

**EFFECT OF PERCEPTION OF SPEECH DIFFICULTIES ON
QUALITY OF LIFE IN INDIVIDUALS WITH PARKINSON DISEASE**

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CERTIFICATE

This is to certify that this dissertation entitled **“Effect of Perception of Speech Difficulties on Quality of Life in Individuals with Parkinson disease”** is a bonafide work submitted in part fulfillment for degree of Master of Science (Speech-Language Pathology) of the student Registration Number: 15SLP003. This has been carried out under the guidance of a faculty of this institute and has not been submitted earlier to any other University for the award of any other Diploma or Degree.

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DECLARATION

This is to certify that this dissertation entitled “**Effect of Perception of Speech Difficulties on Quality of Life in Individuals with Parkinson disease**” is the result of my own study under the guidance of Dr. Swapna. N, Reader in Speech Pathology, Department of Speech-Language Pathology, All India Institute of Speech and Hearing, Mysuru, and has not been submitted earlier to any other University for the award of any other Diploma or Degree.

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*Dedicated to my dear
dearest Acha and all
the people with PD I
have met so far...*

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CHAPTER I

INTRODUCTION

Parkinson disease (PD) is the second most common neurodegenerative progressive disorder affecting aging population (Heller, Dogan, Schulz, & Reetz, 2014). The condition was first described in the essay entitled, 'An Essay of the Shaking Palsy' by James Parkinson in 1817. Almost 2% of the world population above 60 years of age are affected by PD and the number of people affected with the disease is increasing especially in the developed countries (Skodda, Visser, & Schlegel, 2011). In the Indian context, PD is the third most common neurological and movement disorder (86.5%) among the hospital based studies of 2,34,021 new patients with neurogenic disorders (Anand & Singh, 1993).

PD is caused due to various factors such as drugs (neuroleptics), encephalitis, toxins (manganese, carbon monoxide, MPTP, cyanide), vascular insults, brain tumor, and head trauma. However in majority of the reported cases of PD, the cause is unknown which is referred to as idiopathic PD. Depletion of dopaminergic neurons and disruption in motor control pathways are the major reasons for the symptoms seen in persons with PD. Neuronal loss in substantia nigra pars compacta (SNpc) is greater in PD and leads to the neurodegeneration in the central nervous system (Fahn, 2003).

PD is chiefly characterized by a clinical triad of motor disabilities which are resting tremor, bradykinesia or hypokinesia and rigidity. The most easily identified symptom of PD is resting tremor (Shahed & Jankovic, 2007). Bradykinesia refers to slowness of initiating a movement upon a command and reduction in amplitude of voluntary movement. Bradykinesia can contribute to masked face; reduced blinking of eyes; drooling secondary to reduced frequency of swallowing; loss of spontaneous gesturing, micrographia, reduced hand dexterity, shuffling gait with reduced arm swing and difficulty to get up from chair, car or bed. Rigidity is another classical symptom where there is increased resistance to passive

movement, equal in all directions. Adding to these, loss of postural reflexes along with the stooped posture causes festinating gait, where the person moves faster in very small steps (Theodoros & Ramig, 2011). In addition to the motor symptoms, there are some non-motor features which gradually emerge as the condition progresses and in the late onset of PD such as cognitive decline, depression, gastrointestinal and genitourinary disturbances, sleep abnormalities etc. (Lima, Martins, Marcia Delattre, Proenca, Mori, Carabelli, & Ferraz, 2012).

The persons with PD pass through different stages as the disease progresses. The course of PD is subdivided into two distinct phases; *presymptomatic* phase (early stage) where in the physiological changes have begun but no overt signs or symptoms are observed and *symptomatic* phase, which is inclusive of the middle to later stages where the signs and symptoms are overt. The severity of the condition increases from the middle to later stages (Wolters, Francot, Bergmans, Winogrodzka, Booij, Berendse, & Stoof, 2000; Del Tredici, Rüb, Vos RAI de., Bohl, & Braak, 2002; Braak, Del Tredici, Rüb, de Vos, Steur, & Braak, 2003). Due to the progressive nature of the disease, Hoehn and Yahr in 1967 classified the disability occurring due to PD into five stages using an arbitrary scale, where Stage I indicated no functional impairment and Stage V indicated severe impairment wherein, the patient is confined to bed or wheel chair. Studies revealed that as the persons with PD move on to higher Hoehn and Yahr stages, motor decline and impairment of activities of daily living worsens (Giladi, Nicholas, Asgharnejad, Dohin, Woltering, Bauer, & Poewe, 2016).

The motor problems lead to deviant speech output which is referred to as dysarthria. Due to hypokinesia, the muscles of the speech subsystems have difficulty in initiating the movements required for speech in a precise and accurate manner. This results in a host of respiratory, phonatory, resonatory, articulatory and prosodic problems such as reduced vital capacity, reduced loudness and pitch, imprecise consonant production, prolonged phonemes,

monopitch, monoloudness, short rushes of speech, variable rate, and so on. This affects the overall speech intelligibility. In addition, several language deficits also have been reported in persons with PD (Cummings, Darkins, Mendez, Hill, & Benson, 1988; Blonder, Gur, & Ruben 1989; Lewis, Lapointe, Murdoch, & Chenery, 1998). The changes in the speech and language of persons with PD affect the overall communication which in turn has an impact on the individual and family (Miller, Noble, Jones, & Burn, 2006).

All these problems seen in persons with PD hinder their quality of life (QOL) and cause a decline in the functional status. Limitation in functional status and activities of daily living (ADL) leads to a loss of independence and a dip in the individuals' QOL (Yousefi, Tadibi, Khoel, & Montazeri, 2009). In advanced PD, non-motor symptoms which are very evident, causes severe disability, impaired quality of life, and shortened life expectancy. The family members usually take over their role and functions due to which the persons with PD gradually avoid social events and functions and eventually lose social contact. This may trigger depression, which has an impact on the QOL (Theodoros & Ramig, 2011).

Quality of life (QOL) is defined as the “individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (World Health Organization, 1997) (as cited in Majnemer, Shevell, Law, Birnbaum, Chilingaryan, Rosenbaum, & Poulin, 2008). Majnemer et al., (2008) defined QOL as the individual's personal perspective of overall well-being and contentment in life, which includes both psychosocial and physical or health-related domains.

Rahman, Griffin, Quinn, and Jahanshahi (2008) conducted a study on PD and found that sudden unpredictable on/off states, difficulty in dressing, difficulty in walking, falls, depression, and confusion were the symptoms, which had a significant influence on QOL scores. Depression was found to be the strongest factor which affected the QOL in PD

population (Schrag, Jahanshahi, & Quinn, 2000; Behari, Srivastava, & Pandey, 2005; Sławek, Derejko, & Lass, 2005).

Koplas, Gans, Wisely, Kuchibhatla, Cutson, Gold, Taylor, and Schenkman (1999) studied the QOL in persons with PD and concluded that ‘mastery’ (the individuals’ belief that his/her behaviour can influence the outcome of personal situations and life events) predicted the QOL rather than other variables like depression and physical disability. They also pointed out that the psychosocial profile of PD patients may change as the disease progressed and can be seen in five different stages. In an Indian study on PD population, Behari et al., (2005) noted that female gender, presence of depression, low degree of independence, higher levodopa dosage (>400mg/day) and higher UPDRS activity of daily living score had the greatest effect on QOL in PD. Cognitive impairment is reported in 30% of people with PD and it has a massive impact on the functional outcome in PD as well as in their families and caregivers (Heller et al., 2014).

Determining the QOL of persons with PD is challenging as it is influenced by many factors including socioeconomic functioning, physical difficulties, cognitive deficits, confidence and attitude towards disease by the person himself along with the motivation and support given by the caregivers. Understanding the QOL they possess in their life will help every caretaker/family member to be empathetic and provide more motivation to live their life qualitatively. QOL is generally assessed through self-report questionnaires. The self-reports might reflect the inner feelings of the person with PD in relevance to several domains of life.

Several tools have been developed to assess both health and non-health domains. Health-related quality of life (HRQOL) includes domains such as physical, mental/emotional and social well-being (Waters, Maher, Salmon, Reddihough, & Boyd, 2005). It assesses QOL as affected by disease processes, conditions, and disorders. The more generalized wellbeing

that takes into account factors other than health (such as finances, school, autonomy, support, spirituality, social and emotional wellness) is the non-health related QOL. To assess the QOL specifically in persons with dysarthria, attempts have been made in the past to develop tools. One of the tools is PD-QOL, i.e. Parkinson Disease Quality of Life Measure (39- and 8-item versions) (PD-QOL-39 and PD-QOL-8) (Peto, Jenkinson, Fitzpatrick, & Greenhall, 1995). The other tools were Parkinson's Impact Scale (PIMS, Calne et al., 1996), Parkinson disease Quality of life measure (PDQOL, De Boer, Wijker, Speelman, & De Haes in 1996), Parkinson's disease quality of life scale (PDQUALIF, Welsh, McDermott, Holloway, Plumb, Pfeiffer, & Hubble in 2003), European Quality of Life Questionnaire 5 level version (EQ-5D-5L, Alvarado-Bolaños et al., 2015) to assess HRQOL in PD etc.

Few studies have been conducted using these tools to assess the quality of life in different dysarthric groups. Souza et al., (2007) conducted a study on persons with PD and reported that the scores on PDQ-39 (Parkinson Disease Quality of Life Measure) were worse in the items like ADL and communication for persons with PD with more than 5 years of onset of disease. Okunoye, Asekomeh, Qwolabi, Onwuchekwal and Ogunniyi in 2015 conducted a study on Nigerian PD population and found poor QOL in them with mostly affected dimensions in PDQ-39 being the mobility, ADL and emotional well-being.

In addition tools have been developed for assessing the perception of speech problems in persons with dysarthria such as Communication Profile (Yorkston & Bombardier, 1996), communicative effectiveness survey (CES, Husta, 1999), Self –report questionnaire Living with Neurologically Based Speech Difficulties (Hartelius, Elmberg, Holm, Lövberg, & Nikolaidis, 2008), Dysarthria Impact Profile (DIP, Walshe, Peach, & Miller, 2009), Situation intelligibility survey, (Piacentini et al., 2011) etc. A few studies also have been carried out using these tools in different dysarthric groups.

Piacentini, Zuin, Cattaneo, and Schindler (2011) reported that though several tools were developed to study communication problems in individuals with different neurogenic speech disorders, limited tools were available to analyse how patients perceive their own speech and what is its impact on the quality of life of an individual. Piacentini et al., (2011) also stated that the tools like ‘The self-report questionnaire’, ‘Living with Neurologically Based Speech Difficulties’, and ‘Communicative Effectiveness Survey’ is useful in understanding the subjective communication problems, and however, their applicability in daily practice might be problematic. Moreover, certain tools are available to investigate QOL in specific diseases which would not be applicable to all patients with dysarthria such as ‘Assessment protocol for persons with Amyotrophic lateral sclerosis’ and ‘Communicative Effectiveness Survey’ which is specifically for persons with PD. Other tools such as Situation Intelligibility survey, Assessment protocol for persons with Amyotrophic lateral sclerosis’ etc. only analyze some aspects of QOL. Similarly, Piacentini et al., (2011) also stated that the tool ‘The questionnaire Living with Neurologically Based Speech Difficulties’ was adequate for assessing QOL, however some of the items were cognitively demanding. Moreover, even though the PD-QOL-39 provided general information regarding the quality of life in PD and included domains such as mobility, ADL, emotional well-being, stigma, social support, cognition, communication, and bodily discomfort, limited information was available regarding the speech problems faced by people with PD and the extent to which speech problems affected QOL.

In this connection, Piacentini et al., (2011) developed a self-administered questionnaire titled ‘Quality of life for the dysarthric speakers (QOL-DyS) which is a valid tool for assessing the QOL in dysarthric population. This tool specifically provided information regarding the speech related issues faced by the people with dysarthria consequent to different neurogenic pathologies. It is a self-administered 40-item questionnaire

with four sub-domains (speech characteristics of a word (SC), Situational difficulty (SD), Compensatory strategies (CS), and Perceived reactions(PR). The first sub-domain provides information regarding the perceived speech difficulties; the second sub-domain provides information pertaining to how speech difficulties varies with different situations such as size of audience, demand for intelligibility, demand for speed, emotional load and environmental adversity; the third sub-domain provides information about how they cope up with these speech difficulties like strategies or techniques for handling difficult communication situations, such as improved production, environmental modification, avoidance, message modification, partner instruction; and the fourth sub-domain provides information regarding the perceived reaction of others to their speech problems and these items indicate excessive concern for the speaker's welfare or suggest that others penalize the speaker.

Piacentini et al., (2011) conducted a study on participants with both progressive and non-progressive neurological disorders. The group included 9 individuals who had stroke, 5 individuals with traumatic brain injury, 16 individuals with multiple sclerosis, 8 individuals with amyotrophic lateral sclerosis, 6 individuals with Parkinson's disease and 6 individuals with hereditary ataxia. With respect to the perceptual assessment and site of lesions, the participants were divided into different types of dysarthria: 6 had ataxic dysarthria, 6 had hypokinetic dysarthria, 9 had spastic dysarthria and 29 had mixed dysarthria. They found that various dysarthric groups scored differently in QOL-DyS. Hypokinetic dysarthria group scored the highest, and the lowest score was obtained by the group with flaccid dysarthria. For all the groups, PR domain presented the lower scores, while the highest scores were found in the SC and SD domains. Interestingly, the severity score in the four subscales were also not equally distributed in the different groups. e.g., Hypokinetic Dysarthria group scored higher in the SD subscale most affected than the SC subscale, while patients with ataxic dysarthria scored approximately the same in the two subscales.

In 2014, Piacentini, Catteneo, Gilardone and Schindler conducted a study on 163 patients with multiple sclerosis (MS) using QOL-DyS. Among the 163 participants, only 57 of them had dysarthria and majority of them were found to have mild dysarthria. They found that QOL-DyS was significantly compromised only in the dysarthric group with MS. Further and there was no correlation between the QOL DyS and the duration of MS.

Need for the study

Most of the studies that assessed QOL in persons with PD have focussed on ADL and communication. Very limited studies provide a clear idea about the effect of speech problems on QOL. Further, the tools developed to assess QOL in the past have not specifically tapped the influence of speech difficulties on QOL. For example, the disease specific PD-QOL 39 does not provide sufficient information regarding the effect of speech difficulties in the life of people suffering with PD. However the tool QOL-DyS which was developed later was designed to specifically assess the impact of speech difficulties in persons with dysarthria. Though QOL-DyS has been in use for the last five years, not many studies have been conducted on persons with PD to assess the impact of speech problems on the QOL. Studies have found significant factors contributing to QOL like unpredictable on/off states, duration of the problem, socioeconomic status, walking difficulty, falls, postural disability, cognitive impairment, disability, depression etc. (Rahman et al., 2000; Schrag et al., 2000). In addition, studies investigating the link between self-perception of speech difficulties in individuals with PD with respect to the variables like intelligibility, severity, and usage of speech are also limited. Hence, a need was felt to assess the effect of self-perception of speech difficulties on QOL in persons with PD and its relationship with variables such as speech intelligibility, speech naturalness, speech severity, speech usage, duration of PD and duration of speech problem.

The findings from this study will throw light on the feelings of persons with PD regarding speech difficulties, how it varies with different situations, how they cope up with these and the perceived reaction of others to their speech problems. This information would provide the clients' perspective which would help the speech-language pathologists (SLP's) in prioritizing the treatment targets considered for speech therapy depending on the frequency of speech difficulties, importance and situation specific usage of speech that the clients usually encounter in his/her life. The results of this study will also pave way for future clinicians/caretakers to look into the different variables that would influence the self-perception of speech while treating speech of clients with PD. Keeping this in view, the present study was planned.

Aims of the study: The aims of this study were twofold.

- 1) To investigate the effect of self-perception of speech difficulties on the quality of life in persons with PD using the tool QOL-DyS.
- 2) To assess the relationship of scores obtained on QOL-DyS with speech intelligibility and naturalness, speech severity and speech usage, duration of PD and duration of the speech problem.

The specific objectives of the study were:

1. To compare the self-perception of speech difficulties across the early and middle stage of PD using the tool QOL-DyS.
2. To investigate the variation in intelligibility and naturalness of speech, if any, across the early and middle stages of PD.
3. To compare the speech severity and level of speech usage across the early and middle stages of PD.

4. To correlate the results of QOL-DyS with speech intelligibility, naturalness, speech severity and speech usage in both the stages of the PD.
5. To compare the results of QOL-DyS with the duration of PD and duration of the speech problem.

CHAPTER II

REVIEW OF LITERATURE

Parkinson disease (PD) is a degenerative neurologic disease. The term Parkinson disease was coined by Jean-Martin Charcot in 1872, as an honour to James Parkinson, an English physician who initially came with the views about the disease in 1817 in his paper titled “An Essay on the Shaking Palsy” which was based on six persons with PD. Even now, PD may be termed by some as ‘shaking palsy’ or ‘paralysis agitans’ which was the Latin translation for the same. Earlier, Parkinson thought that this condition arose due to an impairment in the cervical spine and medulla. However, it took almost 100 years again to find out that there was loss of cells in the substantia nigra in persons with PD and 40 years more for Carlsson and colleagues in Sweden to find out that the neurotransmitter-dopamine played a major role in this. Later, by the year 1960, Ehringer and Hornykiewicz found a marked reduction in the dopamine concentration in the striatum of PD patients. Of late, genetic mutations, abnormal handling of misfolded proteins by the ubiquitin–proteasome and the autophagy–lysosomal systems, increased oxidative stress, mitochondrial dysfunction, inflammation and other pathogenic mechanisms are regarded as the causatives in the death of dopaminergic and non-dopaminergic cells in the brains of patients with PD (Jancovic, 2008).

During 1870s, Jean-Martin Charcot, a pioneer in this field, provided details regarding ‘bradykinesia’ (slowing of movements) as one of the cardinal symptoms since it is usually seen in PD. Charcot and his followers distinguished the two specific conditions which occurred as either tremor or rigidity/akinesia and not necessarily weakened muscles or paralysis. Hence, he rejected the terms ‘shaking palsy’/ ‘paralysis agitans’ and termed the condition as ‘Parkinson disease’ (Goetz, 2011).

Incidence and Prevalence of PD

Hirsch, Jette, Frolkis, Steeves, and Pringsheim in 2016 examined the incidence of PD from epidemiological studies from 1985-2010 and reported an upsurge in both men and women over the years. Through their systematic and meta-analysis of worldwide data which covered Asia, Africa, South America, Europe/Australia North America, they conveyed that there was a rising trend in the prevalence of PD in the all the age groups from 40 year olds to above 80. Strikingly, in their study, only in the 50 -59 year old group, there was a significant difference across gender, with higher number of males who were affected with PD. Similarly, with respect to geographic location, significant difference was only found for the 70-79 age group with greater prevalence from North America. Women were more resistant to the condition.

A lower incidence of PD and higher age of onset in women was reported (Haaxma, Bloem, Borm, Oyen, Leenders, Eshuis, & Horstink, 2007). This could be attributed to the activity of estrogen which can suppress the early development of symptomatic PD. Almost 2% of the people above 60 years of age were affected by PD, when the world population was considered. The number of people affected with the disease is increasing especially in the developed countries (Skodda, Visser, & Schlegel, 2011). In the Indian context, PD is the third most commonest neurological and movement disorder (86.5%) among the hospital based studies of 2,34,021 new patients with neurogenic disorders (Anand & Singh, 1993).

Causes of PD

PD is found to be caused due to various factors; which can be generally grouped into primary causes (idiopathic PD); secondary causes (symptomatic PD); and PD plus syndromes (Fahn, 2003). Majority of the reported cases of PD falls under the category of idiopathic PD, where the cause is unknown. The symptomatic PD is where the clients are identifiable with

specific causes like PD due to drugs (neuroleptics), encephalitis, toxins (manganese, carbon monoxide, MPTP, cyanide), vascular insults, brain tumor, and head trauma. The PD plus syndromes includes PD which may be caused by a known gene defect and have a distinctive pathology, which includes progressive supranuclear palsy, multiple system atrophy (pyramid and cerebellar type), dementia syndromes (Alzheimer's, normal pressure hydrocephalous, frontotemporal dementia) and hereditary disorders (Wilson disease, Huntington disease, Pantothenate Kinase associated neurodegeneration).

The idiopathic PD is the most predominant disorder constituting 80% of the individuals with PD (Fahn, 2003). The idiopathic PD is considered as a paradigmatic movement disorder as most of the individuals with PD have observable one or more cardinal symptoms. The second most common type of PD is the PD plus syndromes constituting 15% of the individuals with PD.

The exact cause of the disease is still a mystery. Studies on the PD population revealed that only some proportion of them had major gene mutation whereas a large number of them had nongenetic effect which might be due to interaction with susceptibility of genes (De Lau & Breteler, 2006). Theodorus and Ramig in 2011 reported the affected parts in PD as the pars compacta of the substantia nigra (SNc), the locus coeruleus, and the dorsal motor nucleus of the vagus. In addition to reduction in the nerve cells and increase in gliosis, lewy bodies begin to appear, which indicates a sign that the action of clearance of unwanted proteins in cells are pending. There is also the loss of the dopamine from substantia nigra, nor epinephrine from locus coeruleus and serotonin from other pigmented structures. The apparent reduction in dopamine in neostriatum indicates PD and results in symptoms. Nevertheless, insensitivity to certain dopamine replacement treatment method suspects the involvement of other neurotransmitters in the occurrence of PD.

Types of PD

PD is generally grouped into idiopathic PD; symptomatic PD and PD plus syndromes (Fahn, 2003) as stated in the previous section. In addition to this as there are variant symptoms in individuals diagnosed with PD, Van Rooden, Heiser, Kok, Verbaan, van Hilten, and Marinus in 2010 used cluster analysis to find out the subtypes of PD. Based on the age at onset and rate of disease progression, the cluster profiles that arose from their studies included ‘old age-at-onset and rapid disease progression’, ‘young age-at-onset and slow disease’, ‘tremor-dominant’ and a ‘bradykinesia/rigidity and PIGD (Postural instability and gait disorder) dominant’ cluster profile. Even though insignificant, they mentioned that ‘old age-at-onset and rapid disease progression’ cluster profile included axial motor symptoms, bradykinesia, and rigidity, whilst ‘young age-at-onset and slow disease progression’ was associated with mild motor and cognitive impairment.

The study by Todorova, Jenner, and Chaudhuri in 2014 identified groups of motor subtypes of PD such as tremor dominant; akinetic dominant; postural instability and gait disturbances and mixed. The authors claimed that this classification can help in identifying the clinical population in a better way.

Schrag et al., (2000) used the UPDRS rating to classify the persons with PD into different subtypes. Bradykinesia, rigidity and postural instability subscores from the UPDRS motor scale and history were considered and whoever scored >0.5 in the ratio of tremor to bradykinesia scores were interpreted as ‘tremor dominant subtype’ whereas the scores <0.5 indicates ‘akinetic -rigid type.’

Nutt (2016) also reported subtypes of PD such as tremor-dominant (T-D) and postural instability and gait disorder dominant (PIGD-D) or akinetic-rigid dominant (A/R-D). The subtypes like T-D and PIGD-D were drawn from a ratio of the tremor items and the PIGD

items in the activities of daily living(ADL) (part 2) and motor (part 3) of the revised scale, the MDS-UPDRS. The author claimed that initial years of diagnosis was enough to make a distinction between the T-D and PIGD-D subtypes. However, there are some group of patients who do not fall into either the T-D or PIGD-dominant groups. Some of the clinical symptoms linked with the subgroups are cognitive dysfunction, response to treatment, imaging patterns, and speed of progression. As tremor is generally considered to be a neurological sign, most T-D individuals are diagnosed early. However, this is not frequently seen in PIGD-dominant groups, though the severity is more even in the early stages of this particular group. Moreover, there is probability of people relating 'slowness' in the absence of tremor as a consequence of age or arthritis. Most of them are diagnosed only when the gait and balance problem worsens. Similarly, because of the early diagnosis of PD in T-D group, one feels that the course of the disease is longer and progression is slower in comparison with the other group. However, the author also reported greater gray matter atrophy in PIGD-D patients than in T-D patients indicating more severe parkinsonism relating to poorer performance on the pull test and the motor UPDRS score minus the tremor score. However, in summary, Nutt (2016) claimed that T-D and PIGD-D or A/R-D motor subtypes are not convincingly separate biologic entities and could equally well be various stages of PD.

Course and Pathophysiology of PD

PD is a progressive disorder, and considering this fact, Hoehn and Yahr (1967) provided the motor symptoms at various stages of the disease to classify individuals with PD into different stages. This was based on how severely the motor skills were affected in them. Hoehn and Yahr motor staging of PD has been depicted in Table 2.1.

Table 2.1.

Motor staging of PD by Hoehn and Yahr (1967).

| Stage | Characteristics |
|-------|---------------------------------------------------------------------------------------------------------------------------------|
| 0 | Asymptomatic. |
| 1 | Unilateral involvement only. |
| 2 | Bilateral involvement without impairment of balance. |
| 3 | Mild to moderate involvement; some postural instability but physically independent; needs assistance to recover from pull test. |
| 4 | Severe disability; still able to walk or stand unassisted. |
| 5 | Wheelchair bound or bedridden unless aided. |

The course of the PD can be subdivided into two distinct phases, the *presymptomatic* phase (early stage) where in the physiological changes have begun but no overt signs or symptoms of the disorder are observed and the *symptomatic* phase (middle to later stages) where the signs and symptoms are overt and the severity increases from the middle to later stages (Wolters et al., 2000; Del Tredici, Rüb, Vos RAI de., Bohl, & Braak, 2002; Braak et al., 2003a).

Autonomic, limbic, and somatomotor systems gradually become damaged as the disease progression happens in PD. According to Braak and Braak (2000), the persons with PD pass through six neuropathological stages which can be divided under the above two phases mentioned. The presymptomatic stage includes the 1st and the 2nd neuropathological stage of the PD and the symptomatic stage includes the 3rd stage to the 6th stage. Braak, Ghebremedhin, Rüb, Bratzke, and Del Tredici, in 2004 claimed that the persons with PD in

pre-symptomatic stages 1–2, the pathology is confined to the medulla oblongata/pontine tegmentum and olfactory bulb/anterior olfactory nucleus. In stages 3–4, the substantia nigra and other nuclear grays of the midbrain and forebrain will be affected first minimally followed by severe pathological changes. As soon as the damage extends to the mature neocortex, where most of the clinical symptoms are evident, the individual is considered to be in the last stages 5-6 of the disease. Hence, as the pathology gradually extends to different areas, the symptoms also progress, starting with motor symptoms in the initial stages to cognitive and language symptoms in the later stages. These symptoms also gradually increase in their severity as the disease progresses. Hence, PD is known as a progressive neurodegenerative disorder.

Todorova et al., (2014) classified PD into a preclinical phase (with molecular or imaging markers), a premotor phase (with non-motor symptoms,) and a motor phase (with motor symptoms).

Clinical Manifestations of PD

Both motor and non-motor symptoms are seen in persons with PD. One of the classical symptoms in PD is bradykinesia. Bradykinesia is used synonymously with akinesia and hypokinesia, however, there are some differences between the terms. Bradykinesia means slowness of a performed movement whilst akinesia indicates a poverty of spontaneous movements such as seen in facial expression or association of movement like arm swinging. Hypokinesia denotes that not only the movements are slow but also movements are smaller than desired like micrographia (Berardelli, Rothwell, Thompson, & Hallett, 2001).

Some patients with PD have bradykinesia as the predominant symptom. It leads to difficulty in planning, initiating and executing movement and doing sequential and simultaneous tasks. Bradykinesia is often tested by checking the repetitive sequential movement involving isolated finger movements, hand opening/closing or wrist

pronation/supination which usually becomes smaller (hypokinesia) and slower with the repetition of movement (fatigue). The study by Berardelli et al., 2001 also throws light on the fact that patients with PD have more difficulty doing different tasks together than doing each task alone. Moreover, PD clients have more gap between each element in the sequential task. Similar problems are also evident in simultaneous tasks. The symptoms might be noticeable when an individual slows down when doing his usual tasks such as buttoning or using utensils etc. and have slower reaction times. Moreover, they experience lag/absence of spontaneous movements or gesturing, hypomimia (impaired facial expressions), hypophonic dysarthria, impaired swallowing which leads to drooling, decreased eye-blinking, reduced arm swinging during a walk and so on. The common tendency of people to track the eye gaze in different directions along with the head movements also can be affected.

Bradykinesia can be due to the deficit in the putamen and globus pallidus, leading to reduction in the muscle force during the movement initiation. Electromyographic studies on bradykinesia point towards the inability of the individual to energise the appropriate muscles to give sufficient force to start and sustain large fast movements (Jankovic, 2008).

Another classic symptom is the resting tremors. Some persons with PD have tremors as the predominant symptom. Tremors, often called “pill-rolling” seen in the fingers, are usually unilateral, found in the distal part of an extremity. It has a frequency of about 4-6 Hz. The tremor also might occur in the jaw, chin, lips, and legs. Most often, tremor fades away during action or sleep. There is degeneration of a subgroup of midbrain (A8) neurons, in persons with PD who have tremor as the predominant symptom whereas others do not. (Jankovic, 2008).

Recently Nutt (2016) pointed out that unlike in comparison with rigidity and bradykinesia, severity of tremor is not related to dopamine depletion, putaminal dopamine

release, dopamine transporter number, or nigral dopamine neuron degeneration. A PD network imaged with fluorodeoxyglucose in the resting state showed increased metabolic activity in palidothalamic and pontine areas and decreased activity in premotor, supplementary, and parietal association cortical areas. Variation in this network showed a relationship with rigidity and bradykinesia but not with tremor. Another network characterized by metabolic increases in the cerebellum/dorsal pons, striatum, and primary motor cortex correlated with tremor severity. They also reported that the progression of tremor during the disease course was significantly slower than the progression of bradykinesia, rigidity, and PIGD scores. All these findings suggested that tremor had a different pathophysiology than rigidity, bradykinesia, and postural instability and gait disorder signs.

Rigidity is one of the prime features of PD where resistance goes on increasing with respect to passive movement, thereby resulting in stiffness in joints, pain, and loss of functional movement (Tan, Double, Burne, & Diong, 2016). Rigidity is often accompanied by pain especially in shoulder areas. Postural abnormalities such as flexed neck and trunk posture and flexed elbows and knees are mostly the consequences of rigidity. Nevertheless, flexed posture is seen markedly in the late stages of the disease. Postural instability attributable to the loss of postural reflexes is found mostly in late stages of PD. The pull test is used to assess it where the patient is quickly pulled backward or forward by the shoulders. During the pull test, if the person took more than two steps backwards or if there is no postural response, it is an abnormal postural response indication for persons with PD. Postural instability leads to frequent falling in persons with PD (Jankovic, 2008).

Another feature that occurs as a consequence to PD is striatal hand where there is ulnar deviation of the hands, flexion of the metacarpophalangeal joints and extension of the proximal and flexion of the distal interphalangeal joints. Similarly, there is extension of great

toe and flexion of other toes, called striatal toe in individuals with PD. The problems in postural and striatal deformities in PD are due to rigidity and bradykinesia, dystonia, musculoskeletal changes, loss of postural reflexes and the effect of dopaminergic medications. In addition to this, patients with PD were found to have forward flexion of neck and head, referred to as antecollis. If this forward flexion is severe and the chin of the client is bent down upon sternum such condition is termed as dropped head. These two symptoms results in neck pain and occasional swallowing difficulties (Pandey & Garg, 2016).

Jankovic in 2008 reported the secondary motor symptoms usually found in PD as hypomimia (Masked faces or reduced facial expressions which give identity to PD in few), dysarthria, dysphagia, sialorrhoea, micrographia, shuffling gait, festination, freezing, dystonia and glabellar reflexes. 40-70% falls are reported in advanced PD and it can be the consequences of unstable gait, loss of center of gravity, poor balance, orthostatic hypotension, side effects of medications like antidepressants and benzodiazepines, and disturbances of posture (Varanese, Birnbaum, Rossi, & Di Rocco, 2011).

Some of the other features usually found in PD include freezing of gait (FoG) where the person finds it difficult to make a step ahead or walk when he intends to do so. It can result in frequent falls and affect the quality of life (QOL) of these persons. Similarly, festinated gait might be present when persons with PD walk in short and tiny steps. Delval, Rambour, Tard, Dujardin, Devos, Bleuse, and Moreau in 2016 gave an account of not only the occurrence of FoG in lower limbs but also in the upper limbs especially in coordination activities, anti-phase movements and tapping. They also informed that freezing occurs in orofacial area ('speech freezing'), while repeating syllables during performance on diachokinetic tasks. Nearly half of the PD population with FoG and 13% of people even without FoG in the Hoehn and Yahr stages II and III have freezing of speech. Likewise, they also mentioned about oral festination, noticed as an episodic acceleration during repetition of

syllables which can also be found in 45% of PD with FoG. Both FoG and festination in upper and lower limbs can be regarded as early biomarkers of disease progression after diagnosis of PD.

Non Motor Symptoms of PD

James Parkinson, even in those days had mentioned about the non-motor symptoms like sleep disturbance, constipation, dysarthria, dysphonia, dysphagia, sialorrhoea, and constant sleepiness with slight delirium in his essay (Todorova et al., 2014). Other non motor symptoms commonly found include cognitive decline, dementia, pain, fatigue and depression, mood disturbances, apathy, restless leg syndrome, olfactory dysfunction, abnormal sensation and pain etc. Sleep disturbances commonly seen are difficulty in falling asleep, frequent awakening, nocturnal cramps, painful dystonia, difficult to turn over in bed, motor restlessness, nocturnal confusion, daytime sleepiness (Poewe, 2008). Autonomic dysfunctions seen in PD are orthostatic dizziness, bladder dysfunctions, hyperhidrosis (increased sweating) and erectile dysfunctions. As non-motor symptoms has different symptoms in various forms, it can be attributed to diffuse or multiple brain dysfunctions (Hou & Lai, 2007). More than half of the patients do not indicate symptoms such as apathy, pain, sexual difficulty, bowel incontinence or sleep disorder due to embarrassment or not being aware that these are non-motor symptoms of PD.

Todorova et al., (2014) classified PD into a preclinical phase, a premotor phase, and a motor phase. They reported that a few among non-motor symptoms like hyposmia (reduced ability to smell and detect odours), rapid eye movement sleep disorder, constipation and so on make an indicator in the premotor phase of the disease, while a few emerge as the disease progress to later stages such as dementia and can contribute to severe disability, impaired quality of life, and shortened life expectancy. Todorova et al., (2014) also reported that fatigue, depression, anxiety, impaired concentration, inner restlessness were the non-motor

symptoms that occur exclusively during the ‘off’ periods. Off period refers to the reappearance of motor and non-motor symptoms before the timed dose of Levodopa. The on-off fluctuations are sudden unpredictable shifts between “well-” or “over-” treated status (on) and an undertreated state with severe Parkinsonism symptoms (off). These fluctuations overlap especially in advanced patients (Varanese et al., 2011).

Cognitive and linguistic dysfunctions also have been reported in persons with PD. Theodoros et al., (2011) reported cognitive deficits such as impairment in executive functions like planning, sequencing, switching, monitoring, inhibitory control, and information processing speed in persons with PD. In addition, difficulty in procedural memory and working memory with intact declarative memory also has been reported. An impairment in cognitive flexibility also has been reported which would lead to confusion with unfamiliar routines, following multistep commands and dealing with unexpected changes etc.

Semantic knowledge and complex linguistic constructions are impaired in PD (Theodoros et al., 2011). Lewis et al., (1998) studied 20 people with PD and found impaired naming and definitional abilities, and difficulties in interpreting ambiguity and figurative language in all PD participants. Syntax is disturbed in PD and syntactic complexity deteriorates along with the progressive condition of the disease. Ellis, Fang, and Briley in (2016) reported morphosyntactic, lexical semantic and language production breakdowns. These problems in PD could be attributed to the disturbances in the cortical-basal ganglia-thalamic-cortical circuits.

The non-motor symptoms in PD are often poorly recognised and inadequately treated (Chaudhuri, Healy, & Schapira, 2006; Muzerengi, Contrafatto, & Chaudhuri, 2007). The non-motor symptoms are a major factor influencing the quality of life of persons with PD and carers (Varanese et al., 2011; Todorova et al., 2014).

Speech Characteristics of Persons with PD

The motor characteristics such as akinesia, rigidity and tremor are also seen in the oral structures which have an impact on the speech production. There is a reduction in the range of movement of articulators which affect the speech. This can be due to the excessive muscle tone which creates resistance to movement. The chest and abdominal movement during quiet breathing also gets reduced leading to poor breath support for speech. Tremor in the facial or oral structures also can be seen at rest or sustained posture. Voice, articulation, resonance and fluency are compromised in different ranges. Monopitch, reduced stress, monoloudness, imprecise consonants, inappropriate silences, short rushes, harsh and breathy voice (continuous), and low pitch are seen. Rate of speech is affected, which also includes syllable repetitions, shortened syllables, lengthened syllables and excessive pauses. Alternating motion rates (AMR) task reflects the reduced range of movements of jaw, lips and tongue. On the contrary, single movements might be unaffected or better (Duffy, 2013). Darley, Aronson and Brown (1969) described the various speech disturbances and labelled them as ‘Hypokinetic dysarthria’. In addition, there can also be reduction in the swallowing frequency which leads to saliva collection and thereby drooling.

‘Hypokinetic dysarthria’ or ‘parkinsonian dysarthria’ is the term used to define the speech problems faced by PD like monotonous speech, reduced pitch and loudness, breathy and hoarse voice, short rushes of speech, imprecise consonants (Schulz & Grant, 2000). Speech and the voice disorders were found to be present in nearly 90% of the persons with PD (Ramig, Fox, & Sapir, 2008). Logemann, Fisher, Boshes, and Blonsky (1978) found that approximately 90% of the 200 persons with PD had speech impairment with 89% demonstrating voice disorders and 45% demonstrating articulation difficulties. Speech problems in individuals with PD are due to the underlying neuromuscular abnormalities at all levels of speech system which includes respiratory, phonatory, resonatory and articulatory

systems leading to hypokinetic dysarthria. If one or more of the speech systems are disturbed, then speech is impaired.

Respiration

The rigidity in the respiratory muscles leads to absurd movements of the ribcage (Murdoch, Chenery, Bowler, & Ingram, 1989). Goberman and Coelho in 2002 also reported respiration difficulties as a consequence of overall rigidity in PD which can lead to difficulty in producing normal phrasing and intensity.

The variations in the respiratory muscle actions lead to reduced syllables per breath group (Mueller, 1971; Huber et al., 2003) reduced vital capacity, reduced strength and endurance, irregular breathing pattern (Murdoch et al., 1989; Solomon & Hixon, 1993; Bunton, 2005); reduced airflow volume during vowel prolongation; reduced intraoral pressure for AMRs; and difficulty altering automatic breathing patterns for speech (Duffy, 2005). The rib cage volumes are smaller during breathing and the abdominal volumes are large, leading to a limited amount of air reaching the vocal tract. Freed (2011) reported of faster breathing rates, paradoxical movements and reduced range in muscles responsible for respiration in persons with PD. As a consequence of these, there can be shallow breathing, loss of control of exhalation for speech, short breath cycles thereby leading to short rushes of speech.

The reduction in respiratory pressure in PD also can lead to problem in performance in phonation and articulation. Due to these difficulties, the utterance will be short and contain fewer syllables in a breath. Short maximum phonation duration will also be present which altogether affects their speech outcome especially in monologue and reading tasks (Hammen & Yorkston, 1996; Goberman et al., 2002). Schulz and Grant (2000) also reported disturbed prolongation of vowel and reduced air pressure build up during consonant production. Intensity range is also restricted in PD due to the poor breath support.

Phonation

The laryngeal abnormalities found in PD include bowed vocal cords, abnormally large glottis aperture, laryngeal tremor and phase asymmetry during phonation and these might result in hoarseness, breathiness, roughness and tremulousness in voice (Logemann, Fisher, Boshes, & Blonsky, 1978). The rigidity in the laryngeal muscles can be the reason for bowing of vocal folds which is exhibited during phonation in people with PD. There is a loss of proper agonist-antagonist reciprocal activity in the laryngeal muscles leading to limited vocal fold movements (Hirose, Kiritani, Ushijima, Yoshioka, & Sawashima, 1981). Hanson, Gerratt, and Ward (1983) reported that abnormal vocal fold posturing, vibratory patterns and laryngeal aerodynamics are seen in individuals with PD.

Increased tension in the supraglottic structures has also been reported. An increase in the subglottic pressure and laryngeal resistance during speech has also been reported (Gracco, Gracco, Lofqvist, & Marek, 1992; Jiang et al., 1999). All the above factors lead to decreased intensity (Darley, Aronson, & Brown, 1969a, 1969b; Logemann et al., 1978; Ludlow & Bassich, 1984); decreased pitch and loudness variability (Canter, 1963, 1965a); decreased speed to initiate phonation (Ludlow & Bassich, 1984); decreased intensity peaks across syllables; decreased maximum phonation time over disease course (King, Ramig, Lemke & Horli, 1994); poor pitch and loudness control and voice tremor and flutter (Schulz, Peterson, Sapienza, Greer, & Friedman, 1999).

There are incongruous evidences regarding the pitch variation in PD. Whilst Goberman et al., (2002) indicated raised mean F0 in PD clients due to stiffness in laryngeal muscle, Freed (2011) reported low pitch in hypokinetic dysarthria. Duffy (2013) provided reasons for this divergence as inter-subject variability in perception of pitch or F0, gender difference or factors like monoloudness, monopitch, reduced loudness which might be

confused as perception of low pitch. Moreover, they have high F0 variation during the prolongation of vowels and differences in VOT.

Unlike pitch, there is no difference in opinion regarding the reduced intensity level found during speech, prolonged vowel or AMR tasks in PD by various authors (Duffy, 2013). Hypophonia, one of the best indications of hypokinetic dysarthria can be due to muscle rigidity. However, the findings by Ho, Ianssek, and Bradshaw in 1999 revealed that people with PD have the capability to speak with normal volume provided they consciously attend to speaking loudly. They reported that persons with PD increase loudness when the distance between the listeners was increased (Duffy, 2013). They are also able to amplify their speech intensity by at least 5–10 dB SPL when cued by a listener (De Keyser, Santens, Bockstael, Botteldooren, Talsma, De Vos, & De Letter, 2016).

Jitter and shimmer values are high due to lack of control of abductory or adductory muscles of vocal folds. Anatomically, glottis gap and tightly approximating vocal processes results in bowing of vocal folds which corresponds to perception of increased breathiness and reduced intensity (Duffy, 2013). Voice can even become whisper especially if the severity of problem is high and it leads to unintelligible speech.

Voice tremor is another problem which can be noticed during the endoscopic or stroboscopic evaluations as vertical laryngeal tremor or tremor in arytenoid cartilages. However, voice tremor is not an essential factor determining the characteristic of hypokinetic dysarthria found in PD.

Further, the co-ordination between articulation and phonation is affected in PD. Poor phonatory control can lead to omission of final consonants, continuous voicing even for voiceless phonemes within the utterances etc.

Articulation

People suffering with PD confront problems in articulation like imprecise articulation especially of stop consonants, affricates and fricatives. These inabilities are often found when they are asked to do rapid alternating oro-motor movements especially performing diadochokinetic rate. As cited in Duffy (2013), increased lip-muscle stiffness or rigidity leads to abnormal speed of articulatory movements, reduced velocity and range of lip and jaw movements. Similarly, electromyographic studies revealed reduced duration and amplitude of lip muscle action potentials. The strength of the tongue and speech disorder was found to have a negative correlation where greater the weakness in tongue, more were the speech problems (De Letter, Santens, & Van Borsel, 2005).

Duffy (2013) reported articulatory abnormalities in PD as imprecise consonants, distorted and incorrect production of phonemes, reduced range of articulatory movement, abnormal movement velocities, and increased activation of movement velocities in muscles antagonistic to intended movement, weakness or fatigue and so on. Stop consonants become similar to fricatives whereas fricative consonants have ‘mushy quality’ and larger airflow constriction. Affricates are also affected. ‘Articulatory undershoot’ occurs as the articulators are not able to reach the target or maintain sustained contact for sufficient duration. Duffy (2013) also cited that, in persons with PD, there is restricted acoustic vowel space, suggesting a smaller ‘working space’ for vowels (i.e., reduced range of movement). The articulatory deviances lead to disturbances in prosodic aspects such as rate and fluency.

Resonance

The least impaired subsystem of speech in patients with PD is the resonatory system, where only 10% of them have hypernasality due to inadequate velopharyngeal closure. Therefore, this is not considered as characteristic feature in PD (Logemann et al., 1978;

Schulz et al., 2000). Resonatory characteristics in PD speech has been reported to a lesser extent which could be due to the reduced occurrence of resonatory problems in PD.

However, there are contradictory studies, some of which indicated that individuals with PD have no hypernasality, while others reported that there was solid evidence for perceptual difference in the nasality in acoustic studies (Goberman et al., 2002). Freed (2011) reported mild hypernasality in some of the individuals with PD which was attributed to the slow movement and rigidity of the muscles involved in the velopharyngeal mechanism.

Prosody

The abnormalities in the respiratory, phonatory and articulatory systems in persons with PD can lead to prosodic deviancies. Prosody comprises of the rhythm and speed of speech, intonation patterns and stress. The prosodic disturbances are the most prominent features in PD (Darley et al., 1975; Ludlow & Bassich, 1984; Chenery et al., 1988; Plowman-Prine et al., 2009). The most frequently seen dysprosodic features are monopitch, monoloudness, and reduced stress (Darley et al., 1975; Ludlow & Bassich, 1984; Chenery et al., 1988; Plowman-Prine et al., 2009). Schulz et al., (2000) pointed out that individuals with PD have compromised stress patterns, pauses, intonation and rhythm. They reported that persons with PD have difficulty in identifying and producing angry and interrogative statements as compared to the control group. Low mean F₀ difference for question-statement pairs, no differences between the noun phrase and compound phrases etc have also been reported (Schulz et al., 2000). Decrease in the variability of F₀ in the reading task also determines the underlying the prosodic defects in PD. People with PD also have inappropriate pauses in syntactically inappropriate locations than normal. This might be due to akinesia, which hinders the ability to initiate the motor response. This lack of inappropriate silence is more noticeable in initiation of sentences or in between the sentences. Due to this lag in

responding to a question, listeners might misunderstand that the individuals with PD haven't understood the question or have lost his mind while talking.

Individuals with PD have different rate of speech, that is, too fast in some moments of the emission, and occasionally alternating with slower ones. This difference in rate of speech can be attributed to the abnormal patterns of muscle activity, restricted articulatory range of movement, reduced strength, and tremor of the orofacial structures (Lirani-Silva, Mourão & Gobbi, 2015).

Freed (2011) reported an increase in the rate of speech of individuals with PD which might be due to the inability in stopping a voluntary movement once initiated. Another reason for increase in rate of speech could be difficulties in articulation, in which patients might "blur contrasts" between different speech sounds, causing an increase in rate (Goberman, 2002). Duffy (2013) also reported difficulty in changing the rate of speech when asked to do so.

Speech Intelligibility in PD

The intelligibility of speech is compromised in individuals with PD as the disease progresses. De Bodt, Huici, and Heyning (2002) observed that articulation is the most influencing factor contributing to intelligibility in dysarthric individuals as compared to voice quality, nasality and prosody. Plowman-Prine et al., (2009) claimed that imprecision of consonant articulation is the major factor which influence overall intelligibility of speech. Intelligibility is a suitable factor which has an effect on both communication and quality of life in any person.

According to Kempler and Lancker (2002), different types of tasks influence intelligibility. The persons with PD were found to be less intelligible particularly while speaking spontaneously in contrast to the other tasks like reading, repetition, repeated singing,

and spontaneous singing, where each of these used the same phrases except spontaneous singing. Reading single words for an intelligibility test is cognitively relatively undemanding task and the scores falls during regular conversations, however it does not correlate with the disease severity, motor phenotype and disease duration (Miller, Allcock, Jones, Noble, Hildreth & Burn, 2007). De Letter et al., (2005) also conveyed that there was no correlation between the intelligibility and overall severity of the disease or severity of the motor problem in persons with PD. Nevertheless, they reported a noteworthy enhancement in the intelligibility during the on period apart from off period.

Studies to Assess Speech Characteristics

Logemann et al., in 1978 conducted a vast study with 200 people with PD and checked their speech and voice difficulties. Conversation samples and sentence reading were recorded and evaluated. They grouped their participants based on the difficulties exhibited such as Group 1 with laryngeal dysfunction as their only vocal-tract symptom which accounted for 45% of the total; Group 2 which comprised of 13.5% with difficulty in laryngeal and back-tongue involvement; Group 3 (which made up 17% of the total having laryngeal, back-tongue, and tongue-blade dysfunction); Group 4 with laryngeal dysfunction, back-tongue involvement, tongue-blade dysfunction, and labial misarticulations made up 5.5% of all; and Group 5 was 9% with problems in laryngeal dysfunction and misarticulations of the backtongue, tongue blade, lips, and tongue tip. They also inferred that, just like the disease progression, the symptoms also follow a kind of progression, for example, starting with the laryngeal difficulties (breathiness or roughness) and moving on to other areas of vocal tract like loss of control of back of tongue, later anterior tongue movements and so on. However, the authors recommended future long term studies.

Hartelius, Svensson and Bubach in 1993 did a study on PD, multiple sclerosis (MS), and normals. With regard to the intelligibility of speech, they used a procedure given by

Yorkston and Beukelman (1984) which includes lists of one syllable and two syllable words, and sentences. The participants were asked to read aloud, which was later transcribed orthographically by a listener who was unaware of the intended target word or sentence. Their results indicated negligibly slight differences between the normal group (which is 100 per cent intelligible in one and two syllable words and 98 per cent intelligible in sentences) and the MS group (96 per cent intelligible in words as well as sentences), and somewhat greater differences between the normal and the PD group (89 per cent and 92 per cent intelligible in words and 85 per cent in sentences). The authors attributed the differences found between PD and normal group to the lack of classification between the participants as dysarthric and non-dysarthric group in their study.

Another large scale study by Ho, Iansek, Marigliani, Bradshaw, and Gates, in 1999, classified speech impairment in 200 patients with PD into five levels of overall severity. They characterised based on features like voice, articulation and fluency and its extent of impairment on a five-point scale in each those levels. A 2 minute conversation sample was taken from the participants and was assessed by two listeners. They found higher deficits in voice parameters (65%) as against others symptoms in their early stages and this was frequently affected among persons with PD. The second most affected parameter was articulation with 38.5% of the participants having impairment and nearly 30% of them had issues in fluency. Articulatory and fluency deficits occurred in the later stages of PD, articulatory problems reached the same frequency of voice problems during the severe stage. They also concluded that articulators were highly impaired during the last stage of the disease compared to other features.

Around 70-75% of persons with PD show disturbances in speech in any one of the stage of the disease, however it might not correlate with the severity of the disease (Kwan & Whitehill, 2011). Even though there are mixed opinions regarding this issue, these authors

also reported that the underlying pathophysiology might be different for limb movement problems in contrast to speech disturbances. In fact, Kwan and Whitehill, (2011) cited in their study that there are functional imaging studies which indicate negative correlation between disease severity and impaired speech. However, they also reported that there are mixed results regarding this and further studies are needed to confirm it.

Dias, Barbosa, Limongi and Barbosa in 2016 did a study in 50 subjects with PD (Group I with 30 patients with age at onset between 40 and 55 years; Group II with 20 patients with age at onset after 65 years). In order to compare the articulation difficulties of PD patients with their age of onset of PD, Unified Parkinson's Disease Rating Scale scores, Hoehn and Yahr scale and speech evaluation by perceptual and acoustical analysis were used. The outcome of the study revealed no statistically significant difference among the two groups regarding neurological involvement and speech characteristics. So, the authors concluded that 'age at onset of disease' in the demographic data does not influence the articulation problem or global motor disability in PD. However, a positive correlation was found between articulation difficulties with disease duration and higher scores in both groups. In fact, the authors of this study found that speech articulation is associated with staging and axial scores of rigidity and bradykinesia for middle and late-onset.

According to Pawlukowska, Gołab-Janowska, Safranow, Rotter, Amernik, Honczarenko, and Nowacki, (2015) a marked reduction in vocal articulation with PD progression was identified. The authors attributed it to the decreased mobility within the lips and the jaw. Moreover, the exacerbation of articulation disorders due to progression of the disease need not correlate with UPDRSS scores. L-dopa was also found to positively influence the mobility of the lips when the patient is speaking and their arrangement at rest.

Self-perception of Speech Problems in PD

Some studies have been done to assess the self-perception of speech and overall problems in communication resulting from the disease specifically. In 1997, Fox and Ramig conducted a study on 30 people with PD by considering vocal sound pressure level and their self-ratings about their speech and voice qualities. The persons with PD may exhibit different speech or voice performances when they are in clinical surroundings in comparison with other settings. Surprisingly, more or less unimpaired speech were even self-rated by participants as significantly impaired in comparison with the control groups. The study considered four speech and voice tasks for their study such as maximum duration of sustained vowel phonation, reading, monologue and picture description. They used a visual analog scale to get the self-ratings on nine variables related to voice (loudness, shakiness, hoarseness, monotone), speech (slur, mumble), and spoken communication (understood by others, participate in conversation, and start conversation). They were asked to specify their rating on a visual analog scale with respect to their perception of speech is based on “most of the time”. Their results confirmed that their participants had significantly lower vocal SPL (2.0–4.0 dB SPL; 30 cm) during speech and voice tasks than their controls. Moreover, they indicated significantly more severely impaired self-ratings than normal group. This might be because of impaired perception of their own speech and voice abilities. Furthermore, Fox et al., (1997) infer that this might be due to the internal influences such as impaired sense of effort in relation to motor or external factors such as experiences by the participants about others’ request to repeat the information passed in a louder way. Similarly, the reduced confidence and less interest in participating in conversations point out the participants’ negative impact of speech and voice problems in their communicative environment. In their study as they were not able to make out any statistical differences with their gender, they assumed that both genders had similar perception regarding their speech and voice problems and it may require

the similar strategies for treating both sexes. Fox et al., (1977) also mentioned that the awareness regarding the speech problems might motivate them to undergo treatments, whereas a lack of awareness about the extent of their disability should be considered during the treatment procedures for the success.

Walshe, Miller, Leahy and Murray in 2008 assessed the speaker and listener perception of the intelligibility of dysarthric speech to find any difference in the self-perception of dysarthric speech from formal clinical intelligibility ratings. The participants of the study were 20 people with acquired dysarthria, 10 speech language therapists (SLTs) and 20 naive listeners. Here, the authors compared the self- perception of intelligibility ratings with intelligibility scores on the Assessment of Intelligibility of Dysarthric Speech (ASSIDS) given by Yorkston and Beukelman in 1981. The ASSIDS identifies single-word intelligibility, sentence intelligibility, and speaking rate of the people with dysarthria. Strikingly, there was no significant relationship between the perceptions of intelligibility across the three listener groups, eventhough the speakers rate perceptions of intelligibility was different with regards to SLTs and naive listeners.

Kwan and Whitehill (2011) mentioned about the anecdotal reports of distorted self-perception about their own loudness in people with PD. They interpreted that it might be due to overestimation by persons with PD or they sense they are shouting or speaking too loudly, when asked to speak casually with a partner or a speech-language pathologist. Likewise, clients with PD might use sufficient loudness in clinical setting, however they resort back to poor speech or soft speech outside the settings. The discrepancies between the clinical observation and perceived self-reports can be due to internal factors like impairment in sense of effort when the individuals with PD speak and to deny accusations of lowered loudness, as pointed out by others. Externally, they may rate themselves more disabled in communication

as a consequence of increased experience of a communication partner's requests to repeat themselves.

Parveen and Goberman (2016) analysed the self and proxy ratings for voice handicap index and motor-related quality-of-life of 20 persons with PD. They used the Voice Handicap Index (VHI) and PDQ-39 (mobility section) to check the effects on speech and motor-related QOL. The results indicated that no general group differences in VHI and PDQ-39 mobility rating even if it was rated by self or proxy. Thus they concluded that there was a similar perception by individuals with PD and their communication partners for speech and motor-related changes associated with PD. Moreover, no significant correlations between speech and motor-related QOL were found, thereby implying that these domains were independent of each other. Parveen and Goberman (2016) also examined relationships between VHI ratings and PDQ-39 mobility ratings, as well as between QOL measures and other disease related measures (i.e. disease severity, motor deficits, depression scores and cognitive scores). The results revealed that individuals with poorer VHI ratings also had advanced PD severity, greater motor deficits and/or poorer cognitive performance.

Some explanations have been provided by researchers regarding the differences in the self-perception of PD. One of the reasons is the dysfunction in the frontal-subcortical networks which interrupts sensory perceptions as well as self-awareness and problems in metacognition. Similarly, self-under-estimation of motor performance can be because of unawareness of symptoms on the less affected side in early stages of PD, incidence of depression and/or apathy, denial of symptoms or presentation of themselves as better at home to indicate the doctor as there is an improvement. With regard to communication, persons with PD and their caregivers vary in their rankings given for changes in communication due to PD.

Quality of Life in Persons with PD

All these motor and non-motor problems seen in persons with PD hinder their quality of life (QOL) and cause a decline in the functional status. Limitation in functional status and activities of daily living (ADL) leads to a loss of independence and a dip in the individuals' QOL (Yousefi, Tadibi, Khoel, & Montazeri, 2009). In advanced PD, non-motor symptoms which are very evident, causes severe disability, impaired QOL, and shortened life expectancy. The family members usually take over their role and functions and the person with PD gradually avoids social events and functions. This may trigger depression, which has an impact on the quality of life (Theodoros & Ramig, 2011).

Quality of life (QOL) is defined as the “individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (World Health Organization, 1997). Majnemer, Shevell, Law, Birnbaum, Chilingaryan, Rosenbaum, and Poulin (2008) defined QOL as the individual’s personal perspective of overall well-being and contentment in life, which includes both psychosocial and physical or health-related domains.

The notion of QOL is made up of two domains such as health-related QOL (HRQOL) and non-health or environment-based QOL (Parveen & Goberman, 2016). Many researchers have looked into the HRQOL, non-health-related QOL and communication-related QOL in persons with PD. Health-related QOL comprise of an individuals’ overall health or more domain-specific evaluations of a person’s QOL, including physical, social and emotional well-being. Secondly, non-health-related QOL take account of psychological well-being and life satisfaction of individuals. Finally, the communication-related QOL accounts for the different communication issues in speech and voice performance and its consequences on QOL.

Undoubtedly, the QOL is multidimensional and constitutes several aspects like degree of satisfaction in the family, love, social and environmental life, influencing the health of the individuals. Even when it comes to communication, not only the characteristics of speech and voice are relevant, but also other aspects mentioned above can also be related to negative impact of the QOL on the communication of patients with PD (Lirani-Silva et al., 2015). The authors also mentioned that people with PD are not satisfied with the way and the quality of their communication, and stated that they need to get help from other people to maintain their communicative function. Furthermore, they didn't have much hope regarding the improvement in communication, voice, and speech as soon as they knew the knowledge about their condition- PD, a neurodegenerative and chronic Disease. Moreover, they get frustrated with the awareness that medical treatment is just palliative and that there is no treatment available to block the course of the disease and its avoidance. The changes in speech and language of persons with PD has an impact on the individual and their family long before marked impairment of intelligibility is noticeable (Miller, Noble, Jones, & Burn, 2006).

Factors Influencing QOL

QOL depends on various factors and it may vary upon even the personal values an individual possess. Mostly, with increasing prevalence of disease and with increase in the severity of the disease, QOL varies. So, QOL is more compromised in people in later stages of the PD in comparison with those in early stages. There are a lot of factors responsible for the decrease in QOL in people with PD such as restrictions in mobility, falls, emotional disorders, social embarrassment, isolation, sleep disturbances, dyskinesias, fluctuations etc (Martinez-Martín, 1998). Sławek, Derejko, and Lass, (2005) did a study on 100 people with PD using PDQ-39 to identify the factors which affect the QOL. Depression has the most detrimental effect on QOL in people with PD according to PDQ- 39 scores in their study. In

addition to depression, motor fluctuations and disease severity were also have an effect on the wellbeing and functioning of people with PD. Dowding, Shenton, and Salek (2006) have reported that over the duration of disease, patients with PD have changes in their Health related-Quality of life (HR-QOL) which are influenced by depression, motor complications and surgery. Higher levodopa dosage (400 mg/day) was also found to have an effect on QOL(Behari, Srivastava & Pandey, 2005).They attributed it due to higher stage of the disease of patients who obviously need higher doses and drug related complications can be a reason for the negative effect on QOL.

The QOL was evaluated by Kuopio, Marttila, Helenius, Toivonen, and Rinne in 2000 by using SF-36 (The Medical Outcomes Study 36-Item Short Form Health Survey) which was an originally designed self-administered questionnaire. The SF-36 has eight subscales such as physical functioning, role limitations due to physical problems, bodily pain, general health perceptions, vitality, social functioning, role limitations due to emotional problems and mental health. All eight SF-36 subscales scores range between 0 and 100 scale, where 0 represents the lowest QOL and 100 the highest QOL. But in order to avoid missing of information, an interview was done and recorded by the examiner or the assisting nurse. They reported that QOL was lower in the group with PD having possible depression than in the group with no depression, and still lower in the group with probable depression, on all the eight dimensions of SF-36.They concluded that depression was a significant factor in controlling ones' QOL and it was common in both genders. (Kuopio et al., 2000; Lirani-Silva, Mourão & Gobbi, 2015).

Rahman, Griffin, Quinn, and Jahanshahi (2008) conducted a study on PD and found that sudden unpredictable on/off states, difficulty in dressing, difficulty in walking, falls, depression, and confusion were the symptoms, which had a significant influence on QOL

scores. Depression was found to be the strongest factor which affected the QOL in PD population (Schrag et al., 2000).

Koplas, Gans, Wisely, Kuchibhatla, Cutson, Gold, Taylor, and Schenkman (1999) studied the QOL in persons with PD and concluded that ‘mastery’ (the individuals’ belief that his/her behaviour can influence the outcome of personal situations and life events) determined the QOL rather than other variables like depression and physical. They also pointed out that psychosocial profile of PD patients may change as the disease progressed and can be seen in different stages. Cognitive impairment is reported in 30% of people with PD and it has a massive impact on the functional outcome in PD as well as in their families and caregivers (Heller et al., 2014).

Tools to Assess QOL in Persons with PD

Certain tools have been developed to assess the QOL in persons with PD. Parkinson’s Impact Scale (PIMS), a QOL rating to measure the impact of idiopathic PD on ten aspects of a patient’s emotional, social and economic life. It was developed by nurses in the Parkinson Foundation of Canada ,Clinical Assistance/ Outreach Programme (Calne et al.,1996).PIMS has dimensions like Self, family, feelings, work, community, leisure, travel, safety, financial security and sexuality. Each item scored 0–4 Scale (0 indicating no change to 4 the most severe).

The Parkinson disease Quality of life measure (PDQOL) was developed by De Boer, Wijker, Speelman and De Haes in 1996. It includes four subscales such as parkinsonian symptoms, systemic symptoms, emotional functioning, and social functioning. The authors did a study on 284 people with PD and found that more severe the disease, significantly lower was the quality of life measures on all PDQL subscales.

The Parkinson disease quality of life questionnaire (PDQL) was used in an Indian study on 278 PD population by Behari, Srivastava and Pandey in 2005. A face to face interview of PDQL questionnaire comprising 37 question items was administered. The rating scale options are 'all of the time'=1; 'most of the time'= 2; 'some of the time'=3; 'a little of the time'=4; 'never'= 5. PDQL includes subscales such as parkinsonian symptoms, systemic symptoms, social symptoms and emotional symptoms. Each subsection scores were computed by adding up the rating scores. In this PDQL, higher scores indicated a better QOL in PD. The results of the study indicated that female gender, presence of depression, low degree of independence, higher levadopa dosage (>400mg/day) and higher UPDRS activity of daily living score have the greatest effect on QOL in PD.

Most widely used among the scales are the Parkinson's disease questionnaire - PDQ-39 (Jenkinson, Fitzpatrick, Peto, Greenhall & Hyman, 1997) for assessing QOL of PD patients with or without motor fluctuations. Souza et al., (2007) assessed 56 PD patients with an average disease duration of 7.4 years. Amongst these, 41 of them (73.3%) had motor fluctuations. The PDQ-39 included 39 questions with five different options related to its frequency of occurrence. PDQ -39 comprises of eight dimensions such as mobility (10 questions), activities of daily living (ADL) (6), emotional well-being (6), stigma (4), social support (3), cognition (4), communication (3), and bodily discomfort (3). Each question score ranges from zero (0) to four (4): "never"=0; "occasionally"=1; "sometimes"=2; "often"= 3; "always"=4. The final score was obtained by the formulae; the sum of each question score divided by the result times 4 (the maximal score for each question), divided by the total number of questions. This result is multiplied times by 100. Each dimension score ranges from 0 to 100 in a linear scale, in which zero is the best and 100 is the worst quality of life. Souza et al., (2007) used PDQ-39 in the Brazilian population who had PD with and without motor fluctuations. The findings from the study revealed that mobility, ADL, communication

and bodily discomfort were the parameters which are highly affected in PD. The authors also reported that if the participant was in the higher stage of Hoehn and Yahr (HY) scale, they had poor QOL with higher scores. Moreover, they found that QOL also depended on the number of years the disease was diagnosed. That is, the participants who had five years of disease had worse PDQ-39 scores only in the items ADL and communication, in comparison with those who were suffering from the disease for ≤ 5 years. The authors concluded that PDQ-39 is a multidimensional instrument which considers the physical, emotional, and environmental factors of persons suffering with PD.

Welsh, McDermott, Holloway, Plumb, Pfeiffer and Hubble in 2003 developed the Parkinson's disease quality of life scale (PDQUALIF), a 33-item instrument for persons with idiopathic PD. It has seven domains such as social/role function, self-image/ sexuality, sleep, outlook, physical function, independence, urinary function, plus one item of Global HRQOL. It has a 5-point likert- scale (never, rarely, sometimes, frequently, and always). The raw score can be converted to a scale from 0-100 where the lower score would indicate better HR-QOL. The authors regarded this as the only instrument which specifically considers the fatigue and driving ability which matters in people with PD. Moreover, PDQUALIF has more emphasis on nonmotor impairments and disabilities and has more questions regarding the "social" domain of HRQOL.

The European Quality of Life Questionnaire 5 level version (EQ-5D-5L) is newly updated instrument to assess Health-Related Quality of Life (HRQOL) in PD (Alvarado-Bolaños et al., 2015) EQ-5D-5L assesses mobility, self-care, daily activities, pain and discomfort, anxiety and depression. Each item have to be answered using a five-level likert scale such as no problems, slight problems, moderate problems, severe problems and extreme problems (ranging from 1 to 5 points).The authors conveyed that EQ-5D-5L is a valid instrument for evaluating HRQOL in PD, irrespective of heterogeneous clinical and

demographic characteristics, and proved to be sensitive to features of advanced disease and treatment complications.

Tools to Assess the Perception of Speech Problems in Persons with Dysarthria

Some self-report questionnaires have been developed for assessing the perception of speech problems in persons with dysarthria. The Communication Profile is a 100-item self-report questionnaire developed by Yorkston and Bombardier, (1996) for the speakers with motor speech disorders. (Hartelius, Elmberg, Holm, Lövberg & Nikolaidis, 2008). It has 4 subsections such as characteristics (self-perception about the features of the dysarthria), perceived situational difficulties (partner familiarity, size of audience, demand for intelligibility, demand for speed, emotional load and environmental adversity), compensatory strategies (classified as improved production, environmental modification, avoidance, message modification or partner instruction) and perceived reactions of others (categorized as helpful, solicitous or punishing). The participants had to mark a total of 100 statements by choosing a five point rating scale such as ‘strongly agree’, ‘agree’, ‘neutral’, ‘disagree’, ‘strongly disagree’ or ‘does not apply’ scale. The questionnaire was used in an unpublished study by Yorkston and Bombardier (1992) in 33 individuals with different types and degrees of dysarthria and found significant difference only between severity groups on perceived reactions of others (Hartelius et al., 2008). They inferred that individuals with severe dysarthria considered others as more helpful, more solicitous, and more punishing than did individuals with mild or moderate dysarthria.

Similarly, in 1996, Antonius, Beukelman and Reid used the Communication Profile in 15 people with PD and their communication partners (as cited in Hartelius et al., 2008). The authors found that there was no significant difference between the individuals with PD and their partners with respect to areas of situational difficulty and perceived reactions of others.

Nevertheless, the differences were noticed for compensatory strategies used, that is, in comparison with their partners, the dysarthric speakers reported that the higher usage of improved precision and partner instruction. Moreover, the number of dysarthric characteristics identified was higher in the PD group as against their partners.

Yorkston, Bombardier, and Hammen (1994) reported that with respect to dysarthria severity (mild, moderate, and severe) and 4 characteristics such as perceived speech characteristics, situational difficulties, compensatory strategies and reactions of others, significant difference was found only with perceived reactions of others (as cited in Hartelius et al., 2008). Hence, the authors interpret that it is very reasonable to infer questions regarding the perceived reactions of others as it identifies the degree of handicap associated with dysarthria. Another implication from Hartelius et al., (2008) is that if persons with dysarthria are still leading a professional and social life, they have more communication demands and thereby more difficulties in communication irrespective of their dysarthric severity. Even though the severity of speech disorder in neurological disease correlated with severity of disease, this study however, did not found any definite relationship between severity of dysarthria and perceived communicative difficulties.

Similarly, the communicative effectiveness survey (CES) was given by Hustad in 1999 to assess a person's ability to successfully communicate messages in home and community settings to fulfil life roles in individuals with dysarthria. It includes eight items with a 7-level survey such as 1 = not at all effective to 7 = very effective (Donovan, Kendall, Young & Rosenbeck, 2008). In their study, CES was able to differentiate between non-PD participants from those with PD with even mild dysarthria.

The self-report questionnaire Living with Neurologically Based Speech Difficulties (Hartelius, Elmberg, Holm, Lövberg & Nikolaidis, 2008) can be used to identify the self –

perception of speech difficulties in dysarthrics. The authors did a study on 55 individuals with acquired dysarthria and the results revealed that both degree and type of subjectively perceived communicative difficulties were different. They concluded that degree of communicative difficulties was not dependent on age, gender, diagnosis, disease duration or degree of professional activity in their participants. The authors of this study inferred that most problems reported by their participants were with respect to negative self-image and restrictions in communicative participation and their communication was also interrupted by emotions and by the number and familiarity of people present in communicative encounters. The major speech difficulties reported were decreased speech rate and a need for repetition for clarification. Moreover, they indicated that problems vary between different situations in people with dysarthria. Situational difficulties include emotional load, demand for intelligibility and speed, and general environmental adversity. Most difficulty was reported when the audience were high in number.

The Dysarthria Impact Profile (DIP) was developed to assess the self-reported information about the functional impact of an individual's speech/communication impairment in acquired dysarthria (Walshe, Peach, & Miller, 2009). The DIP is divided into five sections with a total of 48 statements. The subjects had to mark a tick on each statement based on a five-point scale as 'Strongly agree' to 'Strongly disagree'. Yet another tool is the Situation intelligibility survey, to assess specifically 25 different situations in an individual (Piacentini et al., 2011).

A self-administered questionnaire titled 'Quality of life for the dysarthric speakers (QOL-DyS)' was developed by Piacentini, Zuin, Cattaneo, and Schindler (2011) for assessing the QOL in dysarthric population. It is a self-administered 40-item questionnaire which provides information regarding the speech related issues faced by the people with dysarthria. All the questions in the four sub-domains in QOL DyS (speech characteristics of a word (SC),

Situational difficulty (SD), Compensatory strategies (CS), and Perceived reactions (PR) served to identify the difficulties faced by people with dysarthria. This 40-item questionnaire was developed from the 100-item 'Dysarthria from the Point of View of the Dysarthric Patient' questionnaire. They used this tool on 50 participants with mixed dysarthria, ataxic dysarthria, spastic dysarthria, hypokinetic dysarthria and flaccid dysarthria. All the questionnaires were filled by the participants themselves. The results revealed that the 40-item QOL-DyS positively correlated with the severity of the dysarthria. Moreover, among the 50 participants, 9 among were with hypokinetic dysarthria and this group scored higher QOL scores. Lower scores were obtained in the ataxic group. SD subscale scores were higher as compared to other subdomains in the hypokinetic dysarthria group. In summary, Piacentini et al., (2011) reported that QOL DyS is not a burdensome instrument, and that it is an easy self-administered tool to assess the individuals with dysarthria. Furthermore, the authors mentioned that there is no need for further encouragement for the subjects to complete the data. The authors concluded that QOL-DyS is a reliable and useful tool to assess QOL in clinical population of various dysarthria.

Lirani-Silva, Mourão, and Gobbi in 2015 conducted an investigation on 13 people with PD. They used vocal assessment, perceptual and acoustic analysis, based on "Dysarthria Assessment Protocol" and analysis of impact of dysarthria on QOL using a questionnaire, "Living with Dysarthria", developed by the Vardal Institute. This questionnaire identifies the perception of difficulties in speech of individuals with dysarthria. It consists of ten sections, with five statements each, in which the subjects choose answer from one to six, the lowest number being "totally disagree" and the highest number being "fully agree". The results revealed that the prosodic changes and habitual frequency in PD, together with physical and cognitive problems, social isolation, the perceptions of change and dissatisfaction with the communication, were the major influencing factors for a negative view of the QOL. Results

indicated that the degree of modification of speech and voice of patients with PD is similar to that of natural aging process, with the exception of prosody and the habitual frequency, giving negative impact on QOL.

In summary, Parkinson disease is becoming a common neurological disease found among elderly these days. They not only have typical motor problems, there are a lot of non-motor symptoms which acts as hurdles in enjoying a good quality of life among PD patients. From the point of view of a speech language pathologist (SLP), it is essential to assess the extent to which these non-motor symptoms such as difficulties in speech, language, cognition and other problems influence the QOL. As communication is all about expressing oneself, there is a need to check the parameters hindering his/her ways to communicate, thereby holistically working towards improving their speech and QOL. All the subsystems of speech are compromised to various extent, thereby hindering the intelligibility of speech. Studies pertaining to the effect of speech problem on QOL are very limited in both western and Indian context. Most of the studies have focused on other non-speech variables such as ADL and communication. In addition, studies that have explained the link between self-perception of speech difficulties and other parameters related to the speech are limited. In this context, this study was planned. The aim of the study was to investigate the self-perception of speech difficulties in persons with PD using a recently developed tool and to study its relationship with speech intelligibility, naturalness, speech severity rating scale, level of speech usage, disease duration and speech problem duration.

CHAPTER III

METHOD

The aims of this study were to investigate the effect of self-perception of speech difficulties on the quality of life in persons with PD using the tool QOL-DyS and assessing its relationship with speech intelligibility and naturalness, speech severity, speech usage, duration of PD and duration of the speech problem across the early and middle stages of the disease. This study was carried out in people who were diagnosed with idiopathic PD. In order to investigate the above mentioned aims and objectives, the following method was adopted.

Participants

15 Kannada speaking individuals (12 males and 3 females) with idiopathic PD were included in the study. The participants were in the age range of 50-85 years and had preserved reading skills in Kannada and English. All of them were clinically diagnosed with idiopathic PD by experienced neurologists. They were recruited from ‘The Parkinson Society, Basal Ganglia Society (BGS) Groups’, in Mysore. Participants in the early and middle stages of the disease were only taken into consideration for the study. Among the 15 participants, 7 were in the early stages of the disease and 8 participants were in the middle stages. They were classified into Group I (Early) and Group II (Middle) based on the Hoehn and Yahr stages (Hoehn & Yahr, 1967) and the checklist on speech, motor, and swallowing problems cited in Amulya (2013). Furthermore, Frenchay Dysarthria Assessment (FDA, Enderby, 1983) was administered among the 15 participants, 11 had accompanying dysarthria and 4 of them did not have any dysarthria.

Inclusion criteria of the participants: The following criteria were used to select the participants in the clinical group:

1. No history of encephalopathy/intake of neuroleptic drugs/exposure to toxins/vascular insults/brain tumour/head trauma.
2. No history of stroke/multiple system atrophy/ progressive supranuclear palsy/ hereditary disorders, which could co-occur with PD.
3. No cognitive or language impairment which was ensured using MMSE (Folstein, Folstein, & McHugh, 1975). Individuals who exhibited a score better than 23 were only included.
4. No visual deficits after visual correction which was ruled out by informal assessment.
5. No psychological issues such as depression and hallucination which was ensured using a 5 point rating scale from Movement Disorder Society - Unified Parkinson's disease rating score (MDS-UPDRS) (Goetz, Fahn, Martinez-Martin, Poewe, Sampaio, Stebbins, & LaPelle, 2007).
6. Minimum education of up to SSLC with preserved reading ability in both English and Kannada language.
7. Under the medication for PD.

The details of the participants have been provided in table 3.1.

Table 3.1

Details of the participants with PD.

| Participant | Age/ gender | Stage of the disease | Highest education | Occupation | Socio economic class |
|--------------------|------------------------|---------------------------------|------------------------------|-----------------------------------|-------------------------------------|
| PD 1 | 66/M | Early | Post graduate | Operation manager | V |
| PD 2 | 72/M | Early | Diploma | Civil engineer & Legal advisor | IV |
| PD 3 | 76/M | Early | Post graduate | Engineer | V |
| PD 4 | 59/M | Early | Graduate | Bank employee* | V |
| PD 5 | 62/M | Early | Graduate | Bank Manger | V |
| PD 6 | 71/M | Early | PhD | Translator and Editor | V |
| PD 7 | 71/M | Early | Graduate | Supervising Agriculturalist* | V |
| PD 8 | 79/M | Middle | PhD | Forest officer | V |
| PD 9 | 61/F | Middle | SSLC | Home-maker | II |
| PD 10 | 62/M | Middle | Graduate | Business* | IV |
| PD 11 | 72/M | Middle | Post graduate | Deputy commissioner | V |
| PD 12 | 66/F | Middle | Post graduate | Teacher | V |
| PD 13 | 68/M | Middle | Graduate | Engineer | V |
| PD 14 | 59/M | Middle | Diploma | Railway section engineer * | II |
| PD 15 | 68/F | Middle | SSLC | Home maker | III |

**PD 4, PD 7, PD 10 and PD 14 were employed. All other participants were retired.*

The participants were informed about the purpose and procedures undertaken in the study and a written consent was obtained. The NIMH-Socio-Economic Status scale (Revised version) developed by Venkatesan (2011) was used to categorize the participants' socio-economic classes. Among the 15 participants, 10 participants belonged to the highest socio-economic status (SES-V), 1 was in the SES-III (middle class) category and 2 participants each fell in the SES- II(lower middle class) and SES IV (upper middle class) category. This has been depicted in table 3.1.

Materials

Mini Mental Status Examination (MMSE, Folstein, Folstein, & McHugh, 1975) was administered to ensure that all the participants in the current study had no cognitive abnormalities. This was done by excluding the participants who obtained a score below 23. The Movement Disorder Society revision of the Unified Parkinson's Disease Rating Scale (MDS-UPDRS; Goetz et al., 2007) was used to rule out psychological issues such as depression and hallucination. MDS-UPDRS is a comprehensive clinical rating scale covering motor and non-motor elements of Parkinson's disease (PD). The scale has been designated by the National Institute of Health Common Data Elements as the recommended scale for the overall assessment of PD. It included four parts; each designed to measure 1 domain of PD: Part 1- Non-motor Experiences of Daily Living; Part 2- Motor Experiences of Daily Living; Part 3- Motor Examination; and Part 4- Complications of Therapy.

Hoehn and Yahr stages (1967) was used to categorize the participants to determine the stage of disease progression. The Hoehn and Yahr scale is a good tool to assess the stage in PD, thereby giving an impression regarding the effect of disease (Hoehn&Yahr, 1967). The details of the scale has been outlined below:

- 0: Asymptomatic.
- 1: Unilateral involvement only.
- 2: Bilateral involvement without impairment of balance.
- 3: Mild to moderate involvement; some postural instability but physically independent;
Needs assistance to recover from pull test.
- 4: Severe disability; still able to walk or stand unassisted.
- 5: Wheelchair bound or bedridden unless aided.

In addition, the checklist based on speech, motor, and swallowing problems cited in Amulya (2013) was also used to identify the stage of idiopathic PD. Based on this, the participants were classified to early and middle stages.

Frenchay Dysarthria Assessment (FDA, Enderby, 1983) was administered in all the participants in order to find out the dysarthria component. FDA has 8 subsections such as reflexes, respiration, lips, palate, tongue, laryngeal, intelligibility, and influencing factors.

NIMH-Socio-Economic Status scale (Revised) developed by Venkatesan (2011) was administered to determine the socioeconomic status of the participants. The scale had sections such as pooled monthly income, the highest education, occupation and family properties to assess the socioeconomic status of the participants. Each section had a 4 point rating scale from 1-5. After adding the scores of each subgroup, a grand total was obtained, thereby facilitating the grouping into 5 socioeconomic status scales (SES). The participants who had an overall SES between 0-4 falls under SES I; 5-8 in SES II; 9 -12 in SES III; 13-16 in SES IV and 17-20 in SES V. SES V indicated high economic status and SES I indicated low economic status.

Quality of life for the Dysarthric speakers (QOL-DyS), a 40-item questionnaire, developed by Piacentini et al., (2011), was used for the study to assess the effect of self-

perception of speech difficulties on quality of life in persons of with PD. This is a self-assessment tool filled by the participant itself. It has four domains like Speech characteristics of a word (SC), Situational difficulty (SD), Compensatory strategies (CS), and Perceived reactions (PR). For each question, the participant had to respond with the following options: always (score = 4), almost always (score = 3), sometimes (score = 2), almost never(score = 1), or never (score = 0), depending on how frequently he/she experienced that situation or feeling in his/her routine activities in their life. The total score ranged from 0 to 160. The participants who obtained a score of 0 were considered to have an optimal QOL, whilst those who obtained a score of 160 were regarded as having a severely compromised QOL. This tool has been provided in Appendix I.

Speech intelligibility and speech naturalness was measured using the Protocol for assessment of speech intelligibility and speech naturalness in dysarthrics in Kannada (D 'Silva & Manjula, 2006). This has three sections with word intelligibility test, sentence intelligibility test, picture description task (narrative discourse task). Based on the word, sentences and narration scores, average intelligibility score was computed and higher scores in average intelligibility indicated better intelligibility of speech in participants. Speech naturalness was also assessed using the same picture description task. As a part of the speech naturalness assessment, the stress, intonation, pauses, rhythm, rate of speech, and articulatory proficiency were assessed on a 2 point rating scale. Score 0 indicated normal and 1 indicated that the parameter was affected. Hence higher naturalness score indicated the inappropriateness of parameters contributing to naturalness of speech. This tool has been provided in Appendix II.

Level of speech usage rating scale (Baylor, Yorkston, Eadie, Miller, & Amtmann, 2008) was used to determine the level of speech usage in the participants. It is another self-assessment tool where participants were requested to choose the best category of speech usage level, according to their frequency, type, amount and importance of speaking situations generally face in their day to day life. The five categories included: Undemanding; Intermittent; Routine; Extensive; or Extraordinary, where explanation of each category was provided along with it. Each category was given a likert scale from 0 to 4 for quantifying the data objectively and for ease in statistical analysis. ‘Undemanding’ scale with a score 0 implied that the people were quiet for long periods of time almost every day; ‘Intermittent’ with a score of 1 indicated that the people were quiet for long periods of time on many days; ‘Routine’ with score of 2 indicated that they used frequent periods of talking on most of the days; ‘Extensive’ with score of 3 indicated higher speech demands where the speech needs consistently go beyond everyday conversational speech such as regular talk for long periods; extraordinary’ with a score of ‘4’ where the participants had very high speech demands and they regularly talk for long periods of time, talk with loud or expressive speech or give presentations or performance. Here lower scores indicated lesser speech usage and higher the score indicated higher the speech usage. A copy of the scale has been provided in Appendix III.

Finally, speech severity was assessed by a speech severity rating scale, cited in Yorkston, Baylor, and Amtmann (2014), where the participant was requested to opt a particular item from the categories that best described their perceived speech difficulties. The categories included: Normal (0); Sounds different but people understand me(1); Sometimes I have to repeat words to be understood(2); I use gestures, writing or drawing to help people understand my speech(3); and Not understandable, I do not use speech for communication(5). Here also, a likert scale (given in brackets after each scale) was prepared for quantifying the

data objectively and for ease in statistical analysis. Here, higher scores on the speech severity rating scale indicated greater speech problem. This scale also has been provided in Appendix IV.

Procedure

The study was conducted individually for each participant. Using the MDS-UPDRS (Goetz et al., 2007), it was ensured that the participants had no freezing or very slight freezing during the data collection. Initially, the participants were seated comfortably in a chair in a well-lit ventilated room with less background noise. A rapport was built with the participant by engaging them in a casual conversation. The purpose of the study was explained to them. The demographic information was obtained wherein they were asked to report their age, gender, age of onset of the disease, onset of speech problem, education level and employment status. Following this, the assessment and screening procedures using MMSE, MDS-UPDRS were carried out.

Then the participants were asked to fill up the QOL-DyS questionnaire. The participants were given the questionnaire and was asked to encircle the ratings for each of the questions under 4 domains. Each domains title was explained and provided examples were provided for better understanding. The examiner clarified the doubts regarding the questions and ratings whenever required. Later as a part of assessing the speech intelligibility, the protocol for assessment of speech intelligibility and speech naturalness was administered where the participants were asked to read out aloud the words, sentences and describe the picture in Kannada. The wordlists included bisyllables to 4 syllables with increasing complexity from level 1 to level 2. Sentence tasks varied from 2 words to 8 word sentences. The sentence lists also comprised of a hierarchy of simple to complex sentences where geminates and clusters were added in the sentences. The picture was a line drawing about a 'market scene' where the participants were asked to describe the line drawing in detail. The

speech sample of reading and narration was collected using a video recorder. All these recordings were made in a room with less ambient noise and distractions.

Apart from this, the same narration sample was used for determining the speech naturalness by using a 2 point rating scale including items like use of stress; use of intonation; use of pauses; use of rhythm; rate of speech and articulatory proficiency. This was rated by the examiner itself and interpretations were made. The score 0 indicated that the parameters were appropriate, whereas 1 indicated that the parameters were inappropriate. Finally, the level of speech usage scale and speech severity rating scale was given to the participants to choose the best rating applicable to them. All ethical procedures were followed. A written consent was taken from all the participants before the data collection

Test-retest reliability

The test-retest reliability was carried out by re-administering the QOL-DyS questionnaire in a randomly selected group of 8 participants amongst the 15 participants within a period of one week. The scores were subjected to statistical analysis and the reliability between the scores obtained on the first and the second administration were checked.

Analysis

Once the data were collected, the responses obtained on the different tools were documented for each participant. The scores specific for each domain and the grand total in QOL-DyS were calculated by adding the sub domain scores for each participant. Similarly, scores for Level of speech usage and speech severity rating scale were obtained using the likert scale. Furthermore, intelligibility scores in percentage were computed for words, sentences and picture description. The transcription of samples obtained by the protocol for assessment of speech intelligibility and speech naturalness were done by post graduate

students in speech- language pathology who were native speakers of Kannada. Later, word intelligibility score, sentence intelligibility score, and narration intelligibility score were calculated using the formulae given below:

$$\text{Word intelligibility score (in percentage)} = \frac{\text{No. of correct words transcribed by the listener} \times 100}{\text{Total no. of words in the sample}}$$

$$\text{Sentence intelligibility score (in percentage)} = \frac{\text{No. of intelligible words identified in the sentences uttered} \times 100}{\text{Total number of words in the sentences}}$$

$$\text{Narration intelligibility score (in percentage)} = \frac{\text{No. of intelligible words in the narrated sample} \times 100}{\text{Total number of words in the narrated sample}}$$

Naturalness scale was also obtained by considering each 6 parameters mentioned in the Protocol for assessment of speech intelligibility and speech naturalness. Finally, the data were tabulated and appropriate statistical analysis was carried out.

Statistical analysis

The data obtained were tabulated for each participant and was subjected to statistical analysis using the SPSS software version 21.0. Cronbach's alpha test was used to assess the test-retest reliability. Descriptive statistics was used to explain mean, median and standard deviation of the data. Shapiro Wilk test was carried out to check for normality. Comparison between the groups were done using Mann Whitney U test and the Spearman correlation coefficient was used to check the correlation between the QOL-DyS and the speech intelligibility, naturalness, speech severity, speech usage, duration of Parkinson disease and the duration of speech problem.

CHAPTER IV

RESULTS AND DISCUSSION

The current study aimed at investigating the effect of self-perception of speech difficulties on the quality of life in persons with PD using the tool QOL-DyS and assessing its relationship with speech intelligibility and naturalness, speech severity and speech usage across the early and middle stages of the disease. The specific objectives of the study were a) to compare the self-perception of speech difficulties across the early and middle stages of PD, b) to investigate the variation in intelligibility and naturalness of speech, if any, across the early and middle stages of PD, c) to compare the speech severity and level of speech usage across the early and middle stages of PD, e) to correlate the results of QOL-DyS with speech intelligibility, naturalness, speech severity and speech usage in both the stages of the PD, and f) to compare the results of QOL-DyS with the duration of PD and the duration of speech problem.

A total of 15 participants (12 males and 3 females) with idiopathic PD were included in the study. They were classified into Group I (Early stage of the PD) with 7 participants and Group II (Middle stage of the PD) with 8 participants. Among the 15 participants, 11 had accompanying dysarthria and 4 of them did not have any dysarthria.

The data obtained through the procedures described in the method were tabulated for each participant and was subjected to statistical analysis using the SPSS software version 21.0. The following statistical procedures were carried out:

- Descriptive statistics to obtain mean, median and standard deviation for both the groups.
- Cronbach's alpha to determine the test-retest reliability.

- Shapiro-Wilk test to assess the normality of the data.
- Mann-Whitney test to assess the significant difference, if any, across the groups, i.e., between the Group I and the Group II on the parameters like QOL-DyS scores, intelligibility and naturalness scores, speech severity, speech usage, duration of PD and duration of the speech problem. This test was also used for the comparison of dysarthric and non-dysarthric group on QOL-DyS total score and subdomain scores.
- Spearman's correlation was used to check the correlation between the QOL-DyS and speech intelligibility, naturalness, speech severity, speech usage, duration of PD and the duration of speech problem.

The results obtained from the statistical procedures described above have been presented and discussed in the following subsections.

- I. Test-retest reliability
- II. Comparison of scores obtained on QOL-DyS in the PD group as a whole and across the stages.
- III. Comparison of intelligibility scores and naturalness between groups.
- IV. Comparison of level of speech usage and speech severity across groups.
- V. Comparison of duration of PD and duration of speech problem across groups.
- VI. Association between QOL-DyS and parameters such as speech intelligibility, naturalness, speech severity, speech usage, duration of Parkinson disease and the duration of speech problem in individuals with PD in both the stages of the disease.
- VII. Comparison of dysarthric and non-dysarthric group on QOL-DyS total score and subdomain scores.

I. Test-retest reliability

Quality of life for the Dysarthric speakers (QOL-DyS, Piacentini et al., 2011) was used to assess the effect of self-perception of speech difficulties on quality of life in persons with PD. It has four domains like Speech characteristics of a word (SC), Situational difficulty (SD), Compensatory strategies (CS), and Perceived reactions (PR). For each question, the participant had responded with the following options: always (score = 4), almost always (score = 3), sometimes (score = 2), almost never (score = 1), or never (score = 0), depending on how frequently he/she experienced that situation or feeling in his/her routine activities in their life.

QOL-DyS was administered on 15 participants with PD as a part of the study. This was re-administered for 8 participants within a duration of 1 week. The test retest reliability was assessed using the Cronbach's alpha test. The Cronbach's alpha values were greater than 0.90 for scores on each domain of QOL-DyS and for the total scores of QOL-DyS which indicated good test-retest reliability. The specific Cronbach's alpha values for the domain on 'Speech characteristics of word' (SC) was 0.97, for 'Situational difficulty' (SD), was 0.96, for 'Compensatory strategies' (CS) was 0.92, for 'Perceived reaction' (PR) was 0.98 and for the total QOL-DYS was 0.98.

II. Comparison of scores obtained on QOL-DyS in the PD group as a whole and across the stages

The scores obtained on QOL-DyS from all the participants were tabulated and the mean, median and the standard deviation were computed initially. As the standard deviation was found to be high, median was considered to best represent the data. The mean, median, and standard deviation on QOL-DyS scores have been depicted in Table 4.1.

Table 4.1:

Mean, median, standard deviation (SD), /Z/ and p values of QOL-DyS scores for both the groups

| Domains on QOL-DyS | GROUP I | | | GROUP II | | | /Z/ value | p value |
|--------------------|---------|-------|--------|----------|-------|--------|-----------|---------|
| | Mean | SD | Median | Mean | SD | Median | | |
| SC | 7.28 | 9.16 | 3.00 | 13.75 | 9.41 | 11.50 | 1.62 | 0.10 |
| SD | 9.86 | 7.99 | 9.00 | 13.12 | 9.82 | 11.00 | 0.58 | 0.57 |
| CS | 11.14 | 9.41 | 9.00 | 16.75 | 8.50 | 20.00 | 1.10 | 0.27 |
| PR | 6.86 | 9.74 | 2.00 | 10.00 | 10.70 | 6.50 | 0.88 | 0.38 |
| Total | 35.14 | 33.30 | 31.00 | 53.62 | 34.93 | 45.50 | 1.16 | 0.25 |

**Note: SC-Speech characteristics of word, SD-Situational difficulty, CS-Compensatory strategies, PR-Perceived reaction, Total-Total QOL-DyS scores*

The total score that can be obtained on QOL-DyS is between 0 and 160, with a maximum of 40 in each domain (Piacentini et al., 2011). According to Piacentini et al., (2011), a score of 0 would suggest an optimal QOL whilst a score of 160 would indicate a severely compromised QOL. Similarly, if the domains on QOL-DyS are considered, a score of 0 would indicate an optimal QOL and score of 40 would indicate a severely compromised QOL. An interpretation criteria was derived for the present study based on the scores of QOL-DyS as pointed out by Piacentini et al., (2011). If the score was between 0-10 on each domain and between 0-40 is obtained as total score, that would indicate an optimal QOL. Likewise, a score between 10-20 on each domain and between 40-80 is obtained as the total score, that would indicate a mildly compromised QOL; a score between 20-30 on each domain and

between 80-120 is obtained as total scores, that would indicate moderately compromised QOL. Finally, if a score between 30-40 is obtained on each domain and between 120 -160 is obtained as a total score, that would indicate a severely compromised QOL.

In this study, the average total score obtained for the whole group on QOL-DyS was 45, which indicated a mildly affected QOL, based on the scoring criteria described above. However Piacentini et al., (2011) used the QOL-DyS in different types of dysarthric populations (Mixed dysarthria, Ataxic dysarthria, Spastic dysarthria, Hypokinetic dysarthria and flaccid dysarthria) and found that group with hypokinetic dysarthria had highest scores (92.6) on QOL-DyS indicating a moderately compromised QOL. This difference in the QOL DyS score between the two studies could be attributed to participant related factors such as the presence of dysarthria. In the current study there were 4 individuals who did not exhibit dysarthria, though they had the PD.

The total score (median) on QOL-DyS for group I (early stage) was 31, which indicated an optimal QOL and the total score (median) on QOL-DyS for group II (middle stage) was 45.5, which indicated a mildly compromised QOL-DyS. When the total median scores between the two groups were compared, it was seen that the median values of group II was higher than that of group I. The higher median scores for the participants in the middle stage in comparison to early stage indicated that QOL deteriorated as the condition of persons with PD worsened. Mann Whitney test was used to compare between the median values obtained for the two groups. Non parametric statistics was used since the Shapiro- Wilk test revealed that data did not follow the normal distribution. The results revealed no significant differences in the total QOL-DyS score as well as the subdomain score between the groups($p>0.05$). The z and the p values have been depicted in the table 4.1.

When the median scores on the different domains of QOL-DyS across groups were compared, it was seen that the participants in the group II (middle stage) obtained highest score on all the domains. This indicated that the speech characteristics worsen and they have difficulties in expressing clearly in different situations as the condition progresses. They also resort to using compensatory strategies and experience strange or abnormal listener reactions when they speak. However, Mann Whitney test revealed no significant difference between the groups on different domains. The mean, median, standard deviation, /z/ and p values have been depicted in the table 4.1.

The finding that the persons in the middle stage of the disease had a poorer QOL than the persons in the early stage is in agreement with the De Boer et al., (1996)'s study where they reported that more severe the disease, significantly lower was the quality of life measures. Souza et al., (2007) also reported that the participant in the higher stage of Hoehn and Yahr (HY) scale have poor QOL. In addition, Souza et al., (2007) reported that higher the stages, greater will be the impact on QOL and QOL also depended upon the number of years, the persons had the disease.

Moreover, the individuals with PD are affected by voice and speech disorders during their course of disease progression and it has an impact on their general communication abilities. Moreover, speech problem also follows the progression pattern such as starting from laryngeal difficulties and reaching to loss of control of articulators. Articulatory and fluency problems are also common in later stages of the disease. Hence, these individuals are themselves less likely to participate in conversations or social interactions, thereby a poor QOL is seen (Logemann et al., 1978; Ho et al., 1999; Pinto et al., 2016).

However there was no statistically significant difference between the two groups. This lack of significant difference between the early and middle group can be attributed to the

inclusion of both dysarthric and non-dysarthric participants in the early as well as in the middle groups. In the group I and group II, there were 3 and 1 patient respectively who did not have dysarthria. The criterion for inclusion in the study was the presence of idiopathic PD. Presence of dysarthria was not a must for inclusion in the study. As QOL-DyS is tailor made to assess the dysarthria related impact on QOL, persons with no dysarthria obtained better scores on the tool. A comparison was also made between the dysarthric and non-dysarthric group later to assess their performance on QOL-DyS.

Also among the four domains, the participants in group I and II scored highest on CS and lowest on PR. Group I scored highest even on the domain of SD. Highest scores in CS for both the groups indicated that they frequently employed different strategies during communication to compensate for the loss in the intelligibility of speech and to satisfy the communication needs. The strategies used were rephrasing words, prefer listening rather than speaking, getting people's attention before speaking etc. On the other hand, Piacentini et al., (2011) has reported that CS can be higher in people even without dysarthria as the similar compensatory strategies are beneficial during certain situations where there is probability of communication breakdowns such as presence of background noise.

The higher scores for the domain of SD obtained by the participants in the group I (early stage) suggested that during the early stages of PD, people face speech difficulties in different situations such talking over the telephone during emergency, talking to a group of class and so on. However as they progress into the middle stage, they learn to use greater number and variety of compensatory strategies to overcome the situational difficulties. Piacentini et al., (2011) also reported that among various dysarthric groups, hypokinetic dysarthria scored higher scores for SD domain on QOL- DyS which indicated that they had difficulties in different situations to express intelligibly.

The least score in both groups was for the PR domain, which indicated that the persons in these groups were less penalized by others in reaction to their speech problem. This indicated a supportive environment for the participants. This could be attributed to the fact most of the participants (approximately 9) in the study were retired employees and not engaged in any other kind of vocation. Most of the time, the participants would spend their time at their homes and had restricted social contact. Since their family members already knew about the condition of the participant and were already familiar with their speech, they did not experience any abnormal reactions from the listeners. This finding is in agreement with the study by Piacentini et al., (2011) who reported that the group with hypokinetic dysarthria received least scores on the domain of PR.

Strikingly, amongst all, only 1 participant in the middle stage had severe compromised QOL-DyS subdomain scores (SC, SD and PR). This can be attributed to his disease progression as well as the effect of post Deep Brain Stimulation (DBS). This speech problem can worsen after the DBS surgery as cited by Frost, Tripoliti, Hariz, Pring, and Limousin, (2010). That is, while altering the stimulation parameters to find the optimum settings for a patient post DBS surgery, the increase in stimulation amplitude to relieve motor symptoms can lead to increased speech difficulties and reduced intelligibility.

III. Comparison of speech intelligibility and speech naturalness between the groups

The Protocol for assessment of speech intelligibility and speech naturalness in dysarthrics in Kannada (D 'Silva & Manjula, 2006) was used to assess intelligibility and naturalness in participants in both the groups. Based on the word, sentences and narration scores, average intelligibility score was computed. Higher scores indicated better intelligibility of speech in participants. Similarly naturalness score was computed using a 2 point rating scale by rating the parameters such as stress, intonation, pauses, rhythm, rate of

speech, and articulatory proficiency. Score ‘0’ indicated normal and ‘1’ indicated that the parameter was affected. Hence higher naturalness score indicated the inappropriateness of parameters contributing to naturalness of speech. The mean, median and standard deviation obtained for the intelligibility and naturalness of the group I and group II is shown in table 4.2.

Table 4.2:

Mean, median and standard deviation (SD) of both groups on intelligibility and naturalness

| Parameters | GROUP I | | | GROUP II | | | /Z/ value | p value |
|--------------------------------|---------|------|--------|----------|-------|--------|-----------|---------|
| | Mean | SD | Median | Mean | SD | Median | | |
| Average intelligibility | 97.31 | 2.43 | 98.10 | 85.33 | 85.33 | 89.44 | 2.20 | 0.03* |
| Naturalness | 2.00 | 1.29 | 2.00 | 4.00 | 4.00 | 4.00 | 1.94 | 0.052* |

p ≤ 0.05*

When the median values of the two groups were compared, it was seen that the group I had higher average intelligibility scores in comparison to Group II (middle). This indicated that persons in early stage of PD had better intelligibility than participants in the middle stage of PD. With respect to naturalness, group I had lower median score compared to group II. As indicated earlier, lower scores in naturalness indicates better naturalness levels. This indicated that participants in early stage had better naturalness in speech. The results of the Mann Whitney test revealed that there was a significant difference between the groups on the average intelligibility and speech naturalness. The /z/ values and p values of intelligibility and naturalness have been depicted in the table 4.2.

This finding is in agreement with studies conducted in the past. There is a positive correlation between the articulation difficulties with respect to disease duration and staging (Dias et al., 2016). Plowman-Prine et al., (2009) also claimed that intelligibility is a suitable factor which has an effect on both communication and quality of life in any person. As cited in Hartelius (1993), dysarthria severity is influenced by the intelligibility of speech. This can be attributed to the less affected systems of speech in the early stages of PD (Logemann et al., 1978; Ho et al., 1999; Pinto et al., 2016). Pawlukowska et al., (2015) also reported a marked reduction in vocal articulation with PD as the disease progressed. However De Letter et al., (2005) reported that there was no correlation between the intelligibility and overall severity of the disease.

These studies also indicated that as the disease progresses in PD, not only the intelligibility is impaired, but naturalness of the speech is also affected. According to Anand et al., (2015), even though not found to be significant, there was a general trend of decreasing intelligibility and naturalness of speech as the PD duration increased. Moreover, they also indicated that naturalness was perceived to be affected initially in PD even before impaired intelligibility was noticeable by the listener.

IV. Comparison of level of speech usage and speech severity across groups.

Level of speech usage rating scale (Baylor, Yorkston, Eadie, Miller, & Amtmann, 2008) was used to determine the level of speech usage generally in the participants. Level of speech usage indicates how people typically use their speech in daily routine. There are five categories in level of speech usage rating scale: Undemanding; Intermittent; Routine; Extensive; or Extraordinary. Each category was given a likert scale from 0 to 4 for quantifying the data objectively and for ease in statistical analysis. 'Undemanding' scale with a score 0 implied that the people are quiet for long periods of time almost every day ,

‘Intermittent’ with a score of ‘1’ specified that people are quiet for long periods of time on many days, ‘Routine’ with score of ‘2’ indicated that they use frequent periods of talking on most of the days, ‘Extensive’ with score of ‘3’ indicated higher speech demands where the speech needs consistently go beyond everyday conversational speech such as regular talk for long periods, and ‘extraordinary’ with a score of ‘4’ where the participants had very high speech demands and they regularly talk for long periods of time, talk with loud or expressive speech or give presentations or performance. Here lower scores indicated lesser speech usage and higher the score indicated higher the speech usage.

Among the 15 participants, nearly half of them rated the ‘routine’ level of speech usage scale and others rated as ‘undemanding’ and ‘intermittent’. In the early group strikingly, except one participant, all others rated ‘routine’ level of speech usage. However, ‘intermittent’ was chosen by a majority of middle group participants along with equal preference for ‘undemanding’ and ‘routine’ level of speech usage scale. This shows the variation in speech usage by the participants across the stages of the disease. As the individuals with PD are affected by voice and speech disorders as the disease progresses, their general communication abilities are compromised. Hence, individuals with PD are less likely to participate in conversations or social interactions in order to avoid uncomfortable speaking situations (Pinto et al., 2016), hence the middle group obtained lower scores on the scale indicating that they used the speech less often than the early group.

Speech severity scale describes the best option selected by the participants based on their perception about their speech difficulties. The categories included: Normal(0); Sounds different but people understand me(1); Sometimes I have to repeat words to be understood(2); I use gestures, writing or drawing to help people understand my speech(3); and Not understandable, I do not use speech for communication(5). Here also, a likert scale (given in brackets after each scale) was prepared for quantifying the data objectively and for ease in

statistical analysis. Here, higher score in speech severity rating scale indicated greater speech severity.

In this study, almost half of the whole group rated the option where ‘Sometimes I have to repeat words to be understood’ and other half rated their speech to be ‘normal’. Apart from two participants in early group who rated ‘Sometimes I have to repeat words to be understood’, all others participants in early group rated that their ‘speech is normal’ in the speech severity rating scale. Majority of the participants in the middle group rated ‘Sometimes I have to repeat words to be understood’. Only one participant in the middle group rated a higher speech severity rating as ‘I use gestures, writing or drawing to help people understand my speech’. This might be due to his increased speech difficulties affecting his intelligibility and compromising his communication needs.

Based on the scores obtained from the speech usage scale and speech severity rating scale, the mean, median and standard deviation scores were obtained using descriptive statistics and have been depicted in table 4.3.

Table 4.3:

Mean, median and standard deviation (SD) of speech usage and speech severity rating and the results of Mann Whitney test

| Parameters | GROUP I | | | GROUP II | | | /Z/ value | p value |
|------------------------|---------|------|--------|----------|------|--------|-----------|---------|
| | Mean | SD | Median | Mean | SD | Median | | |
| Speech usage | 1.71 | 0.75 | 2.00 | 1.00 | 0.75 | 1.00 | 1.91 | 0.07 |
| Speech severity | 0.57 | 0.97 | 0.00 | 1.62 | 1.06 | 2.00 | 1.82 | 0.70 |

When the median values of speech usage between the two groups were compared, it was seen that the median was lesser in the group II compared to group I. This indicated that

the persons in the middle stage of PD used speech to a lesser extent as compared to the persons in the early stage. This indicated that participation or communication restrictions were greater as the disease progressed in persons with PD.

When the median values of speech severity between the two groups were compared, it was seen that the persons in the group II obtained higher score as compared to group I. This indicated that persons with the middle stage of PD rated their speech severity towards greater side as compared to the persons in the early stage. This suggested that the group II had greater problems with speech compared to group I.

However, Mann Whitney test results revealed no significant difference between group I and group II in speech usage as well as in speech severity as the p values were greater than 0.05. The results of the test are shown in the table 4.3.

The lack of significant difference between the early and middle group in speech usage could be due to the fact among 15 participants, only 4 of them were currently employed. The rest of the participants were retired employees and not engaged in any other kind of vocation. Most of the time, the participants would spend their time at their homes and had restricted social contact. Even though many of the participants reported as they were very active before their retirement, most of the participants were now withdrawn from other societal activities and confined to their own family where there were only a few members to converse with. Hence they used speech less often. Hartelius et al., (2008) reported that if persons with dysarthria are still leading a professional and social life, they have more communication demands and thereby more difficulties in communication irrespective of their dysarthric severity.

In a similar fashion, there was no statistically difference between two groups on their speech severity. This is in consensus with the study by Kwan and Whitehill (2011) who reported that around 70-75% of persons with PD have disturbances in speech in any one of the stage of the disease, and it might not correlate with the severity of the disease. Moreover, these authors have also cited in their study that functional imaging studies have indicated a negative correlation between disease severity and impaired speech, but they insisted that more studies are required to support the data. However, the median values indicated that the people in the middle group had greater speech problem and use speech to a lesser extent compared to the people in the early stage. This is in agreement with the study of Dias et al., (2016) who reported that speech impairment is associated with axial symptoms, bradykinesia and stage of the disease.

Further, the participants who self-reported their speech as 'normal' also had a reduction in their intelligibility score. This kind of difference in perceived self-reports and clinical observations were also observed in the study by Kwan and Whitehill (2011). In their study, the participants with PD rated themselves as having more severe speech problems which lead to frequent disruption in communication breakdown with their communication partner.

V. Comparison of duration of Parkinson disease and duration of speech problem across groups

The demographic data revealed that the participants in the study had wide range in the duration of PD and speech problem. There were 3 participants in group I who reported not to have any speech problem and other participants who reported to have the duration of speech problem ranging from 12 to 48 months. One of the participant in the group II reported to have no speech problem and other 7 participants in group II had speech problem for a duration

ranging from 3 months to 24 months. The duration of PD was very high in group II (60-180 months) when compared to group I (15 to 108 months).

The duration of speech problem and duration of PD were compared between the groups and the mean, median, and standard deviation is shown in table 4.4. The median values for group II (middle) was higher in comparison to the group I (early) in terms of both, duration of the speech problem and duration of PD. Mann Whitney test was also carried out and the results revealed a statistically significant difference between the groups on duration of PD ($p < 0.01$). However, there was no statistical difference between the groups for the duration of speech problem between the groups ($p > 0.05$). The z values and p values are shown in the table 4.4.

Table 4.4:

Mean, median and standard deviation (SD) scores between the groups and the results of Mann Whitney test for duration of speech problem and duration of PD

| Duration | GROUP I | | | GROUP II | | | /z/ value | p value |
|-----------------------|---------|-------|--------|----------|-------|--------|-----------|---------|
| | Mean | SD | Median | Mean | SD | Median | | |
| Speech Problem | 17.43 | 19.55 | 12.00 | 14.87 | 10.36 | 18.00 | 0.12 | 0.91 |
| Duration of PD | 49.71 | 29.39 | 48.00 | 124.50 | 42.03 | 126.00 | 2.96 | 0.00** |

** $p < 0.01$

Persons in the middle stage had greater duration of PD and greater duration of the speech problem and there was a significant difference between the groups with respect to the duration of PD. This result is consistent with the study by Heller et al., (2014) who reported

that greater the duration of PD, higher the stage they were in. However, there was no significant difference among the groups on duration of speech problem. One of the reasons for this could be late identification of speech problem reported by a few participants in both groups due to the unawareness of initial symptoms of hypokinetic dysarthria by the individuals with PD. The changes in speech could have been initially perceived by the participants as those related to ageing and hence might have underestimated the exact duration of speech problem. This was felt because a few of the participants in both the groups indicated that their speech was either normal or had slight changes in speech characteristics, while the actual testing of speech intelligibility revealed a greater reduction in scores.

Further Fox et al., (1997) reported that persons with PD had problems in self-perception of their own speech and voice abilities. Similarly, they also reported that there was no significant relationship between the perception of intelligibility across the speaker, SLT and a naïve listener. Kwan and Whitehill (2011) provided some reasons for these discrepancies between the clinical observation and perceived self-reports. They attributed these differences to internal factors like impairment in sense of effort when the individuals with PD speak and to deny accusations of lowered loudness, as pointed out by others. Externally, the speakers may rate themselves more disabled in communication as a consequence of increased experience of a communication partner's requests to repeat themselves.

The non-significance found between groups for duration of speech problem as compared to significant difference in duration of PD indicated that the speech problem in people with PD can occur at any time during the course of the disease irrespective of early or middle stage. This finding was also reported in Pinto et al., (2011) that dysarthria can occur at any stage of PD, and it probably worsened as the disease progressed. Pinto et al., (2016) have reported that in the later stages of PD, non-motor symptoms like dementia, psychosis,

depression and apathy are a major source of disability along with axial symptoms such as alteration of gait, balance, posture and speech. Moreover, Hartelius et al., (2008) stated that individuals with PD usually develop speech symptoms late in their disease process as compared to Parkinson plus syndromes, where the speech disturbance can be one of their first signs. However, in the current study, speech problems were seen in participants in the early stage also. In sum, based on the findings, the present study supports the notion that speech problems can be seen in any stage of the PD.

VI. Relation between QOL-DyS and other parameters (speech intelligibility, naturalness, speech severity, speech usage, duration of Parkinson disease and the duration of speech problem) across the stages of the disease.

In order to assess the relationship between QOL-DyS with the speech intelligibility, naturalness, speech severity, speech usage, duration of Parkinson disease and the duration of speech problem in individuals with PD in both the stages of the disease, Spearman's correlation test was done. The results obtained have been depicted in the table 4.5. A statistically significant high positive correlation was found only between duration of speech problem and QOL-DyS. This was seen only in the early (Group I). In the group II, however there was no significant difference between QOL-DyS and other parameters studied. This is similar to the outcome of study by Piacentini et al., (2014) on multiple sclerosis using the same tool-QOL DyS. They reported that even minor impairment in speech systems can have impact on QOL. In addition, a moderate negative correlation was found between QOL-DyS score and between level of speech usage and between QOL-DyS and average intelligibility of speech, however, both were found to be statistically not significant.

In contrast to group I, there was no statistically significant correlation with QOL-DyS in any of the parameters (speech intelligibility, naturalness, speech severity, speech usage, duration of Parkinson disease and the duration of speech problem) with the QOL-DyS among the middle stage (Group II). However, in group II, QOL-DyS had a moderate positive correlation with speech severity and naturalness scores whereas moderate negative correlation was seen between QOL-DyS and average intelligibility scores.

Table 4.5:

Results of spearman's correlation

| Parameters | GROUP I | | GROUP II | |
|-------------------------------------|--------------------------------|----------------|--------------------------------|----------------|
| | Correlation coefficient | p value | Correlation coefficient | p value |
| Average intelligibility | -0.61 | 0.15 | -0.50 | 0.20 |
| Naturalness | 0.26 | 0.58 | 0.56 | 0.15 |
| Level of speech usage | -0.61 | 0.14 | -0.23 | 0.58 |
| Speech severity rating scale | 0.47 | 0.28 | 0.59 | 0.12 |
| Duration of speech problem | 0.85 | 0.015** | 0.36 | 0.38 |
| Duration of PD | -0.16 | 0.72 | 0.33 | 0.42 |

$p \leq 0.01$ **

A statistically significant high positive correlation found between duration of speech problem and QOL-DyS seen in group I could be attributed to the fact that four participants among seven in group I reported to have the duration of speech problem ranging from 12 to 48 months, while in the group II, seven among eight participants reported to have speech problem for a duration ranging only from 3 months to 24 months.

When the spearman's correlation was carried out for the entire group as a whole to check the correlation between the total QOL-DyS with the naturalness, speech severity, speech usage and the duration of speech problem in individuals with PD, the results of the test indicated that there was a highly moderate significant correlation between QOL-DyS and duration of speech problem and between QOL-DyS and speech severity. A significant moderate correlation was found for QOL-DyS and naturalness. Although not significant, there was a moderate negative correlation between QOL-DyS and level of speech usage. These results are shown in the table 4.6.

Table 4.6:

Result of spearman's correlation

| Parameters | Correlation coefficient | p value |
|-----------------------------------|--------------------------------|----------------|
| Naturalness | 0.57 | 0.03* |
| Level of speech usage | -0.50 | 0.06 |
| Speech severity | 0.61 | 0.015** |
| Duration of speech problem | 0.69 | 0.00** |

* $p < 0.05$, $p \leq 0.01$ **

This indicated that whenever the naturalness of speech is affected or when a person with PD had longer duration of speech problem, greater will be their effect on QOL. Similarly, greater the demand of speech usage, greater will be the impact on QOL. This is attributed to the fact that due to their speech problem, they are unable to communicate effectively through the verbal mode. This is in agreement with the study by Lirani et al., (2015) who reported alterations in the habitual frequency and in prosody which according to

them can be the first finding in identifying dysarthria in groups of patients with PD in the initial stages.

VII. Comparison of dysarthric and non-dysarthric group on QOL-DyS total score and domain scores

As the literature supports that dysarthria can occur in any of the stages of PD (Pinto et al., 2011), further comparison was made between the groups as participants with dysarthria and without dysarthria. Among the 15 participants included in the study, 11 participants had dysarthria and 4 participants did not exhibit dysarthria. Among the 4 participants who did not have dysarthria, had obtained a total score between 1 and 13 with an average of 6.75 on the QOL-DyS and the dysarthric group obtained a score between 31 and 121 with an average of 58.91. This indicated that the non-dysarthric group had an optimal QOL whereas dysarthric group had mildly compromised QOL (Based on the scoring criteria mentioned under section III). The mean, median and standard deviation scores of dysarthria and non-dysarthric group are depicted in the table 4.7.

Table 4.7:

Mean, median, standard deviation (SD) scores and the results of Mann Whitney test on the dysarthric and non dysarthric group on different parameters

| Parameters | Non Dysarthric | | | Dysarthric | | | /Z/ value | p value |
|--------------|----------------|--------|------|------------|--------|-------|-----------|---------|
| | Mean | Median | SD | Mean | Median | SD | | |
| SC | 1.25 | 1.50 | 0.96 | 14.18 | 11.00 | 8.86 | 2.88 | 0.00** |
| SD | 2.50 | 1.00 | 3.78 | 14.91 | 14.00 | 7.76 | 2.62 | 0.01* |
| CS | 2.50 | 1.50 | 3.32 | 18.36 | 21.00 | 6.18 | 2.89 | 0.00** |
| PR | 0.50 | 0.00 | 1.00 | 11.45 | 7.00 | 10.26 | 2.51 | 0.01* |
| Total | 6.75 | 6.50 | 4.92 | 58.91 | 50.00 | 29.01 | 2.87 | 0.00** |

***p<0.01, *p<0.05 ;(SC-Speech characteristics of word, SD-Situational difficulty, CS-Compensatory strategies, PR-Perceived reaction, Total-Total QOL-DyS scores)*

The table 4.7 casts light on the fact that participants with dysarthria had higher median in both total QOL-DyS scores and domain scores. The results of the Mann Whitney test revealed that there was a significant difference between the two groups on all the domains and on the total QOL-Dys score. This could be attributed to the fact that the dysarthric group had speech problems due to the compromised speech systems like respiration, phonation, and articulation. Miller et al., (2006) reported that even if there were slight deviation in speech and language characteristics in PD, their QOL is affected to some extent even if the intelligibility is not compromised.

The dysarthric group obtained highest score on the domain of CS. This indicated that the persons with dysarthria used more compensatory strategies because of their inability to

express clearly. This is not in agreement with the study by Piacentini et al., (2011) who reported highest score in SD in the hypokinetic dysarthric group.

To sum up, the results of the current study indicated that people in the middle stage had mildly compromised QOL as compared to optimal QOL in people in early stage of PD, although there were no statistically significant differences between the groups on QOL-DyS scores. A statistically significant difference was found for intelligibility of speech and naturalness scores between the people in early and middle stage of PD. In fact, there was a statistically high significant difference for duration of PD and no significant difference on speech severity, speech usage and duration of speech problem between the people with early and the middle stage of PD. A statistically significant high positive moderate level correlation was found between QOL-Dys and naturalness, speech severity and duration of speech problem. It can be concluded that QOL was affected in patients with PD which was reflected in the scores obtained on QOL-DyS and there was a strong association between the QOL-DyS and naturalness of speech, speech severity and the duration of speech problem. Moreover, as the disease progressed, intelligibility and naturalness of speech reduced with people in the middle stage having a longer duration of PD.

CHAPTER V

SUMMARY AND CONCLUSIONS

Parkinson disease (PD) is a chronic, neurodegenerative progressive condition which results in progressive motor impairment and non-motor complications. Though there are medications and surgical options available to treat the disease condition, the disease lasts long and has an effect on the persons' and his family's quality of life (QOL). There are many studies carried out to understand the QOL in persons with PD. In fact, there are a few tools to measure the QOL in PD. However, majority of these tools developed and studies done on understanding the effects of ADL focus on communication, depression, disease severity, and its treatment in patients with PD.

Dysarthria and the psychosocial aspects of communication impairments are particularly disabling for individuals with PD. There is a dearth of studies which look into the self-perception of speech problems in PD and its effect on QOL in western as well as in Indian context. Hence, the current study was planned. The primary aim of the study was to investigate the effect of self-perception of speech difficulties on the quality of life in persons with PD using the tool QOL-DyS and assessing its relationship with speech intelligibility and naturalness, speech severity and speech usage across the early and middle stages of the disease.

There were a total of 15 participants with idiopathic PD. The participants were grouped into early (Group I with 7 participants) and middle (Group II with 8 participants) based on the Hoehn and Yahr stages (Hoehn & Yahr, 1967) and the checklist on speech, motor, and swallowing problems cited in Amulya (2013). Furthermore, Frenchay Dysarthria Assessment (FDA, Enderby, 1983) was administered on the 15 participants which revealed that 11 participants had accompanying dysarthria and 4 of them did not have any dysarthria.

After collecting the demographic data and checking the inclusion criteria, the participants were asked to fill the QOL-DyS questionnaire (Piacentini et al., 2011). Secondly, they were asked to rate the level of speech usage using a scale (Baylor, Yorkston, Eadie, Miller, & Amtmann, 2008). The speech severity rating scale as cited in Yorkston, Baylor, and Amtmann (2014) was also used where the participants were requested to opt a particular item from the categories that best described their perceived speech difficulties. Later, by using the Protocol for assessment of speech intelligibility and speech naturalness in dysarthrics in Kannada (D 'Silva & Manjula, 2006), the intelligibility scores and naturalness scores were obtained. A written consent was obtained from each participant after explaining the purpose of the study.

The data obtained through the procedures described in the method were tabulated for each participant and was subjected to statistical analysis using the SPSS software version 21.0. The test-retest reliability was assessed by using Cronbach's alpha test and descriptive statistics was used to explain mean, median and standard deviation of the data. Comparison of early and middle groups were done by means of Mann Whitney U test and the Spearman correlation coefficient was used to check the correlation of QOL-DyS with the speech intelligibility, naturalness, speech severity, speech usage, duration of Parkinson disease and the duration of speech problem.

The results of the current study revealed that people in the middle stage had mildly compromised QOL as compared to optimal QOL in people in early stage of PD, although there were no statistically significant differences between the groups on QOL-DyS scores. A statistically significant difference was found for intelligibility of speech and naturalness scores between the people in early and middle stage of PD. In fact, there was a statistically high significant difference for duration of PD and no significant difference on speech severity,

speech usage and duration of speech problem between the people with early and the middle stage of PD. A statistically significant high positive moderate level correlation was found between QOL-Dys and naturalness, speech severity and duration of speech problem.

It can be concluded that QOL was affected in people with PD which was reflected in the scores obtained on QOL-DyS and there was a strong association between the QOL-DyS and naturalness of speech, speech severity and the duration of speech problem.

Clinical implications

The results of the present study add on to the available information that QOL is compromised in people with PD. The results of this study specifically indicated that an impairment in speech can affect the QOL. The self-reported speech difficulties obtained through QOL-Dys can strengthen the findings of SLP's during both assessment and intervention and this data can be utilized in prioritizing treatment targets. The results can also help in carrying out need based counselling with regard to speech difficulties in persons with PD. As the ultimate goal of any treatment for PD is to improve the QOL, this study highlights the need to incorporate various aspects of speech such as intelligibility and naturalness by the Speech-Language Pathologist while providing the relevant services to persons with PD.

However, there are few limitations of the study such as due to the small sample size, the study cannot be generalised to all PD population. The effect of gender was not investigated as there were no equal participants in both groups. In fact, in addition to PD, the ageing also could have contributed to the speech problems present in these individuals. Even though it was planned to carry out the data collection within an hour of medication, due to the time constraints expressed by few of the participants, this protocol could not be followed strictly.

Future directions

The current study was a preliminary attempt to understand the self-perception of speech difficulties and its influence on their QOL. Further, there is a need for an in depth analysis of speech impairment along with their perceived difficulties. A large sample of PD population in different stages of disease can also help to analyse the speech changes during the disease progression. Similarly, a longitudinal study to assess the self-perception and speech difficulties will pave way for in depth analysis of progressive speech impairment during course of disease. Moreover, such studies can also find out any associative factors which trigger the speech problem in PD.

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APPENDIX I

Quality of Life for the Dysarthric Speakers (QOL DyS)

Piacentini, Zuin , Cattaneo, & Schindler (2011)

These are statements that many people used to describe their speech and the effects of their speech on their lives. Circle the response that indicates how frequently you have the same experience.

0 = never

1 = almost never

2 = sometimes

3 = almost always

4 = always

Speech Characteristic of the Word (SC)

| | |
|--------------------------------------------------------------------------------------|-----------|
| 1 My speech is difficult for strangers to understand | 0 1 2 3 4 |
| 2 My speech is slow | 0 1 2 3 4 |
| 3 My speech is sometimes too loud or too soft | 0 1 2 3 4 |
| 4 My speech sounds unnatural | 0 1 2 3 4 |
| 5 My speech problem is so severe that it is difficult for my family to understand | 0 1 2 3 4 |
| 6 I have significant difficulty speaking when I am in a hurry | 0 1 2 3 4 |
| 7 My speech is worse in the evening | 0 1 2 3 4 |
| 8 I use a great deal of effort to speak | 0 1 2 3 4 |
| 9 My speech has a nasal quality | 0 1 2 3 4 |
| 10 I run out of air when I talk | 0 1 2 3 4 |

Situational Difficulty (SD)

You feel in a difficult situation if:

- | | |
|------------------------------------------------------------------------------------------|-----------|
| 1 You are attempting to convey important information over the telephone in an emergency | 0 1 2 3 4 |
| 2 You are talking to a family member while you are watching TV or listening to the radio | 0 1 2 3 4 |
| 3 You are asking for information in a group or class | 0 1 2 3 4 |
| 4 You are at a dinner and you have a conversation with several other people | 0 1 2 3 4 |
| 5 You are speaking with someone who is obviously in a hurry | 0 1 2 3 4 |
| 6 You are talking to someone that is in another room | 0 1 2 3 4 |
| 7 You are upset and trying to get point across | 0 1 2 3 4 |
| 8 You are trying to resolve a conflict with someone | 0 1 2 3 4 |
| 9 You are making a difficult request of someone | 0 1 2 3 4 |
| 10 You are explaining to a friend that something exciting has happened | 0 1 2 3 4 |

Compensatory Strategies (CS)

- | | |
|--------------------------------------------------------------|-----------|
| 1 I don't change topics without letting my listener know | 0 1 2 3 4 |
| 2 I make sure that people face me when I am speaking to them | 0 1 2 3 4 |

| | |
|-----------------------------------------------------------------------------------------------------|-----------|
| 3 I ask people to repeat what I have said to them so that I know they have understood | 0 1 2 3 4 |
| 4 I get people's attention before trying to communicate with them | 0 1 2 3 4 |
| 5 Even when the conversation regards me, I prefer to listen rather than participate actively | 0 1 2 3 4 |
| 6 In difficult speaking situation, I try to position myself so that I can be seen when I am talking | 0 1 2 3 4 |
| 7 If someone has misunderstood me, I use different wording when I repeat the message | 0 1 2 3 4 |
| 8 If people are not watching me as I speak, I move so that they can see me | 0 1 2 3 4 |
| 9 I avoid trying to talk with someone at a distance or someone in the next room | 0 1 2 3 4 |
| 10 If someone seems irritated when they cannot understand me, I give up | 0 1 2 3 4 |

Perceived Reactions of Others (PR)

| | |
|-----------------------------------------------------------------------------|-----------|
| 1 Because of my speech problem, people treat me as if I am not very bright | 0 1 2 3 4 |
| 2 Others get irritated with my speech | 0 1 2 3 4 |
| 3 Others ignore me if they do not understand what I am saying | 0 1 2 3 4 |
| 4. Others treat me like a child when it comes to communication | 0 1 2 3 4 |
| 5 People tend to get impatient because I speak slowly | 0 1 2 3 4 |
| 6 People fill in words for me before I have a chance to complete my thought | 0 1 2 3 4 |

- | | |
|---------------------------------------------------------------------------------------|-----------|
| 7 People leave me out of conversation | 0 1 2 3 4 |
| 8 People speak louder when talking to me because they think I have a hearing problem. | 0 1 2 3 4 |
| 9 Others have taken over my responsibilities because of my speech problem. | 0 1 2 3 4 |
| 10 When I talk people pretend to understand me | 0 1 2 3 4 |

APPENDIX II

Protocol for assessment of speech intelligibility and speech naturalness in dysarthrics in Kannada

(D'Silva & Manjula, 2006).

Word List-Part I

ಆಸೆ

ಗಾಳಿ

ಲಾಂಛನ

ಕಾಗೆ

ಶಾಲೆ

ಮೂರು

ಕೋತಿ

ಜಾಕು

ಟೋಪಿ

ಒಂಟೆ

ನೋವು

ದಿಂಬು

ನವಿಲು

ಎರಡು

ಚಮಚ

ರುಪಾಯಿ

ಆಹಾರ

ಬಾವುಟ

ಕೊಳಕು

ಆಯಾಸ

ಮೆಣಸು

ಕುದುರೆ
ಸಾಂಬಾರು
ಒಣಗಿಸು
ಗಡಿಯಾರ
ಅರಮನೆ
ಅವಮಾನ
ಬಾಚಣಿಗೆ
ಅಲೋಚನೆ
ಹದಿಮೂರು
ಸೋಮವಾರ

Word List-Part II

ಪೆನ್ನು

ಅಜ್ಜ

ಪಲ್ಕಿ

ಹಕ್ಕಿ

ರಕ್ತ

ಸದ್ದು

ಹಾನ

ಹಣ್ಣು

ಡಬ್ಬಿ

ಜ್ವರ

ಬಣ್ಣ
ಕತ್ತರಿ
ಪುಸ್ತಕ
ಅಕ್ಷರ
ಇಟ್ಟಿಗೆ
ವ್ಯಾಪಾರ
ಆಶ್ಚರ್ಯ
ಉತ್ಸಾಹ
ಮೈಸೂರು
ತೊಟ್ಟಿಲು
ಇರುತ್ತದೆ

ಬಾಳೆಹಣ್ಣು

ಜವಾಬ್ದಾರಿ

ಉದ್ಗಾಟನೆ

ಅಜ್ಞಾಪಿಸು

ಹೋಗುತ್ತಾರೆ

ಆರಕ್ಷಕ

ಪ್ರಸ್ತಕದ

ಹಾಡುತ್ತಾಳೆ

ಆಲುಗೆಡ್ಡೆ

Sentences List-Part I

೧. ಆದು ಮನೆ.

೨. ಆದು ಕಾಯಿ.

೩. ಅವರು ಬಂದರು.

೪. ಗುಹೆಯೊಳಗೆ ಒಂದು ಹುಲಿಯಿದೆ.

೫. ಮನೆಯ ಎದುರುಗಡೆ ಮರವಿದೆ.

೬. ಅವನು ಮೂರು ಗಂಟೆಗೆ ಶಾಲೆಯಿಂದ
ಬಂದನು.

೭. ಮರದ ಮೇಲೆ ತುಂಬಾ ಹೂವಿನ
ಗೊಂಚಲುಗಳಿವೆ.

ಆ. ಪುಡುಗರು ಶಾಲೆಯಿಂದ ಬಂದು ತಿಂಡಿ ತಿಂದು
ಆಡಲು ಹೋಗುವರು.

ಃ. ಬಾವಿಯೊಳಗೆ ಪಲವು ಹಾವುಗಳು ಹಾಗು
ವಿಧವಿಧವಾದ ಮೀನುಗಳಿವೆ.

ಗಂ. ಊರಿನ ಪುಡುಗಿಯರು ಮನೆಯ ಬಳಿ ಇರುವ
ಮರದ ಅಡಿ ಕುಳಿತುಕೊಳ್ಳುವರು.

Sentence List-Part II

೧. ಅವನು ಬರೆಯುತ್ತಾನೆ.
೨. ಅವಳು ಹಾಡುತ್ತಾಳೆ.
೩. ಆದು ಕಥೆ ಪುಸ್ತಕ.
೪. ಆ ಹುಡುಗ ಬುದ್ಧಿವಂತನಾಗಿದ್ದಾನೆ.
೫. ಬುಟ್ಟಿಯಲ್ಲಿ ಸ್ವಲ್ಪ ಅಕ್ಕಿಯಿದೆ.
೬. ಜಾನಕಿ ಬಹಳ ಸುಂದರವಾಗಿದ್ದಾಳೆ.
೭. ಪೇಟೆಗಳಲ್ಲಿ ಹಲವಾರು ದಿಕ್ಷುಕರು ಇರುತ್ತಾರೆ.
೮. ಈ ಊರಿನಲ್ಲಿ ಎತ್ತರವಾದ ಕಟ್ಟಡಗಳನ್ನು
ಕಾಣುತ್ತೇವೆ.

೯. ಕಿತ್ತಲೆ ಪಿಣ್ಣು ಎಲ್ಲಾ ಪಿಣ್ಣುಗಳಿಗಿಂತ ಸಿಹಿಯಾಗಿ
ಇರುತ್ತದೆ.

೧೦. ಮಕ್ಕಳು ನಾಲ್ಕು ಗಂಟೆಯ ಮೇಲೆ ಆಟದ
ಮೈದಾನಕ್ಕೆ ಹೋಗಿ ಬಂದಿನಲ್ಲಿ ಆರುತ್ತಾರೆ.



The judges should listen to 1 minute narration sample and rate the client's speech on 2-point rating scale on the following factors:

Use of stress: appropriate stress = 0, reduced stress / excess stress = 1

Use of intonation: normal intonation = 0, excessive rise-fall / monotonous = 1

Use of pauses: appropriate = 0, inappropriate = 1

Use of rhythm: appropriate = 0, dysrhythmic = 1

Rate of speech: normal = 0, abnormal (slow / fast / variable) = 1

Articulatory proficiency: Good = 0, Poor (imprecise consonants / prolongation of phonemes / repetition of phonemes / distorted vowels / irregular articulatory breakdown) = 1

APPENDIX III

Levels of Speech Usage Scale

(Baylor, Yorkston, Eadie, Miller, & Amtmann, 2008)

What are your speech needs? While communication is important to everyone, different people use their speech in different ways. Think of how you typically need to use your speech day to day. Mark the category below that best describes you.

___ **Undemanding:**

Quiet for long periods of time **almost every day**

Almost never:

- talk for long periods
- raise your voice above a conversational level,
- participate in group discussions, give a speech or other presentation

___ **Intermittent:**

Quiet for long periods of time on **many days**

Most talking is typical conversational speech

Occasionally:

- talk for longer periods
- raise voice above conversational level
- participate in group discussions, give a speech or other presentation

___ **Routine:**

Frequent periods of talking on **most days**

Most talking is typical conversational speech

Occasionally:

- talk for longer periods
- raise voice above conversational level
- participate in group discussions, give a speech or other presentation

___Extensive:

Speech needs consistently go beyond everyday conversational speech.

Regularly:

- talk for long periods
- talk in a loud voice
- participate in group discussions, give presentations or performances

Although the demands on your speech are often high, you are able to continue with most work or social activities even if your speech is not perfect.

___Extraordinary:

Very high speech demands

Regularly:

- talk for long periods of time
- talk with loud or expressive speech or
- give presentations or performance.

The success of your work or personal goals depends almost entirely on the quality of your speech and voice.

APPENDIX IV

Speech severity Rating Scale

(cited in Yorkston, Baylor, & Amtmann ,2014)

A single item where participants have to select one of the following categories describing their speech:

- Normal
- Sounds different but people understand me;
- Sometimes I have to repeat words to be understood;
- I use gestures, writing or drawing to help people understand my speech;
- Not understandable, I do not use speech for communication.