they attempt to make sense of them (Frazier, 2000). This study, therefore, aims to explore the lived experience of individuals facing communication disorders associated with Parkinson's disease.

1.2. Statement of the Problem

Living with communication disorders presents significant challenges for individuals, as it can lead to limited social participation, ultimately impacting their quality of life (Schaling et al., 2018). In Parkinson's disease, communication changes are common, with a high percentage of patients experiencing dysarthria, affecting their ability to interact effectively (Miller et al., 2008; Schaling et al., 2018).

Studies have highlighted the emotional impact of these communication difficulties on individuals with PD, leading to feelings of frustration, anger, and a lack of motivation to engage socially. This can result in shortened conversations and challenges in meeting social expectations (Miller 2008; Altahar, 2020).

Despite the rising prevalence of PD worldwide, it remains one of the least recognized conditions in Africa, including Ethiopia. The disease has been neglected within the Ethiopian health sector, primarily because there is a lack of policy and programmatic documentation addressing this specific disease. The absence of focused attention on this disease within the health sector can have detrimental effects on the well-being of individuals affected by the disease, the healthcare system's capacity to respond effectively, and the overall public health of the population.

This lack of awareness does not indicate a lower occurrence of PD in Africa or Ethiopia. In fact, there is non-governmental organization which is called Parkinson Patients support organization-Ethiopia (PPSO-E) in Addis Ababa dedicated to supporting individuals with PD, highlighting the existing challenges and the need for further exploration of the disease. The limited knowledge about PD in Africa including Ethiopia may be attributed to a lack of research and insufficient diagnostic criteria (Walga, 2019; Kibra, 2018).

Existing studies in Ethiopia have primarily focused on prevalence of specific aspects of PD such as pain, sleep disorders, fatigue, and depression (Hirsi et al., 2019; Melka et al., 2019; Oda, 2020; Worku et al., 2014).

Other research which is done in Ethiopia has explored to understand the challenges faced by caregivers. The study described providing care for a Parkinson's disease patient is a “challenging responsibility that requires a great deal of patience.” This study also highlighted that that Community’s limited understanding and distortion of PD, lack of sufficient support to the caregivers and Shortage and expensiveness of PD drugs/prescriptions (Walga, 2019).

According to Kibra (2018), caring for a PD patient is a demanding journey that involves the patient, caregivers, family members, and close relatives and friends. Research by Helen (2014) has highlighted the complex economic and psychosocial issues faced by PD patients in Ethiopia, as well as their family members, close relatives, and friends, including early retirement, self-stigmatization, loneliness, and social anxiety. Abenet et al (2017) have demonstrated that both the motor and nonmotor symptoms of Parkinson's disease impact the health-related quality of life of patients, with the effects worsening as the disease progresses in severity. Taking a comprehensive approach to describing the challenges of living with Parkinson's disease is essential.

To the best knowledge of the researcher, there are no studies done on the lived experiences of individuals with communication disorders associated with Parkinson disease in Ethiopia. Lived experience represents how the person reflects the significance of what has happened and how he or she engages in trying to make sense of it (Smith et al., 2009). This research gap might be due to the relatively new discipline of speech and language therapy field in the country. The lack of studies on this topic in Ethiopia will limit the understanding of the unique experiences, challenges and coping strategies of individuals with Parkinson related communication disorders within the Ethiopian cultural, linguistic and socioeconomic context.

Healthcare professionals, speech and language therapists (SLTs), caregivers, and policymakers can benefit from a qualitative understanding of the subjective experience of Parkinson's disease (PD) patients with communication disorders. This understanding can assist in providing targeted interventions, support systems, and policies that effectively meet the needs of this specific population.

Regarding the role of SLTs in treatment, it has been found that the treatment of hypokinetic dysarthria in PD patients is most effective when focusing on loud phonation, clarity of speech, or rate of speech. These treatment targets have a global impact, affecting multiple speech systems such as respiration, phonation, and articulation, thereby improving speech intelligibility (Tjaden et al., 2013). It is important for speech training to be intensive and extensive, not only to enhance speech movements and intelligibility, but also to maintain treatment outcomes over an extended period of time (months and years) post-therapy. This type of training should address the main treatment obstacles associated with PD and HKD, including deficits in internal cueing, automatization, perception of one's own speech output, and attention to action as coping strategy (Sapir, 2014).

Understanding the lived experience of individuals with communication changes in PD can assist SLTs in conceptualizing assessment and intervention using the International Classification of Functioning, Disability, and Health (ICF) framework. The ICF will help to highlight the broader effects of the condition beyond its physical symptoms (Yorkston et al., 2016). By gaining better knowledge of the lived experience of individuals with PD, SLTs can develop personalized treatment plans that specifically address the challenges and unique needs of these populations.

However, existing research from other countries may not fully capture the unique aspects of the Ethiopian context, including cultural beliefs, linguistic diversity, and access to healthcare. Therefore,

the current study aims to fill this research gap by exploring the lived experiences of individuals with communication changes associated with Parkinson's disease in Ethiopia.

1.3.Objective

1.3.1. General Objective

The purpose of this study is to explore and understand the lived experiences of individuals with communication disorders associated with Parkinson disease.

1.3.2. Specific Objectives

- To investigate the communication disorders that patient with PD face.
- To assess the challenges posed by communication disorders in patients with PD.
- To investigate the psychosocial impact of communication disorders in patients with PD.
- To assess the coping strategies of patients with PD and communication disorders.

1.4. Significance of the Study

The proposed study on the lived experiences of individuals with communication disorders associated with Parkinson's disease in Ethiopia holds several significant implications:

- **Fill the Research Gap:** The study addresses the significant research gap concerning the experiences of individuals with Parkinson's-related communication disorders in Ethiopia. By conducting this research, we contribute to the limited body of knowledge in this specific area within the Ethiopian context.
- **Cultural and Contextual Relevance:** The study focuses on the Ethiopian population, taking into account cultural beliefs, linguistic diversity, and access to healthcare resources. This approach ensures that the findings are contextually relevant and can inform the development of culturally sensitive interventions and support systems to healthcare providers and policymakers.
- **Tailored Interventions:** Understanding the lived experiences of individuals with Parkinson's-related communication disorders in Ethiopia will provide insights into their unique challenges and coping strategies. This knowledge will help SLTs develop targeted interventions that address the

specific needs of the Ethiopian population, leading to improved communication abilities and overall well-being.

- **Policy and Resource Allocation:** The findings of the study can inform policy makers and resource allocators within the Ethiopian healthcare system. Recognizing the impact of communication changes in Parkinson's disease and the need for tailored interventions can drive policy changes, funding priorities, and the development of guidelines for healthcare professionals.
- **Professional Development:** The study contributes to the professional development of healthcare providers and SLTs by increasing their understanding of the lived experiences of individuals with Parkinson's-related communication changes. This knowledge can be integrated into clinical practice, promoting patient-centered care and improving the communication support offered to individuals with Parkinson's disease.
- **Awareness and Advocacy:** The research outcomes can contribute to raising awareness about Parkinson's-related communication changes in Ethiopia. By disseminating the findings, the study can promote public understanding, reduce stigma, and advocate for improved support and inclusion of individuals with Parkinson's-related communication changes in society.
- **Long-Term Impact:** The findings of the study can have a lasting impact on the healthcare landscape in Ethiopia. The knowledge gained can lay the foundation for future studies, interventions, and policy initiatives focused on communication changes in Parkinson's disease. This can lead to continuous improvements in the understanding, assessment, and management of communication challenges, ultimately benefiting individuals with Parkinson's-related communication changes and their families.
- **Global Contribution:** While the study focuses on the Ethiopian context, its findings can also contribute to the global understanding of communication changes in Parkinson's disease. Cross-cultural comparisons and insights gained from diverse populations enrich the existing knowledge base and support the development of best practices and recommendations that are applicable beyond Ethiopia.

1.5. Scope of the Study

This study is limited to patients with a medical diagnosis of Parkinson's disease, who exhibit communication disorders as a result of PD. Furthermore, the study is conducted within the context of patients diagnosed with Parkinson's that belong to the PPSO-E. Moreover, the study is limited to focusing on finding out and understanding the lived experiences of individuals as they relate to communication disorders associated with Parkinson's disease.

1.6. Definition of Operational Terminologies

PD patients: a Person who has been diagnosed PD by physician from different institutions and who are linked to PPSO-E.

Individuals with Communication disorders; Individuals who diagnosed for communication disorders by SLTs

Lived experience; The unique encounters, challenges, emotions, coping mechanisms and the impact of communication disorders on the daily lives of individuals with Parkinson's disease.

CHAPTER TWO

LITERATURE REVIEW

2.1. Communication Disorders

Communication disorders encompass limitations in receiving, transmitting, understanding, or processing information through verbal, nonverbal, and graphic symbol systems. These disorders can affect hearing, language, and speech and may range from mild to severe in intensity. They can be present from birth or acquired later in life and may occur as the main disability or alongside other disabilities (ASHA, 1993).

2.2. Prevalence

Communication disorders affect approximately 5-10% of the population and commonly manifest in adults as conditions such as aphasia, dysarthria, apraxia of speech, and cognitive-linguistic disorders. These disorders frequently arise due to stroke, traumatic brain injury, Parkinson's disease (PD), and multiple sclerosis. Similarly, children experience speech, language, voice, fluency, and swallowing disorders, with developmental delay being the most prevalent cause among pediatric populations (Ruben RJ, 2000; Brookshire RH, 2007; Law et al., 2000).

2.3. Communication Disorders In Parkinson's Disease

Miller et al. (2008) revealed that Parkinson's disease has a detrimental impact on communication, regardless of age or gender. Communication barriers for individuals with Parkinson's disease (PD) stem from the speech production difficulties associated with hypokinetic dysarthria, as well as the reduced facial expression and mask-like affect. Additionally, it is important to note that many individuals with PD also experience cognitive-linguistic impairments (Hancock AD et al., 2011).

Hypokinetic dysarthria, which is prevalent in approximately 89% of patients with Parkinson's disease (PD) is characterized by certain speech characteristics. These include a monotonous pitch and loudness, reduced stress, variable speech rate, imprecise consonants, and a breathy and harsh voice (Muñoz-Vigueras N et al., 2021; Pinto S et al 2004,).

Moreover, individuals diagnosed with Parkinson's disease commonly encounter cognitive-linguistic difficulties. Roughly 30-40% of patients may display mild cognitive impairment (MCI) at the time of

their Parkinson's diagnosis, and they face a significant risk of progressing to dementia within five years (Yarnall, 2014; Pigott et al., 2015).

Stocci and Brusa (2000) made an observation that 90% of individuals with Parkinson's disease experience some form of cognitive impairment, which significantly affects their daily functioning. Among them, 25% face severe cognitive impairment. These impairments manifest as limitations in attention span, impaired working memory, decreased recent and short-term memory, as well as challenges in planning and reasoning (Hancock AD et al., 2011). Attention and working memory play a coordinated role in the comprehension of language, particularly when dealing with longer and complex sentences, ambiguous words, reference pronouns, and irrelevant information (Engle and Conway, 1998).

The extent of communication difficulties can vary significantly, ranging from slight difficulties to speech that is difficult to hear and understand. This hampers the ability to communicate effectively with family members, caregivers, and healthcare professionals. Functional communication, which is crucial for everyday tasks, encompasses engaging in conversations, speaking spontaneously or with prior preparation, with different individuals (both familiar and unfamiliar) in various physical environments (such as over the phone or in person, in social or occupational settings) (Smith & Caplan, 2018).

2.4. Treatment

Receiving prompt intervention and support from speech and language therapists can have a beneficial impact on individuals by assisting them in developing compensatory strategies, enhancing their communication skills, and improving their overall well-being (Miller et al., 2006).

According to Tjaden & Wilding (2013), the most effective treatment objectives for hypokinetic dysarthria (HKD) are focused on increasing vocal volume, improving speech clarity, and adjusting speech rate. These objectives are considered comprehensive approaches as they target multiple aspects of speech production, including respiration, phonation, and articulation. By addressing these objectives, the treatment aims to enhance the clarity of speech in individuals with HKD, resulting in overall improvement in their speech production and communication abilities.

In the treatment of HKD, Sapir (2014) emphasizes the significance of intensive and extensive speech training. This training not only focuses on improving speech movements and intelligibility but also places importance on maintaining the treatment outcomes for an extended period, spanning months and even years after therapy. The training programs should be specifically tailored to address the unique challenges associated with HKD and Parkinson's disease, such as difficulties in internal cueing, automatization, perception of one's speech output, and attention to action. By targeting these challenges, speech training can enhance the effectiveness of treatment and contribute to sustaining the achieved improvements in the long run.

2.5. Impact of Communication Disorders

The challenges faced by individuals with Parkinson's disease (PD) due to communication disorders have a significant impact on various aspects of their lives, including interactions with family and friends, perceived speech abilities, and daily life functioning. Communication plays a central role not only in successfully navigating day-to-day activities but also in shaping one's self-image and how others perceive and respond to them. Therefore, it is not surprising that alterations in communication have a profound effect on individuals with PD and their communication partners (Miller, 2017).

Hammarlund et al. (2018) highlight that the consequences of Parkinson's disease, such as a loss of identity and dignity, result in changes in family dynamics, feelings of worthlessness due to limitations in participating in social activities, and reduced interactions with loved ones and acquaintances.

The communication changes experienced in PD have a profound impact on individuals and their families. These changes go beyond impairments in speech and language abilities and extend to self-perception, engagement in social activities, and the dynamics of interpersonal relationships (Miller, 2006).

2.5.1. Emotional and psychological impact

Individuals who have speech disorders encounter difficulties in effectively conveying their thoughts, leading to heightened frustration that may even lead to a complete cessation of verbal communication. They experience intense anger and frustration when others struggle to comprehend their intended messages or effectively express their thoughts (Altar et al., 2020).

Swales (2021) emphasized the emotional ramifications of communication disorders, with anxiety and fear being prominent. People with Parkinson's disease may feel anxious about their ability to communicate effectively, resulting in heightened distress during social interactions. Moreover, the fear of being misunderstood or unable to express themselves clearly can further contribute to emotional challenges. The inability to fully engage in conversations or express oneself can lead to a sense of loss, as individuals may find it challenging to maintain meaningful connections with others. These emotional consequences can compound feelings of loneliness and isolation.

Miller et al. (2008) highlighted that a common emotional response to communication disorders is a diminished sense of confidence. Individuals may experience decreased self-assurance in their communication skills, resulting in self-doubt and hesitancy when expressing themselves. This frustration can contribute to feelings of inadequacy, as individuals may perceive their communication abilities as insufficient, leading to lowered self-esteem and a sense of personal failure. The emotional consequences of perceiving a loss of control in communication also extend to a sense of diminished independence.

In general, communication disorders in Parkinson's disease impact self-perception, interpersonal relationships, and social functioning, leading to psychological distress and a reduced quality of life (Altar et al., 2020).

2.5.2. Impaired Social Interactions

Hammarlund et al. (2018) emphasize the emotional consequences of being unable to participate in once-enjoyed activities. Individuals may feel a sense of isolation and withdraw from social engagements as the disease limits their ability to fully engage in social gatherings and events. This reduced social interaction can further contribute to feelings of worthlessness and a diminished sense of belonging.

2.6. Coping strategies

The study conducted by Altar et al. (2020) draws attention to the compensatory strategies utilized by individuals when faced with communication breakdowns. Strategies such as speech repetition, slower speech rate, and increased vocal volume are identified as methods employed to ensure smoother

conversations. These strategies reflect individuals' efforts to enhance clarity, comprehension, and effective communication with their conversation partners.

In a study by Whitehead (2010), various coping strategies employed by individuals to address communication difficulties are highlighted. Extrinsic strategies, including speech and language therapy, opportunities for social interaction, and support from family members, offer external assistance and resources. Intrinsic strategies involve personal adjustments, such as adaptation, concentration, cognitive stimulation, social comparison, and maintaining a positive outlook. These intrinsic strategies enable individuals to approach communication challenges with optimism and resilience.

Miller (2006) discusses coping strategies associated with dealing with negative attitudes and treatment. One identified strategy is to inform others about PD, aiming to educate them and potentially alter their perceptions. Moreover, individuals make a conscious decision not to be intimidated, fearful, or discouraged from trying, showcasing resilience and determination in the face of negative attitudes and treatment.

2.7. Speech and language therapy interventions

The findings of Miller et al. (2006) underscore the importance of early referral to speech and language therapy for individuals with Parkinson's disease (PD). Speech and language changes associated with PD can have a significant impact on an individual's quality of life and family dynamics. Therefore, timely intervention and support from speech and language therapists can assist individuals in developing compensatory strategies, improving their communication abilities, and enhancing their overall well-being.

Whitehead's (2010) study highlights the critical role of early intervention and speech therapy for individuals with PD. Identifying and initiating speech therapy interventions at an early stage can help manage communication difficulties and mitigate their psychosocial consequences. Counseling, group therapy, and social support are essential components of speech therapy interventions that contribute to improved well-being and overall quality of life.

According to Altar et al. (2020), the majority of individuals with PD who undergo speech therapy reported its benefits, leading to improvements in their speech.

CHAPTER THREE

RESEARCH METHODS

3.1. Research Approach and Design

This study utilized a qualitative research approach to delve deeply into the phenomenon under investigation, prioritizing exploration rather than measurement. As Draper (2004) suggests, qualitative research aims to understand and explain the world from the participants' perspectives, taking into account the context of their everyday lives.

The researcher adopted a descriptive phenomenological design to effectively explore the experiences and perceptions of the individuals involved in the study. This approach employs phenomenological reduction to enhance the precision of the research findings. Phenomenological inquiry seeks to fully describe lived experiences and emphasizes that only those who have experienced the phenomena can effectively communicate them to the outside world (Todres and Holloway, 2004).

In phenomenological research, the researcher aims to identify the "essence" of human experiences related to a particular phenomenon, as described by the participants in the study (Moustakas, 1994). Understanding the "lived experiences" is fundamental to phenomenology as both a philosophy and a method. This involves engaging with a small number of subjects extensively and over an extended period to discern patterns and relationships of meaning (Moustakas, 1994).

To achieve this, the researcher set aside personal knowledge about the phenomenon and fully embraced the participants' statements, striving to comprehend the significance they attributed to their lived experiences. This approach ensures a more accurate portrayal of the essence of the experience (Giorgi, 2009).

Consistent with Moustakas (1994), the researcher approached the topic with an unbiased and fresh outlook, refraining from making assumptions. The study's results will serve as a foundation for further examination and research. The researcher chose this approach to obtain a comprehensive understanding of the nature and significance of communication disorders associated with Parkinson's disease (PD) as perceived and lived by the patients themselves.

3.2. Study Site

The study was carried out at Parkinson Patients Support Organization-Ethiopia (PPSO-E) in Addis Ababa, the capital city of Ethiopia. PPSO-E is a local non-governmental charity organization established in May, 2011 G.C. Currently, it is situated in Addis Ababa, Kirkos sub city. The organization was founded by Kibra Kebede, who is also a patient with Parkinson's disease. Kibra Kebede has received recognition for her work, including the 2018 Excellence Award in 2018 and the Ethiopian Begosew Award in 2022 for her efforts in improving the lives of patients with Parkinson's disease and their families. The organization's vision is centered on enhancing the quality of life for individuals with Parkinson's disease and their caregivers through activities such as raising awareness, building capacity, and providing care and support. (Parkinson patients support organization-Ethiopia, 2021).

The selection of this organization as the research site is based on three reasons. The first one is due to its unique dedication to addressing the needs of the growing number of individuals diagnosed with Parkinson's disease in Ethiopia, with the goal of improving their lives and providing support to both patients and caregivers. The second is due to access to participants. PPSO-E can provide a large pool of potential participants who can contribute their unique perspectives and experiences to the research. The third is the potential for collaboration with PPSO-E thereby providing opportunities for future partnerships, knowledge sharing, and potential interventions or support programs that can benefit individuals with Parkinson's-related communication disorders.

The Study period was from March to May, 2024 G.C.

3.3. Study Participants

The focus of this study was on individuals who are experiencing communication disorders related to Parkinson's disease at the PPSO-E. Prior to making initial contact with the patients, their eligibility to participate in the study was assessed. The inclusion criteria consisted of individuals who have received a medical diagnosis of Parkinson's disease from different institutions as well as appeared and registered at PPSO-E. Additionally, who are screened or diagnosed for communication disorders by SLTs as a result of the condition.

In order to ensure a diverse and representative sample within the target population, the researcher also included individuals from different age groups, genders, durations of diagnosis, as well as those on SLT and those who are not on SLT. Additionally, participants who can fluently communicate in Amharic possess intelligible speech without the need for augmentative and alternative communication devices during the interview, and express a willingness to participate in the study is included. Patients who are seriously ill was not included.

3.3.1. Sampling Technique

To understand and arrive at the essence of living as a patient with PD that also has communication difficulties, the researcher applied heterogeneous purposive sampling techniques to get obtain a wide range of patient types with regards to gender, age, duration of living with the diseases, and SLT history. This helped to ensure a heterogeneous sample that will help for a diverse representation by purposefully selecting individuals with different characteristics and experiences from registered data of the patients within the organization.

Selecting Participants was determined by referencing the organization's speech and language therapy (SLT) registered document of PD patients with communication the researcher included 5 participants who has undergone speech and language therapy as well as 4 who have not. The SLTs in the organization utilize non standardized assessment tools to evaluate the communication disorders due to the lack of standardized tools which are tailored to our country and language contexts.

Typically, the researcher selected participants from genders, 7 males and 2 females. The lower number of females is because as the researcher could not find the eligible female patient for the study from the registered document as reflecting the higher prevalence of PD in men, as supported by epidemiological studies (Miller et al., 2008). We also consider participants from different age groups, encompassing both younger and older individuals as much as possible ranging from 45 to 79 years as PD affects the older population as stated in literature (Driver et al., 2009). The study also included individuals who have been diagnosed recently as well as those with a longer history of diagnosis ranging from 5 years to 20 years. Additionally, the researcher included 5 participants who has undergone speech and language therapy as well as 4 who have not.

Palinkas et al (2015) described purposive sampling as a commonly utilized method in qualitative research to select individuals or cases that possess substantial information pertaining to the phenomenon under investigation.

3.3.2. Sample size

In qualitative research, there is no set formula for determining sample size. Instead, many scholars advocate for the concept of data saturation as a guiding principle.

Sim et al (2018), suggested that the determination of the number of units in a sample can be made either a priori or a posteriori, using an adaptive approach based on saturation. The researcher will aimed to gather sufficient data for the study and decide on the sample size based on the knowledge acquired during the research process.

Polkinghorne (1989) recommends that researchers interview from 5 to 25 individuals who have all experienced a phenomenon. What more, the information richness of the sample and the analytical capabilities of the researchers are more important than the sample size for the validity, meaningfulness, and insights generated from qualitative enquiry (Patton, 2002).

The plan was to conduct interviews with a total of ten people. Due to data saturation, the actual number of participants included in study are nine. Out of these, five had undergone SLT, while four had been screened for communication disorders but had not yet started therapy. These individuals were selected from the organization's SLT registered document of patients with communication disorders.

3.4. Data Collection Tool

This study involved conducting in-depth interviews among patients with PD using semi-structured in-depth interview guide as a means of collecting data. Qualitative research seeks to obtain data through diverse approaches, one of which involves conducting interviews with individuals or groups to inquire about their everyday routines or personal encounters (Kvale, 2007). By in-depth interviews, participants had the freedom to articulate their experiences in dealing with communication disorders associated with Parkinson's disease. The researcher prepared a set of guiding questions to facilitate the interview process. The interview guide prepared in English and then translated into the Amharic language. The interviews involved face to face, qualitative, and in-depth discussions, with the

researcher assuming the role of an "investigator." To ensure accuracy and accessibility of the gathered information, the interviews were electronically recorded, allowed the researcher to refer back to the data at any time.

3.4.1. Interview Guide

Creating a semi-structured interview guide was a crucial step in the data collection process. As noted by Kvale and Brinkmann (2009), such a guide is a valuable tool for researchers to generate sufficient data. For this study, the interview guide was crafted based on four research questions by first reviewing relevant literature. This review helped identify key areas for the study, the types of questions to ask, and their logical sequence.

The guide was organized around the four research questions, each containing its own set of interview questions. These questions were systematically designed to explore different aspects of the lived experiences of individuals with communication disorders related to PD. The interview guide consisted of three stages. The introduction provided an overview of the process and aimed to build trust between the participants and the researcher. The next phase included demographic questions and gradually moved to more sensitive and controversial topics. The final stage allowed participants to share any additional information they deemed important that had not been covered during the interview.

3.5. Data Collection Procedure

A letter of cooperation obtained from the special needs department and submitted to the administrative staff members working at the Parkinson Patients Support Organization-Ethiopia. The administrative staff kindly provided a room within the organization's premises for the interviews. Interviews with PD patients were conducted using a semi-structured, open-ended interview guide from April to May 2024 at PPSO-E. All interviews were conducted by the SLT student researcher. The study's pilot phase, using the created guide, was performed with one PD patient who had communication disorders at PPSO.

Participants were selected from the PPSO patient population in Addis Ababa. Since direct access to potential participant contact details was not available, recruitment was managed with the help of an organization staff member. Twenty patients were chosen from the organization's SLT registered

document of patients with communication disorders. With assistance from the staff, the researcher obtained telephone numbers for these twenty patients. Initial contact was made by phone (See Appendix 1) to ensure that individuals felt comfortable coming for the interview.

After explaining the interview content, informants were asked if they could attend on the suggested date. If they couldn't, they were asked to propose an alternative date and place for the interview. Interviews were then scheduled on the dates and place they suggested. Eight patients were interviewed in the SLT room at the PPSO-E compound, and one interview was conducted at a patient's home as she couldn't come alone.

Due to time constraints, each patient was scheduled for a single meeting. Before the interview, the study's purpose was explained, and patients were invited to ask any questions or express concerns. During the interviews, patients were allowed to speak freely about their experiences without interruption. The questions were not always asked in the order outlined in the schedule; the researcher followed the patient's lead and asked follow-up questions when necessary. Notes were taken on additional questions to avoid disrupting the flow of the interview, ensuring clear understanding of the patients' statements.

Each patient was asked the same questions. All interviews were tape-recorded using a phone recorder, and field notes were taken to capture details not picked up by the audio recording. All interviews were conducted in Amharic.

3.6. Data Analysis

According to Patton (2002), data analysis involves organizing the data collected during the study into ordered patterns, categories, and basic descriptive units.

In this study manual thematic qualitative data analysis was conducted. All interview data were first transcribed into Amharic, the language used for the interviews, and then translated into English. The researcher checked the transcripts and translations against the audio recordings for accuracy and consistency. During transcription, the researcher listened to the interview tapes multiple times, noting the tone of voice, pauses, and any emotional expressions such as cries or stutters from patients as they described their experiences. Each recording was listened to at least twice, and the transcripts were re-read several times. The data was then organized into significant and manageable categories, coded

with different colors. Key statements were highlighted and grouped into thematic categories, maintaining the original meaning of the participants' descriptions (Corbin & Strauss, 2008).

To achieve a coherent understanding of patients' experiences with communication disorders associated with PD, the analysis phase involved thematic organization of the interview transcriptions. Patterns were sought between cases to uncover the diversity of experiences among patients. This was done by listing themes for the group and clustering them into master themes, interpreting the transcripts to find meaningful insights.

3.7. Ethical Considerations

Strong adherence to ethical guidelines was a top priority throughout the study. Ethical approval for the study obtained from College of Education and Behavioral science of Addis Ababa University. Then, a letter of cooperation obtained from the special needs department and submitted to the administrative staff members working at the Parkinson Patients Support Organization-Ethiopia. Subsequently, the administrative staff informed of the study's purpose and requested to assist in connecting the researcher with individuals diagnosed with PD.

The research conducted in a transparent manner, ensuring that all participants are fully informed about the study's objectives. Only those who willingly provided their oral consent to participate included. The participants reassured that the data collected will be used solely for research purposes, and their voice recordings will be used exclusively for the research project. To maintain confidentiality, pseudonyms assigned to each participant, and their preferred location for the interviews were respected. At the conclusion of the interviews, a debriefing session conducted to ensure that participants are fully aware of the true purpose and aims of the study. Every effort was made to ensure that participants leave with the same level of comfort and self-assurance as when they arrived, as highlighted by Coolican (1999). Finally, the researcher will offer participants and PPSO-E the opportunity to receive the findings of the research, allowing them to stay informed about the outcomes.

3.8. Trustworthiness and Credibility

This research project was a collaborative effort between the researcher and three experienced advisors. Working together, we established clear research objectives and determined the most suitable

research methods, including the development of semi-structured interview questions. To ensure high-quality data collection, the group held frequent discussions and debriefing sessions via phone and Zoom meetings.

A pilot interview was conducted with a participant from PPSO-E, as this organization specializes in serving patients with PD. The pilot interview data was carefully reviewed by one of my advisor who is experienced in qualitative research interview, and based on his feedback, adjustments were made before proceeding with the full set of interviews.

To ensure the accuracy and reliability of the findings, the researcher coded and interpreted the interview transcripts. The One of my advisors independently coded and interpreted the transcripts, and discrepancies were discussed until a consensus was reached. Detailed field notes and methodological information, including instruments and an inquiry audit, were maintained to ensure the transparency and conformability of the data.

The researcher also considered demographic and sampling issues to maximize the transferability of the findings to other populations and contexts.

3.9. Dissemination of the Study

The findings of this study will be disseminated to the Department of Special needs, Department of Neurology, Tikur Anbessa Specialized Hospital, TAAAC, Addis Ababa university; Ministry of Health of Ethiopia; PPSO-Ethiopia; Ethiopian Medical Association and other concerned organization . I will also plan to publish at national/international journals.

CHAPTER FOUR

RESULTS

This study focused on the experience of patients with PD who have a communication disorders. Accordingly, this chapter presents the main research findings obtained from the semi structured interview process with nine individuals with communication disorders associated with PD, which was combined with the researcher's data analysis or exploration of their experiences. The key findings of the study have been presented by two sections:

- Demographic characteristics of the participants and
- The participants lived experience categorized in seven thematic areas

The main themes are: Experienced communication disorders, psychosocial experience, physical experience, economical experience, coping strategies, SLT service experience and desired supports.

Table 1. Characteristics of the Participants; Table 1 provides an overview of the demographic details of the individuals who took part in the research. To ensure anonymity, the participants were assigned codes instead of using their real identities.

Participants	Age in years	Sex	Education level	Marital status	Occupation prior to PD	Current occupation	Time of PD diagnosis in years	SLTs diagnosis	SLT history
R1	54	M	High school	Divorce	Self employed	Unemployed	5	Screened for communication disorder	No
R2	58	M	Reading and writing	Married	Civil servant	Unemployed	20	HKD	Yes
R3	57	M	College diploma	Married	Self employed	Civil servant	8	HKD	Yes
R4	52	F	Elementary school	Married	Fabric worker	House wife	7	Screened for communication disorder	No
R5	45	M	Elementary School	Married	Self employed	Unemployed	6	HKD	Yes
R6	65	M	Elementary School	Married	Self employed	Unemployed	8	HKD	Yes
R7	60	F	Elementary school	Divorce	Private sector employee	Unemployed	7	Screened for communication disorder	No
R8	79	M	Elementary School	Married	Self employed	Unemployed	8 s	HKD	Yes
R9	57	M	Elementary school	Married	Self employed	unemployed	6	Screened for communication disorder	No

4.1. Experienced Communication disorders

The participants discussed the difficulties they faced with communication disorders that progressively worsened over time following the onset of the disease. They identified various communication disorders associated with their condition, which were classified into five subthemes: reduced voice quality and volume, change in speech rate, articulation issues, diminished understanding and memory, and stuttering. Each participant expressed challenges related to low volume, harsh voice quality, and change in speech rate, resulting in others being unable to hear them properly. One participant vividly described the contrast between his speech before and after Parkinson's disease, stating,

"The difference in my speech before and after PD is like the sky and the earth. I was very loud and fluent before PD, but it has progressively become worse, especially in the last 2-3 years." (R5) (He was stuttering so much)

Voice Problem

The patients with PD encountered difficulties with a low volume of voice, frequently leading to others being unable to hear them. Some participants (R1, R2, R4, R7, R9) were unaware of their low volume until it was brought to their attention. They believed they were speaking loudly but found that people nearby couldn't hear them. They all remembered being able to speak loudly before the disease. Two participants explained their challenges with low voice volume as follows:

"My granddaughter always shouts at me, saying 'Ehhhhh mama, what did you say? You thought you told us something, but we can't hear anything. What should we do?'" (R4)

"Before the disease, people used to tell me, 'Can you please reduce your voice? You are talking to us, not someone outside.' But now, it's the opposite. People say, 'Can you speak louder? We can't hear you'" (R9).

The participants also experienced changes in their voice quality, resulting in a harsh and breathy voice. People would sometimes inquire if they had a common cold due to the voice change. The harsh voice affected the clarity of their speech, making it challenging for others to understand them. One participant described their voice clarity issue by saying,

"I don't have a clear voice. I have a breathy voice. Some people ask me if I have a common cold or if I'm tired when they hear my voice" (R6).

Change in Speech Rate

The participants experienced a reduced speech rate, which hindered their ability to fully express their thoughts. They noticed that most people, including their family members, lacked patience while waiting for them to finish speaking due to the prolonged time it took. One participant expressed his concern, stating,

"I used to be able to talk and express my thoughts like anyone else, but now I'm in trouble; I cannot fully express my thoughts because my speech speed has slowed down" (R3)

In contrast, one participant (R5) experienced a rapid speech rate, resulting in his words and sounds becoming jumbled together. This cluttered speech made it difficult for others to understand him. The participant mentioned being unaware of his rapid speech but sometimes noticed it and attempted to slow down his speech:

"I speak fast without pauses without knowing. My words become cluttered to one another at this time, which distorts the words. Sometimes I notice it in the middle of conversation and try to slow my speech" (R5).

Articulation Problem

Three participants (R3, R5, R6) specifically mentioned encountering difficulties with their speech, including instances of getting stuck and struggling to articulate certain sounds. The specific sounds they struggled with were not consistent and varied over time. They experienced occasional instances where their tongue and throat seemed to get stuck, making it challenging for them to pronounce the sounds correctly. One participant described their articulation problem as follows:

"Sometimes I have trouble saying certain sounds correctly. I don't remember which sounds specifically, as they change over time. My tongue and throat get stuck, and I can't pronounce them accurately. However, these instances are rare" (R3).

Stuttering

One participant (R5) faced significant issues with the fluency of his speech due to stuttering, particularly with the initial sounds of words. He would repeatedly say the initial sound before being able to continue with the rest of the word, which hindered his ability to express himself fluently. He described the progression of his stuttering as follows:

"My stuttering is getting worse. I wasn't like this before. I used to be able to speak fluently and express myself without any problem" (R5, he was stuttering).

Understanding and Memory Problems

The participants (R1, R4, R6, R7, R8, R9) shared concerns about their memory, including forgetting names and frequently misplacing items. They mentioned experiencing instances where they would forget what they were talking about in the middle of a conversation, leading them to stop speaking. They preferred one-on-one conversations to minimize confusion. Additionally, they encountered difficulties understanding long and complex information. Some participants (R1, R3, R4, R5) shared their daily challenges related to communication disorders while using public transportation, going to shops, or visiting other places. Issues like making repeated mistakes in household chores, forgetting to pay for a taxi, paying twice, or forgetting to collect change were specifically mentioned by participants (R1, R4) in relation to memory problems.

"My memory is deteriorating. I frequently misplace things and struggle to remember where I put them. I also have trouble recalling people's names. Understanding what people are saying, especially when there is a lot of information, presents difficulties. In addition to this, I used to serve God through outreach services. I used to preach the Bible using different leaflets, but now I can't do it because of my speech and memory issues. I can't speak clearly and jump from one idea to another, forgetting what I am talking about." (R7)

4.2. The Psychosocial Experience

The participants described how communication disorders related to Parkinson's disease have had a profound effect on their psychological, emotional, and social well-being. They experience feelings of embarrassment, frustration, sadness, stigma, and isolation as a result of these communication challenges. This leads to their withdrawal from social events, difficulty expressing ideas and

engaging in discussions, and the loss of important roles within their families, communities, and religious organizations. Furthermore, their relationships with family and friends are also impacted. The subthemes that emerged from their experiences include frustration, sadness, embarrassment, self-isolation, and misconception and stigma.

Frustration

Participants (R2, R3, R4, and R7) expressed their feelings of frustration and anger resulting from the communication difficulties they face. They experience frustration when they encounter misunderstandings and find it challenging to express themselves clearly, which leads to self-doubt about their abilities. Negative reactions from others, including family members, intensify their anger, especially when they forget important information. The participants shared instances where conversations were abandoned by others due to their speech difficulties, causing them to feel frustrated, particularly in important discussions.

"I usually forget what my husband or children told me to do at home, and it breaks my heart. I get angry with myself at these times. Why do I forget the things which I should never forget? I question myself, 'What happened to me?'" (R4)

"I see some people. When they couldn't hear what I am saying, they will leave me or stop talking with me instead of trying to understand me, and I feel angry, especially when I am trying to talk about important things." (R7)

Sadness

Participants (R4 and R9) expressed deep sadness, loss, and hopelessness due to their communication difficulties in Parkinson's disease. They feel a sense of grief and pain when comparing their current situation to their pre-disease lives. They also experience a strong dependency on others, which contributes to feelings of hopelessness about their future. Specific incidents, such as communication failures in taxis and being ignored by family members, further amplify their sadness.

"I feel intense sadness when I compare my situation before and after PD. It hurts when I think of the things that I've lost." (R4)

“On one Sunday morning, I wanted to go church. I asked my children three times, raising my voice, to bring me a 'gabi' (a traditional blanket for cold weather) so I could wear it and go. But they didn't hear me. I waited and waited and they never heard what I was saying and ignored as usual. Then I went to church without wearing the 'gabi.' It started raining, and it was cold outside. I ended up getting wet and cold without the 'gabi.' When I returned, my wife and children were angry with me, asking why I went out without wearing the 'gabi.' I told them I had told them many times to bring it. It made me sad.”(R9)

Embarrassment

Participants (R1, R2, R4, R6, R7, and R9) expressed feelings of shame and embarrassment related to their communication difficulties. They experience embarrassment when others fail to understand their ideas and when they receive negative reactions from people around them. These communication disorders have had a negative impact on their self-esteem and confidence, leading to a loss of confidence in social situations. They feel hesitant to engage in conversations and prefer shorter interactions to hide their speech difficulties. These experiences have caused them to feel shame and regret when communicating with others.

"Before the disease, I was known for my loud voice and being friendly. I loved dancing and enjoying social gatherings like weddings. But now I don't feel good about my communication. I feel shame and I lost my confidence to meet people at all." (R4)

“I remember a time at a wedding. It was nighttime, and my wife was taking me to the restroom. Someone overheard me talking with her from the other side without seeing me and said, "Is this man drunk?" Eventually, my wife explained my condition to him, and he apologized. This made me feel embarrassed” (R3)

Isolation

Participants (R5 and R6) described self-imposed isolation as a result of communication difficulties and a fear of inconveniencing others. They lack confidence in engaging with people and choose to sit alone, avoiding conversations. They perceive themselves as burdens and prefer to isolate themselves to prevent bothering others. This isolation leads to feelings of loneliness and an inability to participate in conversations. They also expressed a sense of being ignored, avoided, and treated differently by

others, further contributing to their isolation. Most of the participants (R1, R4, R6, R7, R9) mentioned losing most of their friends due to their communication challenges. Participants (R1, R3, R5) reported reduced attendance at social gatherings and refraining from participating in conversations due to difficulties in expressing themselves. In their daily routines, many participants (R1, R2, R4, R6, R7, R9) prefer to stay at home to avoid communication challenges. They expressed feelings of self-isolation and limited engagement with the outside world.

"Before my speech problem, I enjoyed talking about politics and current issues around the country. I would read and argue about them with people. I was known for my humor as well. I loved fun and jokes. But now I can't express my ideas as I want, so I stopped. I isolated myself to avoid interacting with people. I didn't wait for people to isolate me. We don't know the value of clear speech until we lose it." (R5)

"I usually stay at home. I reduced attending weddings or any social gatherings. I restricted myself from going because sometimes when I do, I don't have the confidence to talk with anyone. So usually, I sit alone without talking to anyone, and I won't stay long; I leave early. The longer I stay, the more I have to talk." (R3)

Misconceptions and stigma

The participants shared their experiences regarding attitudes and misconceptions related to their communication disorders in Parkinson's disease. Some participants (R2, R3) mentioned encountering understanding and empathetic individuals, while others faced stigma and negative attitudes, including from their own family members. People in their area often reacted with surprise and sadness, lacking prior knowledge about Parkinson's disease and its communication problems. Some participants appreciated empathy (R3, R6), while others felt uncomfortable when others showed pity. Misconceptions ranged from associating Parkinson's disease with AIDS, sin or evil spirits to believing it was a communicable disease or the result of intentional speech difficulties. These experiences caused frustration, sadness, and further stigmatization among the participants. Some of the participants (R1, R7, R9) expressed that their communication disorders have prevented them from continuing their previous spiritual activities and respected social roles. Here are some statements from the participants:

"My daughter doesn't want to talk to me. She has no patience to listen and understand me because it takes so much effort. She just sits with her phone without talking. This is a big pain for me. I also see bad attitudes and stigma from my church people. They avoid me and seem to hate me, thinking the disease is transmittable." (R7)

"I was the spokesman of 'eder' (traditional unions for social activities) and a member of the church regulatory committee. I was a respected elder and called for various social activities. Now, nobody wants to talk to me. (He cried.) They thought I would get better after treatment, but when they found out it's degenerative, they started avoiding me. People, including my own children, no longer respect me. They avoid me in social situations and don't want to engage with me. My children think my speech issues are intentional because it sometimes improves. One of my friends even said, 'This is because of your bad work. Repent.'" (R9).

4.3. Economic Experience

This theme describes the impact of communication disorders on participants' work and income. Two sub-themes emerged: quitting work and financial struggle.

Quitting Work

The participants, except one (R3), mentioned that they had quit their jobs due to their communication difficulties. Participant R3, despite facing challenges, continued to work by relying on the support of colleagues to compensate for his limitations. The participants (R1, R2, R5, R9) specifically recalled the challenges they faced in their work environments due to the progressive difficulties in speaking and communicating. Their jobs required frequent and extensive communication with customers, employees, and coworkers. Negotiating, conveying information, and engaging in effective communication became significant obstacles. One participant (R5) shared his experience of having to give up their singing career due to the inability to sing and perform as he used to:

"In addition to my main work, I was also a singer. I released a single traditional music five years ago. I used to do vocal exercises in forests and could sing loudly. But now, I stopped singing because I can't even speak properly. I also had a side hustle as a house salesman, which required a lot of talking with people, so I had to stop" (R5).

"The communication problem had a significant impact on my work life. I couldn't communicate and interact with my employees. I had 19 employees in my small business shop. I struggled with negotiating and dealing with customers. My declining memory also affected my financial management, so I had to quit my work and close my business shop" (R1).

Financial Struggle

Participants relied on their family's support as they had no income of their own. They felt dependent on others for their daily needs. Participant (R3) experienced a significant reduction in income he used to work multiple jobs simultaneously before the progression of the disease. On the other hand, one participant (R1) mentioned that although he had stopped working, he has sufficient financial resources and property to sustain himself. The participants expressed their financial situations as follows:

"Now I rely on my children for financial support. I wish I could work and earn my own income, but I need to speak clearly to work" (R9).

"Even though I quit my job, I don't have any financial problems. I have enough property and income sources for myself and my children" (R1).

4.4. Coping Strategies

Participants were asked about the strategies and coping mechanisms they employed to deal with the challenges posed by communication disorders. They mentioned various coping strategies, including speech and language therapy, different compensatory strategies, and social support received in the PPSO-E. The responses were categorized into two sub-themes: strategies to cope with communication disorders and strategies to cope with negative emotions.

Strategies to Cope with Communication Disorders

Some participants (R2, R3, R5, R6, R8) mentioned undergoing speech and language therapy (SLT) as a coping mechanism for their communication difficulties. They also discussed intentionally adjusting their speech rate and volume, taking deep breaths, speaking closely and loudly, emphasizing speech sounds, using gestures or signs to convey their needs when verbal communication was challenging, as they had learned in SLT. Additionally, some participants (R2, R3) relied on family members for

assistance, communicated through intermediaries, as it is easy to be understood by familiar people. One participant (R1) mentioned withdrawing from conversations or remaining quiet as a coping mechanism when faced with miscommunication. They explained their strategies as follows:

"I communicate my needs to my wife, and when someone comes to talk to me, I convey the message through her. If she is not around, I try to raise my voice or get closer to the listener to ensure I am heard. Sometimes I use hand gestures to communicate" (R2)

Furthermore, some participants (R1, R3, R4, R6, R7) found relief by clearing their throat, drinking water, taking PD medication, and getting rest and sleep, which improved the clarity of their voice temporarily to some extent. Some participants (R1, R4) noticed that their speech improved when they were in a positive or happy state but worsened when they were angry or upset. One participant (R8) also mentioned that certain types of food had a positive impact on his communication. They expressed their experiences as follows:

"Drinking water works best for my speech. Especially when my throat gets stuck and my speech worsens, drinking water helps improve my voice" (R4).

"When I consume meat, eggs, and milk, I feel less tired, and my speech improves. During this fasting season, my speech clarity reduces significantly because I don't eat these foods" (R8).

Strategies to Cope with Negative Emotions

Participants employed various strategies to manage negative emotions due to communication difficulties. Some tried to forget the situation and avoid stress (R2, R6, R7, R8), while others found solace in the social support of PPSO-E (R1, R2, R5). Comfort and support from spouses and children played a role for some (R1, R4, R9), and spiritual practices like prayer and positive self-talk were mentioned as coping mechanisms.

"I often remind myself that there are people with far worse diseases, and it's not that bad to experience this at my age. Some people don't even make it to 20. I have a loving family and enough financial resources and property for my children. I find comfort in these thoughts" (R1).

4.5. SLT services Experiences

Some participants (R2, R3, R5, R6, R8) had undergone speech and language therapy (SLT), while others had not. Those who had undergone SLT shared their perceptions and experiences with the therapy. They expressed that the strategies they learned in therapy were beneficial and had a positive impact on their communication skills, despite the progressive nature of their disease. Based on the participants' responses, this theme is divided into subthemes: benefits and learned strategies.

Benefit

Participants (R2, R3, R5, R6) described that SLT was beneficial, even though their condition is progressive and cannot be cured. SLT helped them understand the nature of their speech problems, their origins, and why they speak the way they do. They also learned to be mindful of their speech and how to compensate and adjust their communication to be better understood. They noted that their speech became more easily heard and understood by others.

"I was taking speech therapy a few months ago. I practiced speaking out loud and oral exercises at therapy sessions and at home and found it useful." (R2)

However, one participant (R8) expressed that he did not observe any changes in his communication after undergoing speech therapy. He mentioned that he had only received SLT for a short period and was still in therapy. Despite not experiencing immediate improvements, he remained hopeful and expressed the desire to benefit from continued therapy. He stated:

"I am currently undergoing speech therapy sessions after physiotherapy, and I have been feeling tired all the time. It has only been a short time since I started speech therapy, and I have not noticed any changes in my speech yet, but I hope to see benefits in the future" (R8).

Learned strategies

The participants shared how speech-language therapy (SLT) helped them recognize their speech issues and taught them various compensatory strategies. These strategies included intentionally adjusting their speech rate, increasing vocal volume by taking deep breaths, moving closer when speaking, pausing to take deep breaths for louder and longer speech, stressing speech sounds, and performing vocal exercises. They also mentioned learning to use nonverbal communication, such as

gestures, when verbal communication became challenging. One participant (R2) specifically noted the importance of practicing oral motor exercises during SLT sessions in addressing his oral and facial weakness. They described their experiences as follows:

"In speech therapy, I learned techniques such as taking deep breaths, speaking with stress on speech sounds, intentionally slowing down my speech by taking breaks, pauses, and hand tapping. I found these strategies important for clearer and intelligible speech" (R5).

4.6. Physical experience

Participants (R1, R2, R4, R6, R7, and R8) reported several physical issues in addition to communication disorders, such as tremors, muscle pain, loss of balance, fear of falling, reduced movement, and drooling of saliva. These issues also significantly impact their mobility, daily lives, social participation, and emotions, leading to an inability to function as they did before.

"I isolate myself from people because of my drooling of saliva. I feel ashamed of it." (R6)

"Speech was not a problem to stop my work, but the tremor and other physical issues made me unable to work properly. I was a truck driver from Djibouti to Ethiopia. I have to drive long distances." (R8)

"I limit myself from going to social events as before because in addition to my speech problem I sometimes have difficulty keeping my balance, and I don't want to bother anyone." (R3)

4.7. Desired Support

When asked about the support or resources they believed would benefit individuals with communication disorders associated with Parkinson's disease, participants expressed their desires for new medication, education, and financial support from healthcare professionals, organizations, and the government.

Healthcare professionals

Most participants (R1, R2, R3, R4, R5, R7, R9) expressed their wishes that if it is found a medication that can effectively treat communication disorders associated with Parkinson's disease would be beneficial for them. They expressed the need for medication specifically targeted at improving speech-related symptoms, such as issues with the tongue and throat.

"I recommend people who know about the disease to do something they believe necessary; if the health professionals got a medication to heal it; it would be good if there was medication for our tongue and throat for better speech." (R2)

Organizations

Participants (R2, R3, R4, R5) emphasized the importance of providing support, encouragement, and information to newly diagnosed individuals with Parkinson's disease. This includes helping them understand the nature and progression of the disease and its coping strategies to avoid losing hope. They emphasized the value of organizations regarding supporting and educating individuals with Parkinson's disease about the disease. They also encouraged others to support and stand for this kind of organization.

"If new patients are given the same kind of support as we received, it would encourage them not to give up hope. Who knows, a solution may be found tomorrow. Let them keep taking care of themselves. I say it would be good if they could be taught about the disease's nature and progression. When such an organization exists, it is good to stand for it." (R3)

Government

Participants (R4, R5, R6, R8) suggested that the government should work on improving the current medication supply and availability for individuals with Parkinson's disease. they also request for availability and accessibility speech therapy and physiotherapy services for everyone. Financial support from the government also noted as they cannot work and generate income for themselves. They mentioned the importance of individuals with Parkinson's disease having access to speech therapy.

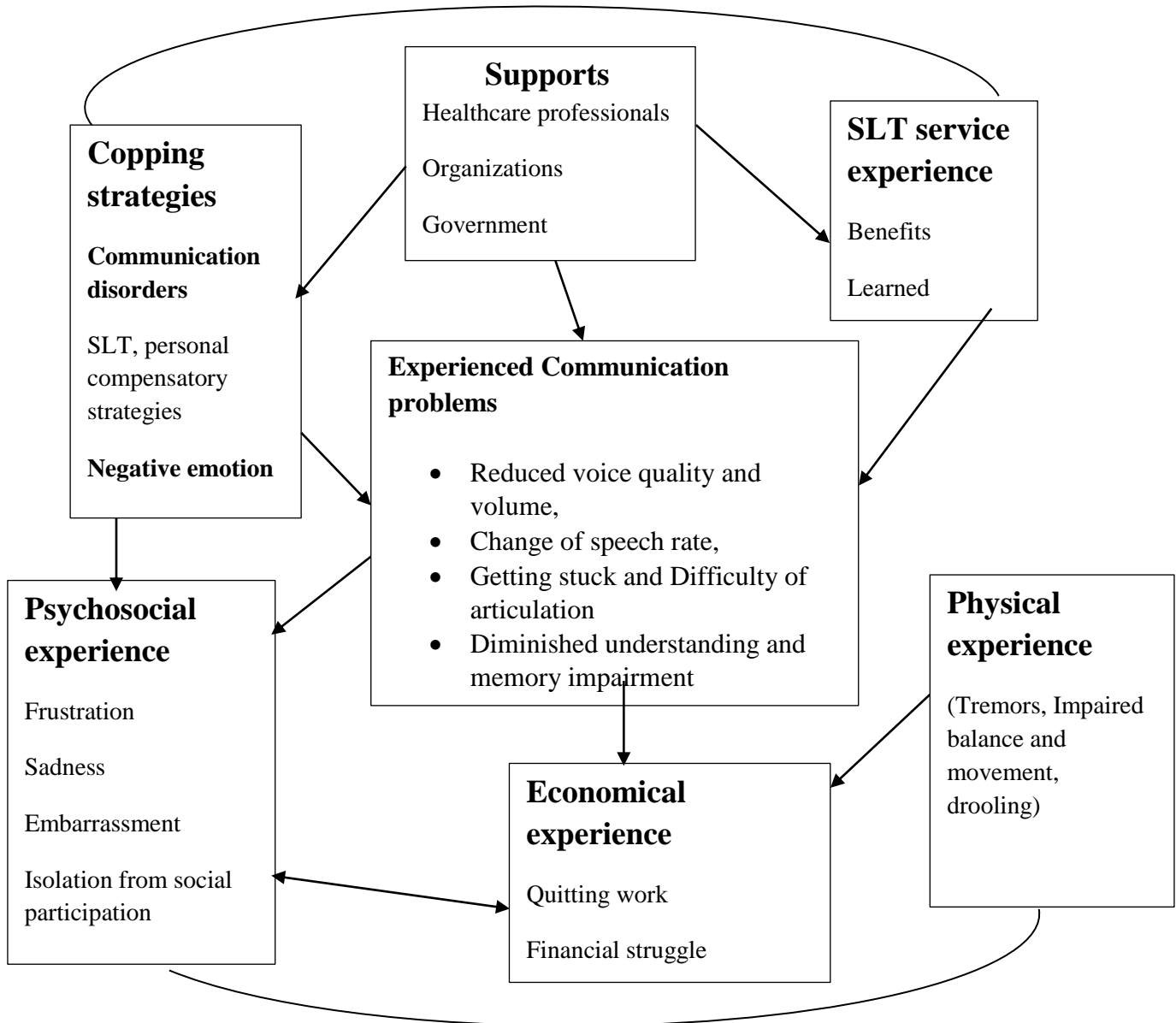
"If speech therapy and physiotherapy services are available everywhere, people with PD will get easy access to it every day, and real change would be observed."(R8). "I suggest, If the government works hard on the current medication supply and availability. Many people are getting problem on that"(R4)

Finally, all of the participants wanted to praise the PPSO-E organization and the Founder Kibra Kebede and all the medical team for all the support they received. This chapter gave insight of the lived experience of individuals with communication disorder associated with PD by their own words. The next chapter will discuss the findings with the relevant literature.

CHAPTER FIVE

DISCUSSION

Main Categories: The seven primary categories of the results and their interconnections are displayed in Matrix 1. Each category and its sub-categories are presented individually.



This chapter discusses the findings and Interconnection of the Main Themes. As shown in the above matrix, the study identified seven main themes, which are experienced communication disorders, psychosocial experience, physical experience, economical experience, coping strategies, SLT service experience and supports. These themes are interconnected, forming a comprehensive understanding of the participants' experiences.

5.1. Communication disorders

that participants frequently experienced communication issues, such as low volume, harsh voice quality, and changes in speech rate and articulation. These findings are consistent with other studies, which highlight hypokinetic dysarthria as a common issue in approximately 89% of Parkinson's disease (PD) patients. This speech disorder is characterized by a monotonous pitch and loudness, reduced stress, variable speech rate, imprecise consonants, and a breathy and harsh voice (Muñoz-Vigueras et al., 2021; Pinto et al., 2004).

Memory problems and difficulties in understanding complex information were also commonly reported by participants. These experiences align with findings from other researchers, such as Yarnall (2014) and Pigott et al. (2015), who confirmed that individuals with Parkinson's disease often face progressive cognitive-linguistic difficulties. According to Hancock et al. (2011) and Engle and Conway (1998), these cognitive-linguistic impairments manifest as limited attention spans, impaired working memory, and decreased recent and short-term memory which collectively impact language comprehension, especially when processing longer and complex sentences, ambiguous words, reference pronouns, and irrelevant information.

5.2. Psychosocial experience

Communication disorders have significant psychosocial impacts. Participants experienced frustration, sadness, and embarrassment due to their communication difficulties, echoing Altar et al. (2020) who noted that communication disorders often lead to intense anger and frustration.

These disorders caused isolation, misconceptions, and stigma, reducing social participation and straining relationships this finding also aligns with study by (Altar et al., 2020) stated communication disorders in Parkinson's disease impact self-perception, interpersonal relationships, and social functioning, leading to psychological distress and a reduced quality of life The withdrawal from

social and religious activities observed aligns with previous studies (Hammarlund et al., 2018; Miller et al., 2008), which highlight the emotional toll of being unable to engage in once-enjoyed activities. This a sense of isolation and social withdrawal can lead to feelings of worthlessness, diminished belonging, and a loss of confidence and independence, further discouraging communication. The psychological burden necessitates a holistic approach to treatment, incorporating both medical and psychological support.

Participants' experiences with stigma and misconceptions about PD underscore the need for public education to reduce stigma and improve understanding of the disease. Misconceptions about PD being communicable or associated with negative spiritual beliefs were particularly troubling, indicating a significant gap in public knowledge. These findings align with other study (Walga, 2019) highlighting the community's limited understanding and distortion of PD

5.3. Physical experience

The physical symptoms associated with Parkinson's disease, such as tremors, impaired movement and balance, and drooling of saliva, were mentioned by participants and found to have an impact on their psychosocial well-being. These symptoms align with the findings of various studies, including the World Health Organization (WHO, 2023) and Prakash et al. (2016), which describe Parkinson's disease as a chronic neurodegenerative condition characterized by motor symptoms like reduced movement, resting tremors, rigidity, and postural disturbances, as well as non-motor symptoms like drooling. The results of this study are consistent with other research, as demonstrated by Abenet et al. (2017), who found that both motor and non-motor symptoms of Parkinson's disease have an impact on the health-related quality of life of patients, with the effects worsening as the disease progresses in severity. The complex clinical manifestations of the disease, along with the gradual decline in self-care, increasing disability, and demanding therapy, significantly influence the lived experience of individuals with Parkinson's disease (Bonner et al., 2020).

5.4. Economical experience

The economic impact of communication disorders was significant, with several participants having to quit their jobs due to their symptoms which results in a significant reduction in income, leading to financial struggle. The economic impact further exacerbates the psychosocial stress, creating a vicious cycle of financial strain and emotional distress. The other motor and non-motor physical

symptoms have also effects on economic challenges. These symptoms can severely impair a person's ability to perform their job effectively, often leading to the necessity of quitting work. As the disease progresses, the motor impairments make it increasingly difficult to maintain employment, particularly in physically demanding or precision-based roles. This finding aligns with studies by Helen (2014) which highlighted the complex economic and psychosocial issues faced by PD patients in Ethiopia, including early retirement. This is the broader socio-economic implications of PD and underscores the importance of supportive employment policies and rehabilitation services to help individuals maintain their livelihoods.

5.5. Coping Strategies

Participants employed various coping mechanisms to manage their communication difficulties and negative emotions. These strategies included internal adjustments such as slowing their speech rate and increasing their volume. This finding is consistent with Altar et al. (2020), who highlighted compensatory strategies like speech repetition, slower speech rate, and increased vocal volume to ensure smoother conversations.

Additionally, participants relied on speech and language therapy (SLT), social support from the organization (PPSO-E), and family assistance to address their communication disorders and negative emotions associated with it. This aligns with Whitehead (2010), who emphasized the importance of extrinsic strategies, including SLT, social interaction opportunities, and family support, as crucial resources for managing communication challenges. According to (Gupta and Bhatia, 2000), PD patients who have effective social interactions experience lower levels of depression and an enhanced sense of personal value which contribute to individual's overall psychosocial well-being.

Participants also mentioned the use of coping strategies such as medication, rest, and specific dietary habits to improve their communication abilities. Medication was reported to provide temporary improvements, which aligns with a study conducted by Dotchin and Walker (2012) that emphasizes the significance of multidisciplinary intervention in managing Parkinson's disease. This approach combines pharmacological and surgical treatments with behavioral, physical, and speech therapy to effectively address the condition.

These coping mechanisms underscore the importance of utilizing both internal and external resources to effectively manage communication difficulties and the emotional challenges that accompany them.

5.6. Speech and Language Therapy experience

Participants who underwent speech and language therapy (SLT) reported significant benefits, which align with existing literature emphasizing the importance of early intervention and ongoing support in managing communication disorders in Parkinson's disease (PD) (Whitehead, 2010). The positive feedback from participants highlights the effectiveness of SLT in improving speech intelligibility and overall communication.

Despite the progressive nature of PD, participants expressed that SLT increased their self-awareness of speech output and provided them with valuable compensatory strategies. Since PD is a neurodegenerative disease, the therapy's goal is not to cure but rather to enhance awareness of speech output and teach compensatory strategies to improve speech intelligibility and overall communication. These findings are consistent with studies conducted by Miller et al. (2006), which demonstrate the positive impact of prompt intervention and support from speech and language therapists in helping individuals develop compensatory strategies, improve communication skills, and enhance overall well-being. The research conducted by Sapir (2014) also supports the importance of designing training programs specifically tailored to address the unique challenges associated with hypokinetic dysarthria (HKD) and Parkinson's disease, such as deficits in internal cueing, automatization, perception of speech output, and attention to action.

These findings align with the experiences of participants who underwent SLT demonstrated greater awareness and utilization of coping strategies to address their communication disorders compared to those who did not undergo SLT. Overall, targeted and individualized interventions can effectively address these challenges and lead to improved outcomes in managing communication difficulties in PD.

5.7. Support

Participants expressed a need for better access to medication, speech therapy, and financial support, reflecting the diverse needs of individuals with PD. They called for enhanced government support, social support from organizations and medications specifically targeting speech-related symptoms from healthcare professionals. These findings aligned with the study done by Whitehead (2010) that emphasized the importance of a multidisciplinary approach, involving speech and language therapy services in such programs, incorporating elements of counselling, group therapy, and social support.

Additionally, including family members in consultations and support program delivery was recommended.

The support which can be provided by organizations, including training facilitation, provision of speech and language therapy services, and sharing experiences with other Parkinson's disease patients, can have a significant positive impact on individuals' communication abilities. This support enables the development of personalized coping strategies that are effective for each individual. Additionally, it helps raise awareness about the benefits of SLT among PD patients who are experiencing communication disorders.

5.8. Limitation

The study had a relatively small sample size of nine participants from a specific demographic group accessing services at the PPSO-Ethiopia, which may limit the representation of diverse experiences among individuals with PD in different settings. Additionally, recruiting participants from a support organization could introduce selection bias and restrict the generalizability of the findings. Due to time constraints, I was unable to conduct follow-up interviews or member checking to elaborate on some responses, and I couldn't use other methods to do methodological triangulation to enhance the research credibility. The pilot test was conducted at PPSO-E, my research site, because there are no other organizations working with PD patients in Addis Ababa, and I didn't have time to seek permission to conduct the pilot test in a hospital setting.

5.9. Implications

Here are the key implications of Speech and Language Therapy (SLT) for individuals with PD;

- **Improved Communication:** Through SLT, individuals learn compensatory techniques such as adjusting speech rate, increasing vocal volume, and stressing speech sounds. These skills can lead to more effective and clearer communication in various social and personal contexts.
- **Increased Self-Awareness:** SLT helps individuals understand their specific speech difficulties, empowering them to actively manage their communication.
- **Assistive Technology Utilization:** SLT professionals can recommend and train individuals to use assistive communication devices, which can be particularly useful as the disease progresses.

- **Strengthened Oral Motor Skills:** Exercises target muscle weakness in the mouth and face, improving speech clarity and reducing swallowing difficulties.
- **Personalized Therapy:** SLT is tailored to each individual's needs and stage of PD, ensuring effective and relevant interventions.
- **Cognitive Maintenance:** SLT activities engage cognitive functions, potentially slowing cognitive decline and maintaining mental sharpness.
- **Emotional & Psychological Benefits:** SLT reduces communication-related frustration and anxiety, boosting self-esteem, confidence, and social engagement, resulting in a better overall quality of life.

CHAPTER SIX

CONCLUSION AND RECOMMENDATION

6.1. Conclusion

As per the core objective of the study, the finding of the research presented preliminary information or facts related to the lived experience of individuals with communication disorders associated with Parkinson's disease. Through in-depth interviews with nine participants, the study explored the specific communication difficulties they faced, the psychosocial impacts of these disorders, additional challenges encountered, and the coping strategies employed to manage their communication disorders.

The findings revealed a range of difficulties associated with communication disorders in PD, such as reduced voice volume and quality, articulation issues, change in speech rate and cognitive-linguistic impairments. The study underscored the profound psychosocial consequences of these disorders, manifesting as frustration, sadness, embarrassment, isolation, misconception and stigma. Consequently, individuals often withdrew from social interactions, leading to a loss of social and familial roles, and even economic hardships.

The participants shared their experiences, highlighting several significant themes. These included the physical ramifications of PD, encompassing both motor and non-motor symptoms, such as tremors, impaired balance and movement, and drooling. These symptoms further compounded the psychosocial challenges and economic burdens faced by individuals.

Moreover, the study identified various coping mechanisms employed by the participants to manage their communication disorders. These strategies included internal adjustments like slowing their speech rate and increasing volume, as well as seeking external support such as speech therapy, social support networks and assistance from family members.

6.2. Recommendations

Based on the findings of this study, the following recommendations are proposed to address the communication challenges faced by individuals with Parkinson's disease (PD) and to improve their overall quality of life:

- Federal Ministry of Health is required to conduct public awareness campaigns aimed at educating the broader community about Parkinson's disease and the communication challenges faced by individuals with PD. These campaigns play a crucial role in fostering a more understanding and accommodating social environment.
- The Federal Ministry of Education, in collaboration with the Federal Ministry of Health, should establish training programs in local universities and colleges to educate and certify new speech and language therapists (SLTs). This initiative aims to alleviate the shortage of SLTs in the country and ensure that there are enough professionals available to provide necessary support.
- Training primary health care providers, family and caregivers basic of SLT for PD at different health institutions.
- The Parkinson's Disease Support Organization - Ethiopia (PPSO-E) should foster increased collaboration with other stakeholders, including SLTs, neurologists, psychiatrists, and funding organizations. This collaborative effort will expand the holistic support provided by PPSO-E to address the overall health-related and social needs of individuals with PD, including the provision of SLT services specifically tailored to cope with communication difficulties.
- It is important to encourage ongoing research into the overall situation of PD, with a particular focus on communication difficulties associated with the disease. This research will contribute to a deeper understanding of the underlying mechanisms involved in communication impairments and facilitate the development of more effective interventions and treatment strategies.

By implementing these recommendations, we can improve the communication abilities and overall quality of life for individuals with Parkinson's disease, enabling them to maintain social connections, participate in daily activities, and achieve a greater sense of well-being.

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APPENDIX 1

First telephone contact

Greetings,

My name is Eyerusalem Tesfaye. I am SLT student at Addis Ababa University. I was given your name and telephone number by the staff member of the PPSO-E. I informed that you have communication disorders associated with PD.

Reminding of the goal: I am doing research exploring the lived experience of individuals with communication disorders associated with PD.

Obtaining permission: Are you interested to share your experience regarding your communication disorders associated with PD? (If yes)

Schedule:

Schedule an appointment and agree where the interview will be held. If they choose their home, ask for their address and when to meet.

Where do you live?

Address:

Interview length:

The session will take 30 to 45 min.

Thank you for your time

APPENDIX 2

Information Sheet

Greetings: I am _____ and I am an MSc SLT student in AAU. We will proceed with an interview, which will take around 30-45 minutes, after hearing the following general information about the study in the language you understand.

Title of the study: The lived experience of individuals with communication disorders associated with Parkinson's disease.

Objective: To describe the communication disorder that patient with PD encounter.

To understand the challenges of having a communication disorder in PD patients

To understand the psychosocial impact of communication disorder in PD patients

To explore the coping strategies of PD patients with communication disorders

Benefits: This study will not give any direct benefit to the participants; but the detailed information you provide us will help to understand the overall impact of PD on communication, best practices and critical challenges related to this disease. Thus, it will help us to recommend the government and other health practitioners to design appropriate intervention and to address the challenges.

Risk: There is no any risk associated with this study and overall process of the interview other than spending 30-45 minutes with me.

Right of the respondents: Any participant will participate on this study voluntarily. You can quit from giving answers to the questions you are not willing to answer and even you can stop at all.

Confidentiality: All the data will not be accessed by anyone other than the study team and any information that you will give will be confidential. Your name and other information related to your private life will not be mentioned at individual level showing your identity, thus you are not expected to mention your name during the discussion.

Whom to contact: If you will have any questions about the research or need further information please contact (Eyerusalem Tesfaye: Email: jerrytesf18@gmail.com Phone: +251917387771)

Are you willing to participate?

Yes _____ No _____

Consent form (Verbal)

I, the undersigned, confirm that, the participant clearly understand the objective and conditions of the study and has given a verbal consent to be part of the study. I have given the necessary information about the research including the right to withdraw from the study at any time using the language he/she understands.

Facilitator name _____

Signature _____

Interview code _____

APPENDIX 3

Guiding questions

Participant code.....

Age.....

Gender.....

Education level.....

Marital status.....

Occupation.....

SLT history.....

Time of diagnosis.....

Aim 1- Communication disorder associated with PD

1. How would you describe the changes in your ability to communicate before and after the onset of Parkinson's disease? What specific communication difficulties have you encountered?
2. What variations Have you noticed in your communication patterns when interacting with familiar and unfamiliar individuals, as well as in different situations?

Aim 2- Challenges of having a communication disorder in PD

3. Can you describe your experiences with communication disorders associated with Parkinson's disease? How has it affected your daily life?
4. Can you discuss any changes in your social participation or engagement in activities as a result of communication disorders associated with Parkinson's disease?
5. How have your relationships with family, friends, and healthcare professionals been influenced by your communication disorders? Can you please explain if you encountered any specific challenges or support in these relationships?

6. How do you describe the effect of communication disorders on your work environment and your income? Can you please explain if you encountered any specific challenges or support in in your work environment?

7. Can you share any particular incidents or situations that highlight the impact of communication disorders on your personal and social life?

Aim 3- the psychosocial impact of communication disorder in PD

8. How do you perceive the emotional and psychological aspects of living with communication disorders in relation to Parkinson's disease? How has it affected your self-esteem and confidence?

9. Can you describe any moments of frustration, loss, or isolation that you have experienced due to communication disorders? How have you managed these emotions and situations?

10. How do you perceive the attitudes and understanding of others towards your communication difficulties? Have you faced any misconceptions or stigma related to Parkinson's disease and its impact on communication?

Aim 4- the coping strategies of PD patients with communication disorders

11. Can you describe any strategies or coping mechanisms you have developed to manage the challenges posed by communication disorders? What has been effective for you?

12. Have you take speech therapy before? What was your experience in taking speech therapy?

13. In your opinion, what support or resources would be beneficial for individuals with communication disorders associated with Parkinson's disease? How do you envision improving the overall experience and well-being of individuals in similar situations?

Conclusion:

- Is there anything else that you think is important to share but not raised during the discussion?
- Could we contact you again if we have additional questions or need clarification? (Take phone number if the respondent agrees)

Thank you for your time and the insights you shared about

APPENDIX 4

GUIDING QUESTIONS TRANSLATED INTO AMHARIC

የቃለ መጠይቅ ማመሳከሪያ ጥያቄዎች

ዓላማ 1 - ከፓርኪንሰን ህመም ጋር የተያያዙ የተግባራት ችግሮች

1. የፓርኪንሰን በሽታ ከመጀመሩ በፊት እና በኋላ አጠቃላይ የተግባራት/የንግግር ችሎታዎ ላይ ያለውን ለውጥ እንዴት ይገልጹታል? በዝርዝር ምን ምን ዓይነት የግንኙነት ችግሮች አጋጥመውታል?
2. ከታወቁ እና ከማያውቋቸው ሰዎች ጋር እንዲሁም በተለያዩ ሁኔታዎች ውስጥ በሚገኙበት ጊዜ የተግባራት ሁኔታዎ ምን ዓይነት ልዩነቶች አስተውለዋል?

ዓላማ 2- ከፓርኪንሰን ህመም ጋር የተያያዙ የተግባራት ችግሮች ምክኒያት የሚያጋጥሙ ተግዳሮቶች

3. ከፓርኪንሰን በሽታ ጋር ተያይዞ ባጋጠምዎት የተግባራት/የንግግር/የንግግር ችግሮች ምክኒያት ያጋጠመዎትን ማንኛውንም ሁኔታ መግለፅ ይችላሉ? በዕለት ተዕለት ሕይወትዎ ላይ እንዴትና ምን ተጽዕኖ አሳድሯል?
4. ከፓርኪንሰን በሽታ ጋር በተያያዙ የተግባራት ችግሮች ምክኒያት በማህበራዊ ተሳትፎ ወይም በእንቅስቃሴዎ ላይ ስላሉት ማንኛውም ለውጦች ሊነግሩን ይችላሉ?
5. ያጋጠምዎ የተግባራት ችግሮች ከቤተሰብ፣ ከጓደኞችዎ እና ከጤና አጠባበቅ ባለሙያዎች ጋር ያለዎት ግንኙነት ላይ ምን ተጽዕኖ አሳድሯል? በእነዚህ ግንኙነቶች ውስጥ ማንኛውም ልዩ ተግዳሮቶች ወይም ድጋፍ ካጋጠሙዎት እባክዎን ማስረዳት ይችላሉ?
6. የተግባራት ችግርን ከስራ አካባቢ ጋር እንዴት ያገናኛሉ? እባክዎን በስራ አካባቢዎ ውስጥ ልዩ ተግዳሮቶች ወይም ድጋፍ ካጋጠሙዎት ማስረዳት ይችላሉ?
7. የተግባራት መታወክ በግል እና በማህበራዊ ህይወትዎ ላይ ያለውን ተጽእኖ የሚያሳሉ ማናቸውንም ያጋጠመዎትን ልዩ ክስተቶችን ወይም ሁኔታዎችን ማጋራት ይችላሉ?

ዓላማ 3- ከፓርኪንሰን ህመም ጋር የተያያዙ የተግባራት ችግሮች የስነ-ልቦና እና -ማህበራዊ ተፅእኖ

8. ከፓርኪንሰን በሽታ ጋር በተገናኘ ካለው የተግባራት ችግሮች ጋር የመኖርን ስሜታዊ እና ስነ ልቦናዊ ገጽታዎች እንዴት ይገነዘባሉ? ለራስዎት ያሎትን ግምት እና መተማመን እንዴት ነካው?

9. በመግባባት ችግር ምክንያት ያጋጠመዎትን የብስጭት፣ የማጣት ወይም የመገለል ጊዜያትን መግለጽ ይችላሉ? እነዚህን ስሜቶች እና ሁኔታዎች እንዴት ተቆጣጠሩት?

10. ለተግባራት ችግሮችዎ የሌሎችን አመለካከት እና ግንዛቤ እንዴት ይረዳሉ? ከፓርኪንሰን በሽታ እና በግንኙነት ላይ ካለው ተጽእኖ ጋር የተያያዙ የተሳሳቱ አመለካከቶች ወይም መገለሎች አጋጥመውዎታል?

ዓላማ 4- የተግባራት ችግሮች ያለባቸው የፓርኪንሰን ህመማን የሚያጋጥማቸውን ችግሮች የመቆጣጠሪያ / የመቋቋሚያ ስልቶች

11. በተግባራት ችግሮች ምክንያት የሚፈጠሩ ችግሮችን ለመቆጣጠር ያዘጋጁትን ስልቶች ወይም የመቋቋሚያ ዘዴዎችን መግለጽ ይችላሉ? የትኞቹ ውጤታማ ሆኖሎታል?

12. ከዚህ ቀደም የንግግር ሕክምናን ወስደው ያውቃሉ? የንግግር ሕክምናን የመውሰድ ልምድዎ ምን ይመስላል?

13. በእርስዎ አስተያየት፣ ከፓርኪንሰን በሽታ ጋር በተገናኘ የተግባራት ችግር ላለባቸው ግለሰቦች ምን አይነት ድጋፍ ወይም ግብአት ጠቃሚ ሊሆን ይችላል? በተመሳሳይ ሁኔታ ውስጥ የግለሰቦችን አጠቃላይ ልምድ እና ደህንነት ማሻሻል እንዴት ይቻላል ብለው ያስባሉ?