Investigating quality of life and communication in Saudi Arabian individuals with progressive dysarthria

by

Mashael Faisal Al Saud

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Research Department of Language and Communication,

University College London

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I, Mashael Faisal Al Saud confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated within the thesis.

Mashael Faisal AlSaud

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ABSTRACT

One functional factor commonly affected by neurodegenerative diseases is communication. Many people with neurodegenerative disease experience a progressive motor speech disorder: dysarthria. It is known that communication is essential for full social participation but there is limited evidence on the role it plays in quality of life (QoL). The aim of this thesis is to explore the QoL of Saudi Arabian individuals with progressive dysarthria associated with neurodegenerative disease.

The thesis includes the development of new intelligibility and functional communication measures for use with an Arabic speaking population. It also explores the relationship between QoL and communication for individuals with neurodegenerative disease. Qualitative and quantitative research methodologies were used. Research participants were recruited from a specialist hospital in Riyadh, Saudi Arabia. 16 people participated in the first part and 34 in the second, all of whom had been diagnosed with neurodegenerative disease associated with different severities of progressive dysarthria. In addition, caregivers participated to explore the difference between their perceptions of participants' QoL and functional communication and that of the participants themselves.

It was established that QoL, as measured by the ASIP, showed the most frequent relationship with functional measures of communication. Additionally, qualitative analysis of interviews highlighted themes related to physical, psychological, social, and environmental factors. Communication was mainly discussed in relation to changes and restrictions in participation and interaction. Finally caregiver and patient perspectives were found to be similar when asked to rate the participants' QoL and functional communication.

Although this research is not without limitations as reflected by some of the methodologies used as well as variable population features within the disease groups, it is an important first step in looking at a Saudi Arabian population with progressive dysarthria and exploring methods for assessing intelligibility, functional communication and the relationship between communication and QoL.

INTRODUCTION AND OVERVIEW

The overall aim of this research is to explore the effects of neurodegenerative disease and dysarthria on quality of life (QoL) and communication in Saudi Arabian individuals. This chapter provides an overview of the thesis and includes an introduction to key areas of neurodegenerative diseases, acquired motor speech disorders (dysarthria), QoL, and the assessment of QoL and dysarthria. This is followed by a summary of the research aims, contributions to knowledge and the research methodology employed. This is followed by the organisation of the thesis and a summary of the chapters.

1.1 Overview of the Research

The research work reported was undertaken in the region of Riyadh, Saudi Arabia and involved an Arabic speaking population of participants with neurodegenerative disease. It was noticed by many researchers that QoL is a general and frequent outcome measure in neurodegenerative conditions in order to understand and assess wellbeing and life satisfaction (Behari, Srivastava, & Pandey, 2005; Benito-Leon, Morales, Rivera-Navarro, & Mitchell, 2003; Simmons, Bremer, Robbins, Walsh, & Fischer, 2000). However, even though progressive dysarthria is a common type of communication impairment linked with neurodegenerative conditions and we know from research that communication plays an important role in individuals' QoL (Nussbaum, 2007), there has been limited research in this area. Researchers have looked at the impact of communication changes on life (Cruice, Hill, Worrall, & Hickson, 2010b; Hartelius, Jonsson, Rickeberg, & Laakso, 2010; Miller, Noble, Jones, & Burn, 2006; Walshe & Miller, 2011). Furthermore, communication is not always included as a factor within the QoL measures (Cruice, Worrall, & Hickson, 2000) and when it is, communication is typically represented as the exactness or accuracy of understanding and production. Social participation is significant and important for well-being and has an effective impact on the quality of the life (QoL), however it is rarely represented within health related QoL measures. The foremost significance of this research is that there is very limited research present regarding the impact of progressive dysarthria on a person's QoL specifically looking at the relationship between the two factors. In addition, since this research takes place with individuals from Saudi Arabia and since this population of individuals is culturally and linguistically different from the western world where the majority of QoL assessment measures have been developed, cultural and linguistic aspects of developing the measures were considered throughout.

QoL and communication are measured via a variety of tools in order to investigate the presence of a relationship between QoL and communication, and to determine if this relationship is influenced by the severity of the dysarthria. The primary caregivers of participants were also included in parts of the research study in order to investigate how caregivers perceived the participants QoL and functional communication, matched with how the participants perceived them. For this particular research both qualitative and quantitative research methodologies were applied to investigate both the available outcome measure for the QoL and communication as well as the personal experiences of the individuals. In addition to exploring and investigating the QoL and communication within the particular population of participants, the research study includes the development of assessment materials for both intelligibility and functional communication for the Arabic speaking population since there are presently no valid, reliable and authentic measures in Arabic. The neurodegenerative conditions included in the study were; Parkinson’s disease (PD), multiple sclerosis (MS) and amyotrophic lateral sclerosis/motor neuron disease (ALS/MND).

1.2 Neurodegenerative Disease, Dysarthria, and QoL

1.2.1 Neurodegenerative disease

Neurodegenerative disease is a medical term for neurological diseases that involve progressive death of neurons. Neurodegenerative diseases may involve the central and/or peripheral nervous system, and they also involve both motor and sensory function. Of the many neurodegenerative diseases, MS, PD and ALS/MND, which are included in this study, are distinct conditions with different neuropathology, medical management and symptoms (Yorkston, Miller, & Strand, 2004). The incidence of each of these conditions is different: Internationally PD has the highest incidence of 1 in 1000 (Raggi *et al.*, 2010); MS affects about 1.1 million world-wide (Jenkinson, Fitzpatrick, & Jenkinson, 2000) and, ALS/MND has an incidence of 1 to 2 individuals *per* 100,000, with men found to be more affected than women in the ratio of 1.5:1 (Ferguson & Elman, 2007). In Saudi Arabia the specific incidence for each condition is unknown. To date there is no cure for ALS/MND, PD, or MS (Yorkston *et al.*, 2004). Treatment focuses on the management of symptoms, attempting to slow disease progression with medication and/or surgery, as in the case of PD deep brain stimulation (DBS). Rehabilitation services are provided with the goal of maintaining function and improving QoL. One shared communality between the conditions is the impact they have on psychological, social wellbeing of the patients and their families (Den Oudsten, Van Heck, & De Vries, 2007; Fernandez, Baumstarck-Barrau, Simeoni,

& Auquier, 2011; Goldstein, Atkins, & Leigh, 2002; Williams, Donnelly, Holmlund, & Battaglia, 2008).

These three neurodegenerative diseases (ALS/MD, PD, MS) were included in the current research study because they can all feature dysarthria at some point during the course of the disease, the type and severity of which varies between the three conditions (Duffy, 2005). These reasons allow us to compare the relationship between QoL and communication within individuals who have very different presentations and severities of progressive dysarthria. Amyotrophic Lateral Sclerosis/Motor Neuron Disease is a rapidly progressing neurodegenerative disease of the neurons of the cerebral cortex, brain stem and spinal cord with an unknown aetiology (Traynor, 2003). Clinically it is characterised by the relentless loss of function of both upper and lower motor neurons. The term ALS is often used synonymously with MND, even though it is only one of a group of conditions. Symptoms include progressive bulbar palsy, progressive muscular atrophy and primary lateral sclerosis. ALS/MND is a devastating illness for the patient, caregiver and relatives. The average incidence worldwide is 1 to 2 individuals *per* 100,000, and men have been found to be more often affected than women, with a ratio of 1.5:1 (Ferguson & Elman, 2007). In ALS/MND, dysarthria occurs as the first symptom in 20% of the patients (Chen & Garrett, 2005) but this figure increases to about 80% of patients in the later stages of the disease and some reach a point where they are anarthric and rely on means other than verbal communication (Yorkston, Beukelman, & Ball, 2002). Raggi, *et al.* (2010) identified that Parkinson's disease is the most common form of neurodegenerative disease. It is a slow-progressing disease of the central nervous system (CNS), specifically of the basal ganglia, due to a deficiency in dopamine. According Yorkston *et al.* (2004), Parkinson's disease usually results in severe disability, mainly in the later stages of the disease. The most common neurological symptoms associated with the Parkinson's disease are rigidity, tremor, and bradykinesia (Yorkston et. al., 2004). For patients with PD, 70% reported that their voice and speech were worse than before disease onset (Hartelius & Svensson, 1994). According to Yorkston *et al.* (2004), Multiple Sclerosis is an inflammatory demyelinising disease of the CNS. It is characterised by scattered plaques in the CNS that produce different combinations of motor, sensory, and/or cognitive impairments (Yorkston *et al.*, 2004). The course of the disease is progressive; however, the early stages are characterised by a remitting-relapsing course. Anderson *et al.*, (1992) reported that MS is the third most common cause of disability in the United States following trauma and arthritis, and is 2 to 3 times more common in women than in men. There are currently three theories regarding the cause of the neurological changes that result in MS: autoimmunity, viral infection and genetic predisposition (Boyden, 2000) Most researchers believe that the cause of MS lies in a complex interaction between these three theoretical bases (Yorkston *et al.*, 2004). For patients with MS 51% of patients reported changes in speech (Hartelius, Runmarker, & Andersen, 2000).

1.2.2 Progressive Dysarthria

Progressive dysarthria is a type of motor speech disorder associated with neurodegenerative diseases. Dysarthria involves changes in speech production related to disturbances in the neuromuscular control of the speech mechanisms (Darley, Aronson, & Brown, 1975b). Traditional assessment of dysarthria is based on the work of Darley *et al.* (1969a, & 1969b) at the Mayo Clinic and includes determining the acoustic and perceptual characteristics of speech production and subdividing these characteristics into six different types of dysarthria. Since the introduction of the World Health Organization (WHO) model of disability (1980), there has been a shift towards a more holistic approach that acknowledges the patient’s own perspective and looks beyond the impairment towards effectiveness of communication function and communication participation. Recently, through the WHO International Classification of Functioning, Disability and Health (ICF) model (2001), attempts have been made to design tools to measure patient’s participation in life situations involving communication (Eadie *et al.*, 2006; Hirsch & Holland, 2000 ; Yorkston *et al.*, 2007; Yorkston *et al.*, 2008b).

Given the importance of communication for social participation, any condition involving communication impairment can have a significant impact on a person’s wellbeing and QoL (Bowling, 1995) and may result in a loss of independence which may also result in further reduced QoL (Muller *et al.*, 2001). Communication is described as being at the essence of human existence (Light, 1997) and an individual’s QoL depends upon their ability and opportunities to communicate (Salomon, Vesterager, & Jagd, 1988).

1.2.3 Quality of life

QoL was defined by the WHO (1998b) as “the individual’s perspectives on their position in life in context of [the] culture and value system in which they live and in relation to their goals, expectations, standards, and concerns” (p.17). QoL is considered a subjective matter and differs from individual to individual as everyone has their own point of view on what constitutes an enjoyable life. Without a doubt, individuals give diverse interpretation to the phrase QoL; some link it to enhanced health and more wealth, while others think that it is only achievable when someone is free and safe. Nevertheless, most agree that QoL is attained with the help of high standards and ways of living. Further, there are some significant and vital factors that can be used to recognise and explore the individual's QoL. Health is considered one of the most important and significant factors. There are different definitions of QoL on the basis of meaning, happiness, stability, and health, but researchers are still debating a single agreed-upon definition for QoL (Cahill & Diaz-Ponce, 2011); although they do agree that it is a multifactorial construct that includes physical, psychological, social, and spiritual factors (Felce & Perry, 1995). QoL has been used as an outcome measure for neurodegenerative diseases (Jenkinson *et al.*, 2000). The aim of using such measures is to monitor changes over the course of the disease, assess the effects that medical or surgical interventions may have on life satisfaction, and to determine if prolonging life leads to a life worth living. Studies have found that the QoL of patients with neurodegenerative conditions is related to functional ability, as well as to psychological and emotional factors including depression, spirituality, social support and religiosity (Epton, *et al.*, 2009; Forbes, While, Mathes, & Griffiths, 2006; Marras *et al.*, 2008).

In the field of communication disorders, QoL measures have also been used and particularly in the areas of voice, fluency, aphasia and hearing loss (Cruice, Worrall, Hickson, & Murison, 2003; Cummins, 2010; Hilari, Wiggins, Roy, Byng, & Smith, 2003; Mares, Montoni, Goncalves, Kowalski, & Angelis, 2011; Ross & Wertz, 2003; Vermeire *et al.*, 2006). The results suggest that QoL is multifactorial: that is, some QoL factors are related to communicative function, and others to external and internal factors such as emotions, distress, health, society and support. Another area of debate is determining the best person to report on QoL - should it be the patient, caregiver, physician or other medical staff? In neurodegenerative conditions the person may have difficulty responding to QoL measures, either in completing a questionnaire or in responding to open-ended questions due to impairments in physical or cognitive functions (Hirsch & Holland, 2000). It may therefore be easier to have the caregiver or physician fill out the QoL measure for the patient, but from the definitions of QoL, it is known that it is a highly subjective and individual concept. Research also shows that physicians and significant others may tend to underestimate the QoL of an individual (Addington-Hall & Kalra, 2001).

1.3 Assessment Tools

There are some assessments tools that are discussed in this research work to assess dysarthria and QoL.

1.3.1 Assessment of Dysarthria

There have been many developments over the years for the assessment of dysarthria including perceptual assessment as described by Darley, Aronson, and Brown (1969a and 1969b), component assessment described by Rosenbek & LaPointe (1985), and overall assessment such as the assessment of intelligibility (Yorkston, Beukelman, 1981) and functional communication (Frattali, 1995). Since the study reported in this thesis takes place within Arabic speaking population, standardised Arabic intelligibility and functional communication assessment tools for adults with dysarthria was sought, but unfortunately no such measure has been published or could be found in the literature. Since communication relies heavily on cultural, linguistic and phonological properties of language, it was not appropriate to translate any of the existing measures without taking certain steps and guidelines to ensure its acceptance, validity and reliability to measure the intended skill within the new culture (Carter *et al.*, 2005; Threats, 2010). Therefore a new measure of intelligibility and functional communication needed to be developed, piloted and validated as part of this study. Therefore the first part of the research involved developing measures, using as a guide existing valid measures such as the Assessment of Intelligibility of Dysarthric Speech (AIDS) (Yorkston & Beukelman,1981) and the American Speech and Hearing Association's (ASHA) Functional Assessment of Communication Skills (FACS) (ASHA, 1995).

1.3.2 Assessment of QoL

Assessment of QoL uses different tools including generic, disease-specific, and patient-centred tools, and each of these methods has its own benefits and shortcomings. Generic tools are weighted towards the functional ability of an individual and can be used to compare different conditions (Tennant, 2008). Disease-specific tools look at both the physical and emotional consequences of the disease and are sensitive to the special symptoms of each condition (Bowling, 2001). Some researchers also advocate the use of a patient-centred approach whereby the patient nominates the areas that are important to their own QoL and then weights their importance against one other (Clarke, *et al.*, 2001). Qualitative research using structured or semi-structured interviews has generated some shared themes that are common amongst individuals suffering from the same medical condition (Cruice, *et al.*, 2010; Foley, *et al.*, 2007; Williams *et al.*, 2008).

Since each QoL measure has its strengths and weaknesses, several studies were consulted when undertaking the research reported in this thesis. For the Health Related Quality of Life measure (HRQoL), two Arabic assessment measures were found; the Short Form-36 (SF-36) (Coons, *et al.*, 1998) and the Arabic Sickness Impact Profile (A-SIP) (Almansoori, 2003). After reviewing the reliability and validity of these two measures it was decided to use the A-SIP as a measure of HRQoL, and this is discussed in Chapter 2. In addition, the Schedule for the Evaluation of Individual Quality of Life Direct Weighting (SEIQoL-DW) patient-centred measure was also used (Hickey *et al.*, 1996) as was the McGill Quality of Life – Single Item Scale (MQoL-SIS) (Cohen, *et al.*, 1995). Finally, semi-structured interviews were undertaken to explore the participants' individual experiences in depth, to explore the exact and differentiating natures of the presentation of progressive dysarthria, and to explore the participants' quality of life.

1.4 Rationale of the research study

Quality of life and communication for individuals with neurodegenerative dysarthria was been chosen for this research since understanding the impact that a communication disorder has on a persons' overall wellbeing and QoL is significant (Cruice, Worrall, & Hickson, 2010a; LaPointe, 1999; Meyer *et al.*, 2004; Nussbaum, 2007; Yaruss, 2010). In addition there is very limited knowledge and research focusing on Arabic speaking individuals with progressive dysarthria. The motivation to undertake this research came from clinical practice where it was observed that traditional assessment of motor speech function and intelligibility do not capture the entire range of an individual's experiences; it does not reflect the impact that changes, in some cases the loss of the ability to communicate, has on the QoL and the wellbeing of individuals with progressive dysarthria. This research work provided and offered detailed background information regarding the quality of life and communication and its impact on the person suffering from neurodegenerative dysarthria by investigating the association between quality of life and communication in Saudi Arabians suffering from different forms of neurodegenerative diseases. In addition it provided the opportunity to develop and test culturally and linguistically acceptable instruments to measure both intelligibility and functional communication.

1.5 **Research aims and objectives**

The main aim of this research is to investigate the relationship between communication and quality of life in Saudi Arabian individuals sufferings from one of three different forms of neurodegenerative condition. This research focuses on individuals in Saudi Arabia and how they conceptualise matters related to communication and QoL as well as the presence of a relationship between communication and QoL using assessments for both factors. The research does not seek to compare results from individuals from different cultures. For diseases such as these where there is no cure, the focus of clinical rehabilitation is to maintain or improve the QoL of an individual by decreasing the gap between experiences and expectations. In order to do so the role that communication plays within the construct of QoL needs to be understood. Due to the lack of such measures for Arabic speakers, the second aim of this research was to develop effective and appropriate intelligibility and functional communication assessment instruments. The researcher also investigated and explored the role that the communication plays in the QoL of individuals with progressive neurodegenerative conditions.

QoL assessment continues to be an area of debate within the literature, therefore different measures are used, including a generic HRQoL measure Arabic Sickness Impact Profile (A-SIP); a patient-centred method known as Scheduled Evaluation for Individual QoL – Direct weighting (SEIQoL-DW); and a single item scale on the McGill Quality of Life (MQoL-SIS). These measures were then compared to communication measures, including intelligibility and functional communication in order to investigate the presence or absence of a relationship between QoL and communication, and to test whether the presence of a relationship depends on the type of measure used. The influence of the type of neurodegenerative disease and the severity of the dysarthria on this relationship was also investigated. There was an intentional focus on the severity of dysarthria within this study because where comparing QoL between different neurodegenerative conditions it is important to determine if the rate of progression and the characteristics of each disease have an impact on the components and changes in QoL. The work presented in this thesis aims to add to this specific area of research.

The fourth aim of the research was to investigate the relationship between patients' judgment of their QoL and communication function and their caregivers' judgment. To measure QoL patients and their caregivers were asked to complete the A-SIP, while for functional communication they were asked to complete the measurement tool developed in the first part of this thesis.

Finally, since QoL is a highly individualised and multi-factorial construct, investigating patient-specific themes through qualitative methodologies was another aim of this research. This was to determine what themes would be generated and were important in this client group, but the aim was also intended as a focus to observe the relationships, if present, the themes had to each other and their relationship to the severity of the dysarthria.

In summary, the overall aims and objectives of this research were to:

- Investigate the relationship between communication and QoL in Saudi Arabian individuals suffering from different forms of neurodegenerative condition;
- Explore and examine the role that communication plays in the QoL of individuals with neurodegenerative conditions;
- Determine and comprehend if there is an association between the severity of the communication impairment and the QoL of people;
- Compare the patients' judgement of health related QoL and functional communication and that of their caregivers; and
- Explore participant generated themes and domains related to their QoL as it relates to their communication.

1.6 **Research Questions**

This research was conducted mainly to reveal the relationship between communication changes and QoL of Saudi Arabian individuals suffering from different forms of neurodegenerative conditions. To achieve the research objectives of this study, the following research questions were asked:

- What is the relationship between communication and QoL in Saudi Arabian individuals suffering from different forms of neurodegenerative conditions?
- What is the role that communication plays in the QoL of individuals with neurodegenerative conditions?
- Is there an association between the severity of communication impairment and QoL?
- Is there a relationship between participants' own judgements of health related QoL and that of their caregivers?
- Is there a relationship between participants' own judgements of functional communication and that of their caregivers?
- What are the QoL and communication themes and domains that are important to individuals with neurodegenerative conditions?

1.7 Research Methodology

The methodology considered most suitable for this research was the mixed research methodology. According to the Tashakkori and Teddlie (2010), a mixed approach for research methodology refers to a holistic research process containing an array of techniques and commitments. For the present study the researcher used both quantitative and qualitative methods for data analysis. The aim of the mixed research methodology is to combine the overall quantitative and qualitative processes of the research in order to address the questions of the research study. For the first part, the development of intelligibility and functional communication measures, statistical analysis was used to investigate the correlation between intra-judge reliability and analysis of variance in order to analyse inter-judge reliability. Semi-structured interviews were used to generate themes related to everyday communication experiences. Qualitative content analysis using the framework described by Ritchie and Spencer (1994) was then used to analyse these interviews. Following the development of the functional communication scale (FCS), Chronbach's alpha coefficient of reliability was used on a pilot sample to investigate internal consistency. Qualitative analysis is an analytical tool used for the analysis of content. This analytical tool is defined as a method used for the subjective analysis of the research content and data through the systematic classification process of coding and identifying themes or patterns (Hsieh & Shannon, 2005). For the second part of the study, SPSS software was used to perform various statistical analyses to answer the research questions. The same qualitative methodology was used for the analysis of the semi-structured interviews to answer the questions. The aim of the mixed research methodology is to combine the qualitative and quantitative procedures of the research in order to address the research questions. Therefore, this research was designed mixing both quantitative and qualitative approaches of the research.

1.8 Contribution to Knowledge

Overall, the outcomes of this thesis will provide a fuller understanding of QoL and communication for people with progressive dysarthria in addition to the development of intelligibility and functional communication assessment tools in Arabic. Based on the analysis of the qualitative and quantitative data, this thesis offers the following new contributions:

- The development of an Arabic intelligibility assessment measure for Saudi Arabian adults with progressive dysarthria. Due to the lack of standardised instruments to measure intelligibility, clinicians are required to rely more on percentage estimates which has been found to provide less consistent results than standard orthographic transcriptions (Hustad, 2006). In addition, translated measures of functional communication may not be culturally or linguistically acceptable (Carter *et al.*, 2005). The Arabic assessment of intelligibility will offer a valid and reliable measure that can be used within clinical settings. It provides a reliable calculation of intelligibility that can be used to evaluate intelligibility before and after treatment or the rate of deterioration over time (Yorkston & Beukelman, 1981a). In addition, it can be used to estimate the severity of dysarthria in a valid and reliable manner (Hustad, 2006; Yorkston & Beukelman, 1981b).

- Development of a functional communication scale (FCS) rated by individuals themselves. This measure reflects an individual's communication experiences in everyday life. It allows the restrictions faced by an individual whilst communicating which renders them unable to perform an action in a manner that is considered normal to be assessed (Yorkston, *et al.*, 1996).
- The various relationships found between QoL and communication reflects the importance of including some form of QoL measure in clinical practice in order to determine how a patient is doing overall, and what effect the communication disorder has on their wellbeing. In addition, and from a research standpoint, some of the measures used for QoL are reported for the first time for an Arabic speaking population. These include the MQoL-SIS and SEIQoL-DW. These are discussed further in Chapter 7.
- The individual nature of the themes generated through the content analysis of interview transcripts highlights the fact that QoL measures may not cover all aspects of life that are equally important for all individual participants.
- Communication, when discussed as part of overall QoL, is usually indicated as communication participation, communication in social settings, and changes in interaction opportunities. This finding highlights the need to move from traditional assessments and therapy to include increasing the opportunities of participation and social interaction within an individuals' environment.

1.9 Structure of the thesis

This thesis is presented in seven chapters. Chapter 1 examines the research background, aims and objectives. It also highlights the key questions on which assumptions of the research can be made. The rationale of the research study and definition of different terms are also presented.

Chapter 2 contains a review of relevant literature in the areas of neurodegenerative disease, dysarthria, QoL, assessment of QoL and communication, and also explores cultural considerations when developing assessment tools. Research looking at QoL and communication disorders and QoL and neurodegenerative diseases is also discussed.

Chapter 3 describes the methodology followed for the two parts of the thesis; the development of the assessment tools and the investigations into QoL and communication in progressive dysarthria. It includes the ethical considerations, selection criteria and procedure, the research protocol, data analysis, validity and reliability considerations.

Chapter 4 details the development of the intelligibility and functional communication assessments. It describes the development of each assessment measure including selection of items on the measure, and data analysis for both qualitative and quantitative data.

Chapter 5 presents the statistical analysis used to investigate the relationship between QoL and communication. The impact that dysarthria severity or type of neurodegenerative disease may have on this relationship is also investigated. The correlation between the patient and caregivers perception of QoL and communication is also presented in this chapter. Finally, four randomly selected profiles of participants using the SEIQoL-DW are included at the end of this chapter.

Chapter 6 presents the qualitative data analysis using qualitative content analysis techniques, and transcription and analysis of the interviews is discussed within the chapter. This chapter addresses the qualitative questions of this thesis investigating the participants' perceptions of their QoL and the impact of changes in communication has on it.

Finally, Chapter 7 contains a discussion of the research presented and joins the two forms of data (quantitative and qualitative) to help understand and suggest answers for the overall questions and aims of the thesis. The chapter begins with a discussion of the research aims and the findings, and is followed by a discussion of the development of the assessment measures. The limitations of each part of the research are also discussed. Finally, the clinical implications of the findings from the study and possible future research areas are presented.

Chapter 2 - LITERATURE REVIEW

2.1 Introduction

This chapter will review the current research literature on neurodegenerative diseases and the communication disorders (dysarthria) associated with them. Dysarthria is a collective term for a group of related speech disorders that occur as a consequence of weakness, incoordination or paralysis of speech musculatures caused by damage to the central or peripheral nervous system (Kent, Kent, Duffy, & Weismer, 1998). This chapter will critically review the methodologies used to assess dysarthria, and evaluate the definitions and measurement of QoL, paying particular attention to where it relates to neurodegenerative diseases and communication disorders.

A number of arguments will be posited: first, QoL is a very complex and highly individualised concept that is not often clearly defined within research studies (Bishop & Allen, 2003; Bond, 1999); and second, communication is often ignored or defined as merely the clarity of speech output rather than the means of natural social interaction (Cruice *et al.*, 2000). In addition, an overview of test adaptation methodologies that allow the use of assessment measures for a different culture and language will also be reviewed since adaptation of measures constitutes a significant part of the research conducted. Finally, a brief overview of QoL, intelligibility and functional communication assessment measures is presented at the end of the chapter.

2.2 Neurodegenerative Diseases

Neurodegenerative disease is a medical term for a class of diseases that involve the progressive loss of structure or function of neurons, including neuron death. Neurodegenerative diseases may involve the central and/or peripheral nervous system, and they also affect both motor and sensory function. There are many neurodegenerative diseases including MS, PD and ALS/MND, and these three distinct conditions have different neuropathology, medical management and symptoms (Yorkston *et al.*, 2004). In some cases such as for ALS/MND, the disease rapidly progresses with a greatly shortened life expectancy of 3 to 5 years from diagnosis (Yorkston *et al.*, 2004). In other conditions such as MS, the disease course is highly variable with a remission-relapsing pattern, whilst in PD progression is slow. Some degree of cognitive impairment is seen in all three conditions; however, the degree of impairment varies from one disease to another (Aarsland, Andersen, & Larsen, 2003; Abrahams *et al.*, 1996; Rao, 1995;). Progressive dysarthria, which is a motor disorder characterised by progressive deterioration in the articulation and intelligibility of speech (Tomik & Guiloff, 2010), is a very common symptom that occurs within the above neurodegenerative conditions. Dysarthria can be a first symptom in some individuals or alternatively occur at later stages of the disease. This communication disorder never occurs in isolation and is always accompanied by other sensory and motor symptoms.

These three neurodegenerative diseases (ALS/MND, PD, MS) were selected for inclusion in this research for three reasons: first, all three involve progressive dysarthria; second, the speed of progression varies significantly among the three; and third, the severity of the dysarthria differs among the three. These reasons allow the relationship between QoL and communication in individuals who have very different presentations and severities of progressive dysarthria to be compared. In ALS/MND dysarthria occurs as the first symptom in 20% of patients (Chen & Garrett, 2005) but in later stages of the disease about 80% develop dysarthria and some reach a point where they are anarthric and rely on means other than verbal communication (Yorkston *et al.*, 2002). For PD 70% of patients reported that their voice and speech were worse than before disease onset (Hartelius & Svensson, 1994) and 51% of patients with MS reported changes in speech (Hartelius *et al.*, 2000).

In order to gain a better understanding of each neurodegenerative condition and the impact that each may have on a person's QoL, the individual features of each condition must be understood. Whilst reviewing the literature investigating all three neurodegenerative diseases and progressive dysarthria, no research could be identified that looked at progressive dysarthria in these conditions in an Arabic speaking population. It is known that communication reflects complex features of social roles, relationships, and personal attitudes (Simmons-Mackie & Damico, 2003), and these factors are influenced by cultural backgrounds. Therefore examining and investigating the effects of progressive dysarthria on communication is important, as communication is culture-specific (Carter *et al.*, 2005; Laing & Kamhi, 2003). It is important for there to be research within specific cultures for there to be resource for evidence-based practice within different cultures, rather than simply translating research published for different cultures or languages. The reason for the focus on a Saudi population is because Saudi practitioners have voiced the need for more assessments and new and innovative practice within the field of progressive dysarthria, and this gap is reflected in the current research literature.

2.2.1 Parkinson's Disease

Parkinson's Disease (PD) is one of the most common neurodegenerative diseases (Raggi *et al.,* 2010). It is a slowly-progressing disease of the central nervous system

(CNS), specifically of the basal ganglia, due to a deficiency in dopamine. It usually results in severe disability, especially in the later stages of the disease. The classic neurological symptoms associated with PD are tremor, bradykinesia, and rigidity (Yorkston *et al.*, 2004). Yorkston *et al.* (2004) reviewed PD and reported that there are several aetiological groups within PD, of which idiopathic PD, where the origin of the disease is unknown, is by far the most frequent. A second group is the acquired group, in which the symptoms of PD become apparent due to exposure to certain drugs or toxins, or the occurrence of vascular lesions resulting from trauma to the head as seen in boxers. Finally, there is a third group termed Parkinson's Plus Syndromes.

These patients are usually misdiagnosed early on in the disease process as having idiopathic PD, since the initial symptoms are similar to those seen in idiopathic Parkinsonism. However, patients do not respond to levodopa therapy and develop additional signs and symptoms as the disease progresses that are not typically seen in idiopathic PD. When the symptoms do not respond to levodopa then patients have a worse prognosis in comparison to idiopathic PD. These include multiple system atrophy and progressive supranuclear palsy (Tanner & Aston, 2000). Idiopathic PD occurs in 1% of the population above the age of 50 (Nutt & Wooten, 2005), with the incidence increasing with advancing age. Research suggests that the incidence rate is similar in different countries (Duvoisin, 1991), and that both men and women are equally affected. For the purposes of this research, only participants with idiopathic PD were included since they have a more predictable disease course.

At present there is no cure for PD, despite the variety of pharmacological and surgical treatment options available. Medications used for the management of PD are designed to re-establish the balance between neurotransmitters (including dopamine) within the nervous system (Nutt & Wooten, 2005). Surgical intervention may be used for selected individuals with PD for whom drug therapy does not help. Such surgical procedures include deep brain stimulation (DBS) of the thalamus or subthalamic nuclei (Nutt & Wooten, 2005). Rehabilitation programme goals include the enhancement and maintenance of the level of function of individuals with PD, and the rehabilitation team has a role at all levels of the disease progression.

Symptoms associated with PD include tremor, gait disorders, rigidity, painful dystonia, akinesia, bradykinesia, postural abnormalities and sleep disturbances (Raggi *et al.*, 2010). In addition to the motor symptoms, many individuals with PD experience other difficulties, the most common being depression, cognitive changes and subtle changes in the use of language. Poewe (2007) reported a 30 to 40% prevalence of depression in PD patients, which is characterised by pessimism and hopelessness, decreased motivation and drive, and increased concern regarding their health (Reijnders, Ehrt, Weber, Aarsland, & Leentjens, 2008). The specific origin of depression in PD is unclear, but it can be controlled via a variety of antidepressant drugs. Cognitive dementia is also six times higher in individuals with PD than in the non-impaired population (Aarsland *et al.*, 2003). The most frequently reported cognitive disturbance in PD is a visuospatial deficit (Levin, Tomer, & Rey, 1992) although other forms of dementia are also associated, including mild to moderate executive function deficits (Dubois, Slachevsky, Litvan, & Pillon, 2000). Dementia is also found to correlate with the severity of PD (Ebmeier *et al.*, 1991).

Dysarthria is common in PD although speech changes associated with PD are usually not amongst the first symptoms observed. In a study by Hartelius and Svensson (1994) 70% of patients with PD reported that their voice and speech were worse than before disease onset. Dysarthria in PD is distinct from other types of dysarthria and is known as hypokinetic dysarthria. Specific features include monopitch, monoloudness, loudness decay, increased segment rate, increased overall rate, reduced stresses, inappropriate silences, short rushes of speech, and repeated phonemes (Duffy, 2005). Symptoms range from a mild voice weakness early on in the disease process, to total inability to initiate speech movements, which can occur during the later stages of the disease. Patients with PD have reported a decrease in effectiveness of communication that was not related to the severity of dysarthria or level of intelligibility (Donovan, Kendall, Young, & Rosenbek, 2008). These changes affect the naturalness of speech output and have been found to have a psychosocial impact on the individual and their family (Miller *et al.*, 2006; Miller, Noble, Jones, Allcock, & Burn, 2008), as well as an impact on employment, leisure, social and family dynamics, and hence QoL.

2.2.2 Multiple Sclerosis

MS is an inflammatory demyelinating disease of the CNS. It is characterised by scattered plaques in the CNS that produce different combinations of motor, sensory, and/or cognitive impairments (Yorkston *et al.*, 2004). It is most commonly seen in young and middle-aged adults. The course of the disease is progressive; however, the early stages of the disease are characterised by a remitting-relapsing course. Anderson *et al.*, (1992) reported that MS is the third most common cause of disability in the United States following trauma and arthritis, and is 2 to 3 times more common in women than in men. There are currently three theories regarding the cause of the neurological changes that result in MS: autoimmunity, viral infection and genetic predisposition (Boyden, 2000), and most researchers believe that the cause of MS lies in a complex interaction between these three theoretical bases (Yorkston *et al.*, 2004).

The symptoms associated with MS vary extensively depending on size, age, activity, and the location of the lesions. Commonly seen motor symptoms in MS include spasticity, weakness, spasm, ataxia and tremor, while commonly seen sensory changes include decreased touch, pain and position sense. Symptoms include tingling, shooting pain, visual changes, numbness, burning and impairments. It is estimated that half the population with MS will have cognitive changes (Rao, 1995). These changes target specific cognitive processes and these deficits are called ‘subcortical dementia’ (Rao, 1986). This dementia is characterised by failures in memory retrieval with intact encoding and storage capacity, absence of aphasia, impaired conceptual reasoning with near-normal intellect, slow information processing and changes in personality characterised by depression and apathy (Ehrensperger *et al.*, 2008; Jose Sá, 2008). Cognitive changes have been found to affect language skills (Yorkston, Klasner, & Swanson, 2001) including word-finding difficulties in verbal and written organisation. Fatigue and irritability are also commonly seen in MS (Ehrensperger *et al.*, 2008; Jose Sá, 2008).

Treatment of symptoms such as spasticity or fatigue is part of the standard care, and in addition, some disease-modifying drugs may be used to reduce the frequency and severity of the attacks (Noseworthy, 2003). Despite the fact that the course of the disease and the frequency of attacks can be altered, rehabilitation still plays an important role in the management of MS. Although dysarthria is not universal in MS, it is still an important feature in a substantial number of patients. Hartalius *et al.* (2000) reported changes in speech function in approximately 51% of patients with MS. These occurred in all components of speech production including respiration, phonation, prosody, articulation and nasality. The type of dysarthria most commonly associated with MS is a mixed type of dysarthria with spastic and ataxic components (Duffy, 2005).

2.2.3 Amyotrophic Lateral Sclerosis/Motor Neuron Disease

ALS/MND is a rapidly progressing neurodegenerative disease of the neurons of the cerebral cortex, brain stem and spinal cord with an unknown aetiology (Traynor, 2003). Clinically it is characterised by the relentless loss of function of both upper and lower motor neurons. The term ALS is often used synonymously with MND even though it is only one of a group of conditions. Symptoms include progressive muscular atrophy, primary lateral sclerosis and progressive bulbar palsy. ALS is a devastating illness for the patient, caregiver and relatives. The average incidence worldwide is 1 to 2 individuals *per* 100,000, and men have been found to be more often affected than women, with a ratio of 1.5:1 (Ferguson & Elman, 2007).

There are two main types of ALS; sporadic and familial. They differ and vary mostly in age of onset, rate of progression and survival duration. Familial ALS is a hereditary condition and represents about 10% of all ALS cases with onset occurring during the early 20s (Louvel, Hugon, & Doble, 1997). The progression of the disease is slow and patients survive for about 10 years. In contrast, onset of sporadic ALS occurs between the ages of 50 and 70 (Eisen & Krieger, 1998). This disease follows a ruthless course and early onset of bulbar symptoms indicates a poor prognosis. Overall, life expectancy is about 3 to 7 years from time of diagnosis (Ferguson, Robinson, & Splaine, 2002; Mitchell & Borasio, 2007). The rate of progression can vary considerably between patients but is usually linear within a patient; that is to say, the weakness progresses at the same rate for an individual over time (Yorkston *et al.,* 2004). There are also reported correlations between the deterioration of arm and leg strength (Pradas *et al.*, 1993) and between speech and swallowing functions (Yorkston, Strand, Miller, Hillel, & Smith, 1993).

Early signs and symptoms of ALS/MND may vary between patients and are divided into bulbar features and spinal features depending on the site of the lesion. As the disease progresses, motor fibres of both the central and peripheral nervous systems are involved. Bulbar features are those that involve speech and swallowing functions, while the spinal features include upper and lower limb extremities. Respiratory function is significantly affected in ALS/MND and is thought to be a function of both bulbar and spinal involvement, and this is the most common cause of death in these patients (Shoesmith, Findlater, Rowe, & Strong, 2007). Weakness usually starts unilaterally in a single segment (bulbar, cervical, thoracic, or lumbosacral). Initially the symptoms worsen in the affected segment and then, over time, the weakness will spread to other regions of the body. A third of patients may present with bulbar symptoms (dysphagia and dysarthria) at disease onset (Mitsumoto & Norris, 1994). Complaints associated with respiratory involvement include shortness of breath, orthopnea, and morning headaches. Other complaints include cramps, weakness, slow movement, increased tone, muscle atrophy and wasting, fasciculation and emotional lability.

Although ALS/MND was thought to be purely a disorder affecting motor skills, research in the last decade has demonstrated cognitive changes similar to those seen in frontotemporal lobe dementia (Abrahams *et al.*, 1996; Abrahams, Leigh, & Goldstein, 2005; Bak, 2004; Hudson, 1981; Raaphorst, de Visser, Linssen, de Haan, & Schmand, 2010). Mild cognitive impairment has been observed in patients with ALS and can involve executive function, verbal skills, memory and new learning. Researchers have estimated that approximately 25 to 35% of patients will present with mild cognitive impairments associated with frontal lobe syndrome (Abrahams *et al.*, 1996; Kiernan &

Hudson, 1994), and some have associated the changes in cognitive function with a decrease in vital capacity (Kim *et al.*, 2007). There is also clear evidence in the research literature that language dysfunction is a pronounced and well-documented symptom of ALS/MND (Abrahams *et al,* 1995; Bak & Hodges, 2001; Raaphorst *et al.*, 2010; Wilkinson, Yorkston, Strand, & Rogers, 2004). In addition to the cognitive and language changes seen in ALS/MND patients, depression is also commonly reported (Kubler, *et al.*, 2005; McLeod and Clarke, 2007; Olney and Lomen-Hoerth, 2005; Wicks *et al.*, 2007).

As previously noted, progressive dysarthria is a frequent consequence of ALS. It is related to the damage of motor neurons in the brain and spinal cord. Dysarthria occurs in about 80% of ALS/MND patients and is described as mixed flaccid or spastic dysarthria depending on the site of the lesion (Darley, Aronson, & Brown, 1969b; Kent *et al.*, 1990; Tomik & Guiloff, 2010). Dysarthria may sometimes be the first sign of the disease, particularly with bulbar onset. When dysarthria and dysphagia are the primary symptoms of ALS, they tend to remain the most functionally limiting features as the disease progresses (Yorkston *et al.*, 1993). This communication impairment continues to deteriorate and reaches a level whereby the person cannot rely on speech as their primary mode of communication, at which stage they start to use various augmentative and assistive communication (AAC) devices to assist with communication (Beukelman, Fager, Ball, & Dietz, 2007; Brownlee & Palovcak, 2007). The changes and loss of communication may lead to social isolation and therefore impact on their QoL (Bach, 1993; Mitsumoto & Bene, 2000).

To date there is no known cure for ALS/MND, and medical management is mainly symptomatic within a multidisciplinary setting (Traynor, 2003). The management team usually consists of a speech language pathologist, physical therapist, nurse, neurologist, and occupational therapist. The goal of therapy focuses on maintaining the participation of the person in everyday activities for as long as possible and in eliminating fatigue. The management team must also prepare the patient and their families to anticipate critical periods in the disease process.

2.2.4 Summary

The neurodegenerative diseases impact on various aspects of a person’s functioning and QoL, including physical, psychological, and social elements. Being diagnosed with such a condition can be devastating for the patient and their families. As the disease progresses and there is continued loss of function, this will have an effect on the QoL of the patients and their care providers. In progressive conditions where there is no cure, the aim of therapy is to maintain a person’s independent function for as long as possible and to provide any assistive devices when required, as well as counselling the patient and family on what can be expected during critical periods of the disease process. In order to develop these rehabilitation goals and to ensure a more successful outcome concerning communication, the impact of impaired communication on a patient's overall QoL must be understood. As specific areas are targeted and goals more relevant to the patient are developed, there is more likely to be patient and family compliance, and satisfaction with the disease management. It is therefore essential to understand what constitutes wellbeing and life satisfaction for individuals with neurodegenerative conditions. Current research in the area of communication and QoL in neurodegenerative diseases is very limited, as will be demonstrated later in this chapter, and is essentially non-existent for the Arabic speaking population.

2.3 Communication Disorders associated with Neurodegenerative Disease

2.3.1 Introduction

Communication is an integral part of being human; it allows social interaction and is essential for full participation in society. It is the means by which we interact with our environment and socialise with others. The importance of communication is reflected in the suggestion that in the 21st century, a person's fitness for survival will be defined in terms of their ability to communicate effectively (Ruben, 2000). To be an effective communicator, one must possess the ability to express needs, develop social closeness, exchange information, be able to express that information shared by social interaction has been received, and fulfil social etiquette and routines (Light, 1988). Communication competence is defined by Light (1989) as "…the quality or state of being functionally adequate in daily communication, or of having sufficient knowledge, judgment and skill to communicate". It is not until a person is faced with an illness or trauma that affects their communication that they realise how important and complex communication is. Importantly, communication has also been found to be critical for the receipt of adequate health care (Hoffman *et al.*, 2005).

Progressive dysarthria is a common feature of neurodegenerative diseases. It should be noted that the dysarthria does not occur on its own but frequently exists in the presence of other debilitating neurological disabilities. These disabilities are not stable and continue to deteriorate as the disease progresses, although the extent and rate of deterioration differs between conditions and individuals. This means that the patient with the disabilities is always forced to adapt to increasingly worsening circumstances.

The possibility of not being able to communicate is one of the most distressing aspects of a neurodegenerative condition (Yorkston, 2007), and therefore it would be expected to be reflected in a person's functional and emotional QoL or wellbeing. Miller *et al.* (2008) reported on the perception of an individual with PD as a communicator. They found that changes in speech and language were often associated with negative changes in perception of oneself as a communicator, although they found no significant relationship between self-perception changes over time and the changes seen in other clinical assessments.

It was not until the impairment occurred that a person realised the importance that communication played in their life by allowing them to interact with society. Speech and language changes have been found to have an impact on the individual and on family life and how the individual is perceived and communicated to by others, and this can take place long before apparent changes occur in a person's speech (Miller *et al.*, 2006). Therefore, the traditional assessments of intelligibility and functional communication alone may not be sufficient to obtain a clear picture of the actual experiences that an individual may be experiencing.

2.3.2 Dysarthria Assessment

The communication impairment that is associated with neurodegenerative diseases is known as a motor speech disorder or dysarthria. Dysarthria is present in 19 to 100% of individuals with neurodegenerative diseases (Darley, Brown, & Goldstein, 1972; Darley, Aronson, & Brown, 1975b; Darley & Spriesterbach, 1978; Logemann & Fisher, 1981). The definition of dysarthria was established by the early work of Darley *et al.* (1969a; 1969b) and has been universally accepted by speech language pathologists. It is defined as

> … a collective name for a group of speech disorders resulting from the disturbances of the muscular control over the speech mechanism due to damage of the central or peripheral nervous system. It designates problems in oral communication due to paralysis, weakness, or in-coordination of the speech mechanism.
>
> (Darley *et al.*, 1969b, p. PP. 246).

This definition implies that the disorder is neurological in origin and is related to damage present in the central and peripheral nervous systems. It affects the accuracy of the speech mechanism movement, and it is further divided into different types depending on auditory and perceptual characteristics of the speech output. Dysarthria is mainly related to weakness, paralysis and incoordination of the speech musculature (Darley *et al.*, 1969b), resulting in slow, weak or poorly-coordinated production of speech sounds, which in turn influences consonant/vowel production, volume, resonance, voice quality, and prosody (Duffy, 2005). This is reflected in problems with articulation, phonation, resonance, respiration and/or prosodic control of speech. Not all types of dysarthria are progressive, with those following a stroke or head injury improving or remaining static. However, the type of dysarthria that this research is considering which is due to neurodegenerative conditions, usually progressively worsens over the course of the disease. The rate of progression and the features of the dysarthria vary depending on the type of disease. Darley *et al.*'s definition of dysarthria mainly focuses on structural and functional changes that are associated with the motor speech disorder known as dysarthria.

The WHO ICF (2001) framework is used by many researchers to investigate dysarthria. The purpose of this model is to provide clinicians with a common language with which to describe human functioning and disability, as well as a framework for gathering data and measuring clinical outcomes. This model is also useful for speech-language pathologists as it allows them to describe the consequences of communication impairment at different levels, and includes the social consequences (Ma *et al.*, 2008; McCormack and Worrall, 2008; Worrall and Hickson, 2008) The ICF defines a person's function and disability in relation to their health conditions and contextual factors (personal and environmental).

It consists of three levels: (a) “Body Structures and Functions”, which consists of the physiological functions of the anatomical and body elements, and also includes the assessment of the speech structures motor and sensory functions; (b) “Activities”, which are the execution of specific actions and may include intelligibility and communication function measures; and (c) “Participation”, which encompasses involvement in life situations and finally the related factors which include environmental and personal factors that can act as a barrier or facilitator (WHO, 2001). According to this model, the communication between contextual factors and health conditions affect the disability and functioning of a person.

It is a well-established fact that difficulties in body functioning and structures are the most studied outcome in communication disorders (Eadie, 2001; Threats, 2000). According to Dickson (2008), who employed the WHO ICF framework to dysarthria, the research literature reflects that activity and participation elements of the disorder have received limited attention whilst the majority of the research has focused on the pathology (disease and diagnosis) and the associated impairments (signs and symptoms). Whilst this focus of research is imperative in better understanding the progression of dysarthria, this focus does not allow for patient experience, satisfaction and support in managing or better understanding the progression of symptoms; i.e. their quality of life. Current research focus on dysarthria has led to a better understanding of disease progression by categorising anatomic and physiologic deficits of function and structure, with a particular emphasis being placed on physiologic examination of the speech subsystems, including respiration, phonation, velopharyngeal function, and oral articulation. An example of an assessment at the body function and structure level is the assessment of velopharyngeal function, which can lead to hypernasality in the speech signal. Based on the auditory and perceptual classification first proposed by Darley *et al.* (Darley *et al.*, 1969a; Darley *et al.*, 1969b; Darley *et al.*, 1975b), dysarthria is classified into six types; flaccid, spastic, ataxic, hyperkinetic, hypokinetic and mixed. This classification is based on a number of salient features associated with lesions in the nervous system.

Traditionally dysarthria assessment includes different forms of assessment including perceptual assessment which was described by Darley, Arenson and Brown (1969a & 1969b) who described 38 speech dimensions on seven point scales to help describe the speech characteristics of speakers and categorise them into the 6 different dysarthria types. The dimensions that they described are closely related to one aspect of speech production. For example imprecise consonants, irregular articulation breakdown, and distorted vowels are related to articulation. Others are more general like intelligibility, bizarreness, and reduced stress. Another method for the assessment of dysarthria is component assessment described by Rosenbeck and LaPointe (1985). They suggested a point to place procedure that draws heavily on the speech physiology system as well as some traditional perceptual based assessments. By using this system, speech is systematically assessed by evaluating and determining the type and location of the breakdown along the vocal track. Finally we come to overall assessment such as the assessment of intelligibility. Sarno (1968) suggested the use of a functional intelligibility rating to show how well the speaker can make himself understood.

One thing to note is that the assessment of overall performance on its own is not sufficient, as it does not provide a complete evaluation. Therefore overall assessment requires some form of perceptual information to differentiate dysarthrias as well as information on specific components of the speech mechanism that needs remediation. Researchers have also investigated acoustic and phonetic factors that are responsible for the variation in intelligibility scores, by identifying patterns to determine the acoustic features that have an influence on the persons' intelligibility (Ansel & Kent, 1992; Kent, Weismer, Kent, & Rosenbek, 1989; Weismer, Kent, Hodge, & Martin, 1988). In addition to the above methodologies researchers and clinicians alike have been interested in communication assessment as it occurs in real life to determine if the individual can make themselves understood as well as the personal and environmental factors that influence communication (Frattali & ASHA, 1995; Holland, Porter, & Howard, 1999; Lomas *et al.*, 1989).

2.3.3 Intelligibility

The assessment of speech intelligibility is an important construct in the assessment of individuals with dysarthria. Reduction in intelligibility is a feature that is common to all types of dysarthria regardless of the underlying aetiology (Hustad, 2006). Speech intelligibility has been broadly defined as the accuracy with which an acoustic signal is converted by the speaker and recovered by the listener (Yorkston and Beukelman, 1980; Yorkston *et al.*, 1996). Management of dysarthria is usually focused on improvement in intelligibility to improve signal transfer (Hustad, 2006). Netsell and Rosenbek (1985) emphasised the importance of compensatory strategies to improve intelligibility as a primary goal of dysarthria management. Even though a reduction in intelligibility results from the complex interaction of changes in the physiology (body function) and anatomy (body structure) of speech musculatures (Dykstra, Hakel, & Adams, 2007), it is mostly associated with the “activity” level of the WHO ICF (2001) model. Measures of intelligibility provide useful information that can be clinically implemented, such as an index of severity (Hustad, Beukelman, & Yorkston, 1998; Yorkston, Beukelman, Strand, & Bell, 1999), and a means of documenting and monitoring changes in speech function over time. It is important to understand that intelligibility depends on a number of factors including the speaker characteristics, the listener, the message (word, sentence, paragraph), familiarity to the message and the environment in which this exchange is taking place. These factors are also important to consider in research and clinical practice. In addition not one single message format can be used across all dysarthria types to estimate the severity of the dysarthria (Yorkston & Beukelman, 1978). Participants with mild dysarthria tend to get slightly lower scores on word intelligibility than on sentence intelligibility and this may be related to the contextual information that a sentence adds (Beukelman & Yorkston, 1979; Duffy & Giolas, 1974). In addition sentences that are more predictable tend to have higher scores than less predictable sentences (Garcia & Cannito, 1996; Garcia & Dagenais, 1998).

Assessment of intelligibility usually takes place in a quiet listening environment; in order to control for the environmental influences, and requires transcription by an unfamiliar listener of an audio-recorded sample of words, sentences and passages read by the dysarthric speaker. This type of evaluation gives information on the exactness of the signal of speech in segregation from the context. Various numbers of standardised tools are used to assess the speech intelligibility of adults with dysarthria. One of these tools is the Assessment of Intelligibility of Dysarthric Speech (Yorkston & Beukelman, 1981a). The focus of this assessment is the quality of the speech signal, and how clearly the listener can understand it.

Intelligibility tests may be scored in an open or a closed format. In an open format, the judge transcribes the word they believe the speaker said, whilst in a closed format, the judge selects the item they think they heard from a fixed list containing the target and some critical lures. However, only two studies have compared open and closed scoring formats (Yorkston & Beukelman 1978, 1980). Yorkston & Beukelman (1978, 1980) found scores derived from the open format were significantly lower than scores from the closed format, a relationship found in other research (Black & Haagen, 1963; Kent *et al.*, 1989; Yorkston & Beukelman, 1981). However, despite differences in intelligibility scores, both versions ranked dysarthric speakers similarly, and each is recommended as equally reliable and applicable methods of evaluation (Black & Haagen, 1963; Kent *et al.* 1989).

In the assessment of intelligibility, there may be an underestimation of a speaker's actual functional communication ability since the assessment extracts the speech signal from the communication context, event and purpose, which are all elements that are usually present during a typical conversation. Therefore, intelligibility measures are not necessarily predictive of real-world communication circumstances where listeners have contact with related information in addition to signals of speech during a conversation. Adding contextual information (namely syntactic context, providing the first letter of a word, gestures, or semantic context) increases the comprehension of the intended message and is referred to as comprehensibility. This reflects the adequacy of the speech performance in a social context (Yorkston, Strand, & Kennedy, 1996) and can include any additional information available to the listener to supplement the acoustic signal, including semantic and syntactic cues, gestures, facial expressions and alphabet cues. Barefoot *et al.* (1993) defined comprehensibility as "the extent to which a listener understands utterances produced by a speaker in a communication context" (p. 32). Comprehensibility facilitates the measurement of intelligibility in a natural communicative context and may therefore provide a closer estimate of functional communication (Dykstra *et al.*, 2007).

2.3.4 Functional Communication

Within acquired dysarthria research the focus has been on assessment tools of impairment rather than on comprehensive tools that reflect the impact of the disease on a person's everyday life and social function. Functional communication is the means by which the ability to communicate in everyday life situations is assessed. This is usually done by the clinician through observation in a natural environment, by the caregiver, or by the patient themselves. (ASHA, 1990; Frattali, 1995; Holland *et al.*, 1999; Hustad *et al.*, 1998; Worral, McCooey, Davidson, Larkins, & Hickson, 2002)

The American Speech Language and Hearing Association (ASHA) defines functional communication as "… the ability to receive or convey a message, regardless of the model, to communicate effectively and independently in [natural] environment" (ASHA, 1990). The functional assessment of communication is defined as:

> the extent of ability to communicate with others in a variety of contexts, considering environmental modifications, adaptive equipment, time required to communicate, and listener familiarity with the client. Special accommodations of the communication partner to either receive or enhance the reception must be considered.
>
> (ASHA, 1990)

Simmons-Mackie and Daminco (1995) challenged the ASHA definition of functional communication, as they argued that functional communication includes more than simply receiving and conveying messages. Their ethnographic studies found that a high degree of interactional communication serves to establish and maintain relationships, in addition to transactional communication, which is used to exchange information. The assessment of functional communication enables the identification of restrictions on an individual whilst communicating, which makes them incapable of carrying out an act in a way that is considered normal (Yorkston *et al.,* 1996).

Reverting back to the WHO ICF (2001) model, functional communication is firmly based in the activity/participation category. This means that functional approaches could target the activity level through activities such as telephone conversations and shopping, as well as targeting the participation level through for example, improving the accessibility of public transportation for people with a communication problem (Ma, Threats, & Worrall, 2008; McCormack & Worrall, 2008; Worrall & Hickson, 2008). Functional communication assessment tools generally consist of a list of items that are scored based on effectiveness or efficiency of communication, and the items represent everyday communication acts. They are usually derived from the expert opinions of speech language pathologists working with a particular population, or through interviewing people with a specific communication disorder or their family members.

Use of generic functional communication assessment tools has raised further questions regarding the role of functional communication assessments. Are the lists of everyday communication activities found in these measures representative for all people with communication disorders in all situations? Does everyday communication vary between individuals, genders, disorders, cultures and environments? Do the test items represent the real communication activities of the patient?

Another method of gathering data on functional communication of people with communication impairments is through direct observation of their everyday communication activities. This is usually performed through qualitative research methods; however, the results obtained cannot be generalised to a larger population (Yorkston *et al.*, 2001). Worrall *et al.*, (1998) investigated the everyday communication activities of individuals with aphasia and found that the concept of everyday communicative activity was multidimensional, dependent on a number of interacting factors that may include communicative function, partner, setting, duration, topic and modality, similar to the variety of interacting factors that are known to affect quality of life (Cahill & Diaz-Ponce., 2011). Similarly, Murphy (2004) carried out qualitative research with ALS/MND patients and reported that even though communication continued to deteriorate, patients were able to communicate in a way that was focused on topics by using various strategies. Murphy (2004) determined that the main purpose of communication was developing and maintaining social closeness.

2.3.5 Participation

Participation refers to the nature and extent of an individual's participation in society, and the response of others can either hinder or facilitate this participation. In the context of communication, participation was defined by Eadie *et al.* (2006) as:

> "...taking part in life situations where knowledge, information, ideas, or feelings are exchanged. It may take the form of speaking, listening, reading, writing, or nonverbal communication. It may occur in multiple life situations or domains and includes, but not limited to, personal care, household management, leisure, learning, employment and community life."

Participation is multidimensional, involving comfort, success of the outcome, and the personal meaning of participation (Yorkston *et al.*, 2008b) and is linked to the personal, physical and social environment that can either facilitate or hinder a person's participation in life situations involving communication.

In spinal cord injury research, and research in the area of head and neck cancer patients, participation was found to correlate with measures of QoL and wellbeing

(Eadie, 2007). In aphasia research, an overlap between participation and QoL has also been demonstrated (Hirsch & Holland, 2000) and researchers often use participation methodologies to assess QoL. It is not known whether this correlation is because participation determines the person's QoL or because the measurement instruments are assessing the same variable (Cruice, 2008).

This holistic view of rehabilitation has been recognised for some time, and a number of self-assessment questionnaires have been developed in an attempt to capture an individual's own perspective on communication function and limitations. The majority of research in this area has been on patients with aphasia. Some tools have though been developed for dysarthria, including the ASHA Functional Assessment of Communication Skills for Adults (Frattali & ASHA, 1995); the ASHA Quality of Communication Life Scale (Paul *et al.*, 2004); the Communication Effectiveness index (Ball, Beukelman, & Pattee, 2004; Hartelius, Elmberg, Holm, Lovberg, & Nikolaidis, 2008); and the Communication Profile for Speakers with Dysarthria (Yorkston, Bombardier, & Hammen, 1994). An important finding in the self-assessment of people with dysarthria is that the perceived communication difficulty was not always related to the severity of the dysarthria or to communication impairment, age, gender, diagnosis, disease duration or employment status. It was generally related to restrictions in communicative participation in daily life (Yorkston *et al.*, 2007).

Development of an acceptable tool to assess communication participation is an on going process. Eadie *et al.* (2006) reviewed a number of self-reported assessment tools to identify if any of these tools assess participation as defined by the WHO ICF (2001) model. It was noted that currently there were no tools available in the field of communication disorders that were solely dedicated to measuring communicative participation. Eadie *et al.* (2006) proposed self-reporting to measure communication disorders in speech-language pathology. Yorkston *et al.*, (2008a) explored three specific dimensions of participation (frequency, importance, and self-efficacy) in people with MS, and found that participation yielded different responses depending on the participant's life situations and was independent from other measures of mobility, health, depression, fatigue and pain. The authors also cautioned when interpreting measures of participation, since it is a multidimensional, complex construct.

There is a danger in focusing on individual components of the WHO ICF model (Worrall & Hickson, 2008) since this will ignore the effect that communication impairment can have on all other aspects of life. In an attempt to look at other aspects of life that can be affected by communication impairments, Walshe *et al.* (2009) developed the Dysarthria Impact Profile (DIP). This aims to assess the psychological impact of dysarthria that can directly affect participation, as has been documented in previous research (Dickson *et al.*, 2008; Yorkston *et al.*, 2001). Threats (2006) suggested that having an accurate measure of communicative participation would allow the study of the relationship between communication and the important issue of QoL. Therefore, in order to accurately assess and treat communication disorders associated with neurodegenerative diseases, Threats (2006) determined that it was necessary to measure communication at the level of impairment, function and participation as well as the individual's perspective of the impact that this disorder has on other aspects of their life such as QoL.

Since communication is a key component in many life activities, it is logical to assume that communication is an important factor in participation across many life domains, including personal, professional, educational and leisure activities (Yorkston *et al.*, 2007). Acquired dysarthria has been found to have a negative effect on the speaker's life, with people reporting that they feel they are treated differently by others and that communication experiences have changed, they associate negative emotions with the presence of dysarthria, and note the presence of barriers in communication (Walshe & Miller, 2011). All of these factors therefore make it reasonable to assume that changes in communication will have an impact on a neurodegenerative patient's perceived QoL. Unfortunately, most treatment and assessment studies on progressive dysarthria focus on changes in speech characteristics, with far fewer studies examining the broader consequences of dysarthria. Consequently, the focus is remains on the medical model rather than the more recent holistic biopsychosocial model, which examines the biological, psychological and social causes, consequences, and treatment of illness or disease. The purpose of human communication can be to communicate needs and wants, to transfer information, to enable social closeness, and to meet the requirements of social etiquette (Light, 1997). Many of the assessment tools in current use for assessment of QoL, whether generic or disease-specific, do not include communication as a factor (Cruice *et al.*, 2000). Those that do include communication view it as a set of skills which include speaking, listening, reading and writing (Paul *et al.*, 2004). Failing to recognise the complexities involved in the act of communication leaves a critical gap in our understanding of the important role that communication plays in our life satisfaction and wellbeing. It is known that a reduction in communication participation has a negative effect on a person's QoL (Yorkston, 1996), and this can be related to the psychological, social, and emotional impacts associated with dysarthria. However, research in this area is very limited and is non-existent for the Arabic speaking population.

2.3.6 Phonology and Morphology of Arabic

Arabic Belongs to the Afro-Asiatic group of languages formerly known as Hamito-Semitic (Newman, 2002) Arabic is the sixth most widely spoken language in the world today, with approximately 186 million native speakers over a wide geographic area from North Africa to the Middle East. It is the official language of seventeen countries; including Oman, Qatar, Libya, Sudan, Algeria, Saudi Arabia, Tunisia, Egypt, Yemen, Jordan, Morocco, the United Arab Emirates, Lebanon, Kuwait, Bahrain, Syria, and Iraq.

One feature of Arabic is the gap between the written and spoken forms of the language. In the case of Arabic, the difference between the two are such that the person has to formally learn the classical form in order to gain access to newspapers, most radio and television broadcasts, as well as literary works (Newman, 2002). The first language of Arabic children would be their regional variety of Arabic, while modern standard Arabic is learnt in school as part of the child's education. In some regions of the Arab world regional varieties of Arabic differ significantly for standard Arabic in terms of phonology, morphology, syntax and lexicon. The dialects that have exhibited the most innovation are the urban dialects spoken outside the Arabian Peninsula. Dialects within the Peninsula tend to retain most features of classical and standard Arabic phoneme inventory (Watson, 2007).

As far back as the Middle Ages, Arabic philologists staring back with the Persian-born Sibawayh (8th century) highlighted the uniqueness of Arabic in the use of pharyngeal sounds. Arabic is known as the language of *dAAd* – the name of the letter representing the voiced pharyngealised dento-alveolar plosive.

Modern Standard Arabic contains 28 phonologically distinct consonant segments, whose manner and places of articulation are represented in Table 2.1, in addition to 6 vowels shown in Table 2.2. This shows that Arabic like other Semitic languages is marked by a rich consonant system and a limited vocalic system (Watson, 2007).

One distinguishing feature of Arabic is the root and pattern methodology. The root is a sematic abstraction consisting of two, three or (less commonly) four consonants from which words are derived through the superimposition of templatic pattern (Holes, 2004). For enample the root /katab/ has a lexical sense and meaning of 'writing' from which the words or 'book' /kita:b/ is derived, written' /maktu:b/, 'writer' /ka:tib/ and 'office' /maktab/ are derived. Similarly for verb adding prefix and changing the stem vowels of the root changes the verb form. For example /daras/ meaning to learn, perfect active verb form /daras/, perfect passive verb form /duris/, imperfect active form uses prefix /ʔu/, / ju/, /tu/, and /nu/ + /daris/ to mean 'I teach', 'he teach', 'you teach', and ‘we teach’. The Arabic phonology and morphology is distinct from that of English and therefore we cannot simply translate between the languages and have to take the steps to develop and linguistically appropriate measure.

Table 2-1 - The Arabic consonant inventory

	Bilabial	Labio-dental	Dental	Dento-alveolar	Post-alveolar	Palatal	Velar	Labial - velar	Uvular	Pharyngeal	Glottal
Plosive	b		t d				k		q		ʔ
Nasal	m			n							
Trill				r							
Fricative		f	θ ð	s z	ʃ				χ ʁ	ħ ʕ	h
Affricate					dʒ						
Approximant						j		w			
Lateral				l							

Pharyngealised consonants: tˤ dˤ sˤ ðˤ

Table 2-2 - Thevowels of Arabic

	Front	Central	Back
Closed	i i:		u u:
Open		a a:	

2.4 Quality of Life and Health Related Quality of Life

QoL is about the goodness, satisfaction and wellbeing of life; however, there is no clear agreement on the definition of QoL (Cummins, 2010). Early work in the area of QoL was in the field of social sciences in the 1970s, and was used to measure and reflect the index of wellbeing of a population (Sarvimaki & Stenbock-Hult, 2000). This early work focused mostly on living standards and researchers looked at poverty, health, unemployment and other factors in order to reflect how satisfied a population was with its living situation. Today, the term QoL is used in every context, from advertising clothes to social sciences and health care.

2.4.1 Quality of life

So what is QoL? To date there is still no universally accepted definition for QoL and no gold standard for the assessment and measurement of it (Cahill & Diaz-Ponce, 2011). The dictionary defines 'quality' as a degree of excellence; therefore QoL, by extrapolation, includes the factors and elements in life that make it excellent and worth living by providing some enjoyment (Bowling, 2005). QoL is unique and may mean something different for each individual. Determining a list of elements and factors that are universally shared and defining what makes them excellent is not possible, and consequently comparing the QoL of two individuals may be very difficult. Calman (1984) suggested that QoL is a measure of the gap at a particular period of time between the hopes, expectations and dreams of an individual and their current experience. Therefore, to improve QoL, attempts should be made to narrow that gap. QoL represents a holistic concept and goes beyond the activities of daily living. It encompasses physical health, psychological or emotional health, social support, employment, and economic and material wellbeing (Bishop & Allen, 2003). How these factors interact for each individual depends on their environment and the circumstances (Bowling, 2005).

Research on QoL started by examining epidemiological factors such as morbidity, mortality and health services in general (Fayers & Machin, 2007). Recently, there has been a shift to a more holistic approach with QoL being perceived as a multi-factorial and complex construct which is highly individualised. It includes factors such as social, cultural, psychological and physical aspects of life, and is a reflection of a person's own opinion about their own satisfaction with life and wellbeing. Hirsch and Holland (2000) defined QoL as:

> ...a product of life domains (physical functioning, social environment, economic status, and spiritual status) filtered through the individual's personal perspective.

The WHO in their health promotion glossary, defined QoL as:

> … the individual's perception on their position in life in context of culture and the value system in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad-ranging concept, incorporating in a complex way the person's physical health, psychological state, level of independence, social relationships and his/her relation to salient features of their environment.
>
> (WHO, 1998a, p.17).

Common to all definitions is that QoL is a complex multidimensional construct that includes physical, psychological, social and spiritual factors. QoL is highly individualised and is the result of the complex interaction between these various factors (Felce & Perry, 1995). As well as being a changing construct, it can also change depending on circumstances and a person's expectations, as they may be set higher or lower depending on their current life situation (Bernhard, Lowy, Mathys, Herrmann, & Hürny, 2004; Calman, 1984; Felce & Perry, 1995).

2.4.2 Health Related Quality of Life

With the introduction of the WHO definition of health as "a state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity" and the introduction of the WHO model of disability (1980), there has been an increased focus in the medical field on how a patient feels rather than how the clinician thinks they feel. This view has continued with the introduction of the ICF framework to encourage the focus on the person's functioning and wellbeing in addition to the impact of health related factors. Information concerning symptom response to medical treatment and survival rates is no longer sufficient.

There has been genuine interest in the research literature following this development, especially for chronic and progressive conditions, to understand what constitutes QoL or life satisfaction, as it may be the only way to document treatment and management outcomes, as well as to reflect whether taking measures to prolong life leads to a life worth living (Bowling, 2005). Researchers continue to be interested in assessing QoL as an outcome measure in clinical trials in order to reflect the impact that surgical or medical management and side-effects may have on life satisfaction. They are also interested in investigating its use in clinical practice to ensure that a more holistic view of the patient is obtained, and that management and therapy are focused on the patient rather than on the disease (Higginson, 2001). By encouraging clinicians to consider and examine QoL, it allows them to focus beyond their scope of practice and see the individual as a whole.

QoL has been measured within health care for a number of reasons: to expand baseline information to determine the efficiency of consequent intercession; to demonstrate clinicians' attention to part in which the patient is understanding complications; to assist clinicians comprehend the patient's viewpoint; to prioritise treatment intercession; and to direct patient self-management and education (Bishop & Allen, 2003; Bowling, 2005).

The concept of Health-Related quality of life HRQoL is defined as “the optimum levels of mental, physical, role, and social functioning including relationships, and perceptions of health, fitness, life satisfaction, and well-being” (Bowling, 2001). QoL and HRQoL are distinctly different outcome measures and represent different concepts. Despite the definition above, HRQoL in practice emphasises symptoms of the disease and treatment, and the effects on function, thereby reflecting the person’s health status. Yet QoL goes beyond that, including in addition to an individual’s health status, personal, social, economic, environmental, spiritual and demographic factors. Health does not have to be a necessary component for good QoL, but it is seen as a potential influential factor (Sarvimaki & Stenbock-Hult, 2000; Doward & McKenna, 2004). When evaluating QoL and HRQoL research, it should be noted that the two terms are sometimes used interchangeably. In addition, on many occasions HRQoL has been synonymous with function and hence could be considered a treatable and measurable factor within healthcare provision (Cruice *et al.*, 2010b). By focusing on function alone, health practitioners and researchers can lose sight of the more holistic goal of rehabilitation in chronic and degenerative conditions that is to improve or maintain wellbeing, satisfaction and overall QoL.

A HRQoL measure should ideally take into account all areas of a patient’s life and past life experiences, as well as the impact of the disease or disability on the patient, and should not simply reflect the severity of the disease. In accordance with the WHO definition of health, good health is not just freedom from disease, but rather helping a person live the best life possible given their current life situation by decreasing the gap between their expectations and experiences (Calman, 1984; Carr, Gibson, & Robinson, 2001). HRQoL is used in health care to supplement clinical and biological measures of disease, and to assess the quality of services, the need for health care and the effectiveness of intervention. HRQoL is sometimes used interchangeably with measures of health status. However, both of these fail to address an individual’s uniqueness and unique situation since they impose a standardised model of preselected categories that emphasise function and symptoms related to the disease (Carr *et al.*, 2001) An example would be questions such as; ‘I stand up only with someone’s help’, or ‘I am going out less to visit people’, as found in the in the Sickness Impact Profile (SIP), a generic HRQoL questionnaire (Bergner, Bobbitt, Carter, & Gilson, 1981). Sometimes these measures contain factors that are of little or no importance to an individual patient.

Although QoL is a very important construct in understanding what is important to a person, there have been great flaws in the conceptual basis of the existing outcomes (Keenan *et al.*, 2008). Carr *et al.* (2001) argued that measuring QoL using a tool that was devised by a clinician without the inclusion of patient’s needs might be inappropriate, and is likely to compromise the validity and usefulness of that tool, especially if the items tested do not represent factors that are important to that individual. It is assumed that there are some aspects of life that are relevant to everyone’s QoL. While this may be true for some factors, the weight that each individual attaches to each factor will vary considerably. For example, family might be an important factor for most individuals, but if a person was a ‘loner’ before the occurrence of their disease, they may remain that way afterwards. It is therefore important to individualise the weight given to familial life according to each individual. Other aspects may be important only to one individual and not to others. Values and priorities change along with life circumstances and as a patient adapts to his/her illness, age and other circumstances, they continue to re-evaluate their life situations, expectations and needs (Stewart, Teno, Patrick, & Lynn, 1999; Bernhard *et al.*, 2004). This has generated debate among researchers regarding the best means to measure QoL, and whether any one outcome measure really represents patients’ perspectives.

In neurodegenerative conditions, debate regarding the best methods of measuring QoL is essential, largely because these conditions are characterised by increasing disability over the course of the disease, affecting different levels of function (physical, psychological and social). These conditions are often associated with changes in social activity, work or employment, leisure, interaction with society, relationships, responsibilities, and eventually loss of employment and the ability to carry out self-care, care of others, and activities of daily living, all of which will impact on an individual’s wellbeing. Since the relationship between QoL and symptom severity is not a direct one (Carr *et al.*, 2001; Simmons *et al.*, 2000; Robbins, Simmons, Bremer, Walsh, & Fischer, 2001), QoL assessment tools allow researchers and clinicians to go beyond the continuum suggested by the WHO ICF (2001) to reflect a more holistic personal measure, thereby revealing the social and emotional impact of the disease on the individual.

Another important area of debate is determining who is the best person to report on QoL Should this be the patient, the caregiver, the physician or other medical personnel? In neurodegenerative conditions, the patient may have difficulty responding to QoL assessments, either in filling out the questionnaire or in responding to open-ended questions, due to impairments in physical or cognitive functions (Hirsch & Holland, 2000). It may therefore be easier to have the caregiver or physician fill out the QoL assessment for them. However, from the definitions given, QoL is highly specific to each individual as a concept. The findings in this area are mixed, with some researchers having demonstrated that when using physicians and/or significant others as proxies then they tend to underestimate the QoL of an individual (Rothman, Hedrick, Bulcroft, Hickam, & Rubenstein, 1991; Schiffczyk *et al.*, 2010). QoL assessments completed by a proxy (either a medical professional or a lay caregiver) can be influenced by their own feelings and experiences of caring for the individual concerned (Addington-Hall & Kalra, 2001). In contrast, other studies have found a correlation between the patient's and the proxy's assessment of the patient's QoL (Schmidt *et al.*, 2010).

2.4.3 Quality of Life and Neurodegenerative Conditions

According to the global burden of disease study published by the WHO, even though neuropsychiatric diseases cause only 1.4% of all deaths, they account for 28% of years lived with a disability (Menken, Munsat, & Toole, 2000). Neurodegenerative diseases represent a percentage of these long-term conditions, therefore making rehabilitation services important in their management. In the absence of a cure, the goal of rehabilitation is to help the person adapt and live as good a life as possible within their current medical condition. Treatments and therapies have been developed to increase the survival duration of these degenerative conditions, but currently these diseases are incurable. The therapies developed may have detrimental side-effects on a patient in addition to the impact that increasing life expectancy has on an individual's wellbeing and satisfaction with life. Since prolonging life may not always improve life satisfaction, understanding a person's priorities in life allows the rehabilitation and medical team to assist a person in improving their life satisfaction and to achieve their expectations.

Therefore, the evaluation of subjective health is central to the assessment and measurement of illness and disease. In summary, the standard functional assessments for physical or psychological function cannot give a full picture of what a person experiences as a consequence of disease and the associated disabilities. The research conducted with patients suffering from neurodegenerative diseases indicates that researchers have tried to determine factors that are relevant to a good or poor QoL. These include physical function, depression, spirituality, fatigue, social support and religiosity, as will be discussed in the next section. Generic, disease-specific and patient-centred methods have been used to conduct these studies in addition to qualitative research, and this has shown that changes in QoL are only partially explained by deteriorating physical function. Some research has demonstrated that individuals with the same diagnosis, age and length of disease show QoL experiences that were described as being subjective and individual (Nordeson, Engström, & Norberg, 1998). Mitchell *et al.* (2010) reviewed the influence that subtle cognitive changes may have on HRQoL in adults with neurological diseases including neurodegenerative diseases, and found that even subtle changes in cognitive function such as inattention, processing speed, and executive function could have a significant impact on some aspects of life quality.

2.4.3.1 Quality of Life and Parkinson's Disease

QoL in Parkinson's disease has been linked to several factors including physical function, mental ability, emotional wellbeing, health, self-image, social function, cognitive function, communication, sleep, eating, energy fatigue, and sexual function (Chapuis, Ouchchane, Metz, Gerbaud, & Durif, 2005; Damiano, Snyder, Strausser, & Willian, 1999). In addition depression has been shown to impact QoL in other studies (Behari *et al.*, 2005). In a review of QoL research in PD Den Oudsten (2007) noted that almost all studies inappropriately used measures of health status to measure QoL in people with PD, and patients were asked about physical, psychological, and social functioning rather than life satisfaction. Depression rather than disease duration and physical function were closely related to HRQoL measures (Marras *et al.*, 2008; Schrag, 2006; Sławek, Derejko, & Lass, 2005). QoL measures were also used in PD patients to determine the impact that disease management through surgical or medical intervention had on QoL (Noyes, Dick, & Holloway, 2006). There was no significant difference between the QoL of individuals receiving Deep Brain Stimulation (DBS) and those receiving dopamine therapy except for the component of communication, where stimulated patients scored less on QoL measures than those receiving dopamine (Montel & Bungener, 2009) on a PD specific QoL assessment (PDQ 39). Various methods have been included in the assessment of QoL for patients with PD including HRQoL measure (Hobson & Meara, 1997) and measures specifically developed for PD (Behari *et al.*, 2005; Bushnell & Martin, 1999; Chapuis *et al.*, 2005; de Boer, Wijker, Speelman, & Haes, 1996). In addition on factor that researchers recognised when looking at QoL was the impact and burden that the functional changes in PD have on the caregivers and the patients alike (Martínez-Martín *et al.*, 2005).

2.4.3.2 Quality of life and Multiple Sclerosis

To date, there have been over 90 research studies that have investigated QoL and MS (Mitchell, Benito-Leon, Gonzalez, & Rivera-Navarro, 2005) and more than 20 MS specific QoL measures. MS QoL has been found to correlate with depression and fatigue (Forbes *et al.*, 2006; Janardhan & Bakshi, 2002), and anxiety and cognitive impairments (Benito-Leon, Morales, & Rivera-Navarro, 2002). Mitchell *et al.* (2005) reviewed several studies and reported that the tools used were not representative of a person's own perspective as they were heavily weighted on function and instead represented the clinician's perspective. The strongest correlation was found to be between emotional adjustment and QoL rather than impairment and disability (Benito-Leon *et al.*, 2003). People who are suffering from the MS disease, are expected to live a longer life, however there is no assurance given for the QoL for these patients.

Many aspects of the life of an individual can be threatened due to the progression of MS because it is known as unpredictable and heterogeneous. The QoL of MS patientsis substantially affected as it influences the capacity to perform the daily activities as well as the health perception. There is a reduction in the aspects of health-related quality of life (HRQoL) among the population of MS. However, the term HRQoL is defined as the significance which is associated with the duration of life, defined by functional status, perceptions, impairments, and influential opportunities of policy, injury, disease and treatment. Generally, there is distinction found between the overall QoL in terms of those aspects of life that are influenced by health (Katsarou, *et al.,* 2001).

There are some factors which are considered as altered and affected by MS, for example social engagement, MS symptoms, emotional and mental health, physical function, sexual intimacy and personal control. All these factors are the domains of HRQL. Therefore the QoL of MS patients have been significantly affected because the function and well-being of the patients is highly impacted by MS. These dimensions need to be highlighted and addressed while managing the health of the patients of MS (Jenkinson, Fitzpatrick, Peto, 2000).

2.4.3.3 Quality of life and Amyotrophic Lateral Sclerosis/Motor Neuron Disease

In a review study, Epton *et al.* (2009) examined QoL measures used for patients with ALS/MND, and noted that the recommended measure based on validation and reliability would be the SF-36 (Jenkinson, Coulter, & Wright, 1993), as well as the Amyotrophic Lateral Sclerosis Assessment Questionnaire 40 (ALSAQ-40) (Jenkinson *et al.*, 1993). This correlates with the World Federation of Neurology Consensus (1998) recommendation for the use of generic QoL measures in conjunction with disease-specific measures when measuring QoL in ALS patients. Assessment tools that are heavily weighted on physical function such as the SIP (Bergner *et al.*, 1981), SF-36 (Jenkinson *et al.*, 1993) and SIP/ALS-19 (Damiano *et al.*, 1999) were found to correlate with the ALS Functional Rating Scale (ALSFRS) (Kaufmann *et al.*, 2005), a measure of physical functioning in ALS. However, they did not correlate with the patient-centred measures, SEIQoL and SEIQoL-DW (Clarke, Hickey, O'Boyle, & Hardiman, 2001; Robbins *et al.*, 2001; Goldstein *et al.*, 2002; Simmons *et al.*, 2006). As in MS, fatigue and depression were related to QoL as well as spirituality and religiosity (Lou, Reeves, Benice, & Sexton, 2003; Chio *et al.*, 2004).

Qualitative research revealed that faith, the need for control, dignity, identity, family, support systems, fighting ALS and an appreciation of life were all important elements reported by patients (Foley, O'Mahony, & Hardiman, 2007). Overall, the research suggests that QoL for ALS patients is dependent on factors other than simply physical function. Comparing QoL between different neurodegenerative conditions is important to determine if the rate of progression and the characteristics of each disease has an impact on the components and changes in QoL. However, research in this area is limited. In one study, O'Doherty *et al.* (2010) compared the QoL of patients with ALS/MND and patients with MS. One hundred patients with ALS/MND and MS were interviewed at baseline and six months later, and data on measured function, HRQoL, individualised QoL and psychological distress was analysed. They reported that the patient groups did not differ on individualised QoL or mental wellbeing, and distress was within normal range. Despite a marked deterioration in health, particularly within the ALS/MND group, there were no changes in mental wellbeing or QoL. Simmons, et al., (2000), found that physical disability is not related to the QoL. The progression of discouragement is more highly and strongly contributed by the range of social and psychological factors as compared to the physical illness (Clarke, et al., 2005).

Therefore, they concluded that psychological wellbeing was more important than physical function in predicting QoL. There was also evidence of psychological adaptation to the deterioration in function. There is evidence that the QoL of individuals with ALS is related to increased depression (Gauthier, 2007).

2.4.3.4 Quality of Life and Communication Disorders

Although QoL is presumed to be influenced by a person's disability, a number of investigators have looked at the impact of communication impairment on a person's QoL (de Haan, Aaronson, Limburg, Hewer, & van Crevel, 1993). Communication is not always represented within the QoL tools used, and those measures that do include communication, define it as the physical function of speech output. Questions posed are related to the degree of speech intelligibility, changes in voice, handwriting and facial expressions, rather than the impact that the change or loss of communication may have on a person's role in society and in societal participation. Yet it is known that communication is a factor that is affected in all the neurodegenerative conditions; it influences a person's ability to interact with their environment and defines their place in society. Changes in speech, language and cognitive skills emerge as the most significant features of perceived reduction in life quality (LaPointe, 1999). According to

Nussbaum (2007) "… no individual can adapt, maintain, or obtain the necessary requisites of a quality of life throughout the life span without competent communication" (p. 3).

In addition to the inappropriate representation of communication within the tools, patients who have communication difficulties have sometimes been excluded from QoL research due to their potential difficulties with the assessment process. In instances where patients with communication impairments were not excluded, the level of communicative impairment and function were not clearly defined (Hirsch & Holland, 2000). When searching for research that looks at communication in neurodegenerative research related to QoL it was found that it had barely been reported. In one study it was seen to be associated with changes in PD patients' QoL (Chapuis *et al.*, 2005), together with activities of daily living and mobility. Another research study specifically investigated communication and swallowing as it related to QoL in patients with MS. This study found that 53% of patients reported that their swallowing function had an impact on their QoL and 62% reported that language and speech function influenced their QoL (Klugman & Ross, 2002). The tools used in this study were developed by the researchers and were based on the input of clinicians familiar with patients with MS. Communication intelligibility was reported as a factor in determining a person's ability to cope with MS (Ehrensperger *et al.*, 2008). Calvo *et al.* (2008) reported improvement in the QoL of three patients with ALS following the introduction of a communication device that allowed eye tracking, which could have been due to their increased independence in their communicative function. Although research has shown that acquired dysarthria has a significant impact on a speaker's self-perception, this impact is often independent of the severity of the dysarthria (Walshe & Miller, 2011).

Within the field of communication disorders there has also been a shift towards a more holistic approach to patient management. An effective definition of QoL for adults was proposed by Cruice (2008) who proposed an operational definition of QoL for adults with acquired communication:

> Quality of life for adults with acquired communication and swallowing disorders is determined by the individual, as well as being construed in the clinical sense as psychological well being and social-health – related quality of life. Quality of life reflects the whole life experience for the individual, of which the presence and the consequences of the communication and/or swallowing disorder is a part (not the whole). It is self evaluated in the context of the person's life, in consideration of the influence if the following factors: emotional health, physical functioning, age, gender, coping skills (personal factors); and caregiver welfare, family and friends' support, society's attitudes towards communication and swallowing, family and friends' communication access in the community (environmental factors). In the clinical domain, the areas of functional communication ability, overall speech language and/or

> swallowing functioning, and social networks and activities deserve exploration for performance, importance, satisfaction, personal meaning, and current and future aspirations.

Cruice's proposed definition suggests that QoL, as it relates to communication disorders, is (1) individually determined, (2) multidimensional, (3) includes physical and psychological factors, (4) includes ratings and satisfaction of areas of communication and/or swallowing in addition to overall life experiences, and (5) includes a person's environment and social context.

Although some research has been carried out regarding QoL, particularly in the areas of aphasia, voice and hearing loss, research in impairment assessment and management is still dominant. QoL has been studied in relation to voice disorders (Eadie & Doyle, 2004; Hogikyan & Sethuraman, 1999; Meyer *et al.*, 2004; Baylor, Yorkston, & Eadie, 2005; Krischke *et al.*, 2005) hearing loss (Vermeire *et al.*, 2006), and fluency (Bramlett, Bothe, & Franic, 2006), and these will be examined in more detail in the following section. Overall, QoL is related to both external (society, social responses and other people) and internal (personal and physical components) factors. A much larger body of research exists in the area of aphasia and QoL. QoL has been measured using generic assessment tools such as the WHO QoL Instrument Short Form (WHO, 1998b), SF-36 (Jenkinson *et al.*, 1993), and aphasia-specific measures such as the Stroke and Aphasia Quality of Life Scale -39 (SAQoL-39) (Hilari *et al.*, 2003).

In addition, qualitative research using structured interviews to tap into factors that represent QoL for individuals with mild to moderate aphasia has also been undertaken (Cruice *et al.*, 2010b). Some researchers have reported that QoL is not influenced by the severity of the language impairment associated with aphasia (Ross & Wertz, 2002; Williams *et al.*, 2008), whilst other have reported that QoL is multi-factorial and is influenced to some degree by factors related to communication impairment, especially communicative function and participation, more than language function (Cruice, Worrall, Hickson, & Murison, 2003; Cruice *et al.*, 2010b; Hilari *et al.*, 2003). Emotional wellbeing and distress are also reported as important factors in predicting QoL (Hilari *et al.*, 2003; Worral *et al.*, 2002). When comparing QoL stroke survivors with and without aphasia, the factors that distinguished QoL are level of independence, social relationships and environmental factors (Ross & Wertz, 2002). The knowledge gained from extensive research performed in the area of aphasia may not represent the experiences of individuals with dysarthria, particularly when it is present with a neurodegenerative disease. This is because dysarthria is often present in addition to a debilitating neurological condition.

These conditions continuously deteriorate, which marks the experiences of these individuals very differently to those of others. Worthington (1996) suggested that the rapidly progressing nature of ALS/MND presents unique psychological problems. These patients become dependent, immobile and often anarthric as the disease progresses, therefore forcing a continuous adaptation to change and requiring different coping strategies compared to more stable conditions associated with aphasia. Similarly, in PD and MS, although the disease progression is slower, patients are still unstable. Continuously progressive conditions such as these include side effects that also have an impact on communication such as fatigue in MS (Yorkston *et al.*, 2001) and distractibility, diminished attention span, and problems initiating speech movements in PD (Miller *et al.*, 2006).

2.5 Cultural Considerations When Adapting and Developing Assessment Tools

The research presented in this thesis focuses on patients with PD, MS or MND living in Saudi Arabia who speak Arabic as their first language. Reviewing the research literature and assessment measures for both communication and QoL in Arabic has revealed that there are very few reports of published measures that are valid and reliable for this patient population. Research has shown that there is an increased demand for the development of speech and language measures for both adults and children to be used in different linguistic and cultural environments from those in which they were originally developed. It is integral to understand the cultural variations and possible cultural bias when providing speech and language therapy services (Isaac, 2002). This is especially true since language is a medium for conveying culture and is therefore embedded in it and *vice versa* (Carter *et al.*, 2005). Culture is defined as a set of values, beliefs, perceptions, institutions, technologies, survival systems, and codes of conduct held by a group of people (Payne & Taylor, 2002). For an assessment to be valid it needs to be conducted using procedures that can differentiate the pathological from normal behaviours, and not discriminate unfairly either for or against the participant for cultural reasons (Taylor & Payne, 1983).

In a review by Carter, *et al.* (2005) on cross-cultural assessment of speech and language for children they reported on five areas that are related to cross-cultural assessment development or adaptation. These were:

- The influence of culture on performance; the experiences of individuals from physical and social environments have an influence on their development and therefore the appropriateness of the assessment measures.

- The familiarity of testing situations; the social rules of language interact by determining who can speak to whom and in what manner between genders or between age groups (adult and child).
- The level of formal education may impact on the testing of certain linguistic skills.
- Language is an important factor that plays an important role in cognitive development and social interaction therefore it is important to consider the language of the country where testing is taking place because a translated sentence from a test may not generate the same intended response as it would in the original language.
- Picture recognition, as it involves symbolic representations that are influenced by exposure to the real objects or their pictorial representations.

For these reasons, research was needed to determine if there are any assessment measures that can be used which are considered reliable and valid to measure the areas of communication and QoL in these patient populations. According to Geisinger (1994) assessment instruments must be adapted for new target populations, particularly when the new population differs appreciably from the original population for which the assessment device was conceived in terms of culture, language, and country. Due to cultural and language differences, it is not sufficient to simply translate a test for it to be reliable and valid for use in a different language or even in a different culture speaking the same language. The options are to either develop new assessment using new intelligibility and functional communication assessment tools, or to adapt an existing measure. For communication purposes, a review was carried out to determine whether there were any valid and reliable assessment tools available to investigate speech intelligibility and functional communication in Arabic; such tests were not found within published research. Therefore, it was decided that, since speech and communication rely heavily on the linguistic and phonological properties of the language as well as being heavily influenced by a person's cultural background, the only option was to develop, pilot and validate new assessment tools for intelligibility and functional communication. Guillemin *et al.* (1993) reported that, when an instrument is to be used with another culture, language and country, it requires both translation and cultural adaptation. The measures of intelligibility were developed based on approaches used to develop valid and reliable measures already published in other languages.

A few guidelines regarding test adaptation for a different culture and language have been developed. According to Geisinger (1994), any time that a test or measure is used with a population that is qualitatively different from the one for which it was originally developed, one must check its continued validity and usefulness for the new population. Since the population that we are dealing with differs significantly both culturally and linguistically from the population of individuals for which the majority of communication measures have been developed (USA and Europe), we know that we need to adapt the communication measures in a way that takes into account the linguistic and cultural uniqueness of this population. By reviewing test adaptation techniques, we notice that tests sometimes are adapted and translated on a question-by-question basis and other times they are adapted only in concept. So for our purpose some aspects of communication are similar across cultures while others are more culture specific as they relate to certain language and speech characteristics. Therefore, an intelligibility measure that is optimised for English-speaking individuals will not be appropriate to translate on a question-by-question basis, but rather will require the development of an entirely new measure. The measure will be developed with the adaptation of the techniques and methods of that were used in the development of the original instrument, taking into account the specific features of the culture and language we are targeting. Another factor which is important and gives strength when translating and adapting a measure is to review the adapted version individuals from the target population and/or individuals who are fluent in both languages (Guillemin *et al.*, 1993; Lent, Hahn, Eremenco, Webster, & Cella, 1999). This is followed by the adaptation the instrument based on comments of reviewers, piloting the instrument, and finally field-testing the instrument once the pilot testing has been performed (Guillemin *et al.*, 1993). These factors that ensure the validity and reliability of the assessment measure must be taken into consideration when thinking about the methodology to be followed in the adaptation and development of the measures that looks at functional communication and an instrument to assess speech intelligibility.

In the area of QoL, a review of the literature found that the majority of research in this area has been conducted in the Western world, including Europe, USA, and Australia. Measures have then been adapted and translated into many languages, including French, Spanish, and German; research undertaken in other areas, and particularly focusing on Arabic speaking nations, is virtually non-existent, with the exception of a few studies aimed at linguistically and culturally adapting QoL assessment tools into

Arabic, following the standards suggested by Guillemin *et al.*, (1993). These two HRQoL assessment measures were the Short Form -36 (SF-36) (Coons, Alabdulmohsin, Draugalis, & Hays, 1998) and the Arabic Sickness Impact Profile (A-SIP) (Almansoori, 2003). The SF-36 has been used several times in different Arab countries, including Morocco, Tunisia and Lebanon, to investigate the QoL of patients post-discharge from intensive care units of individuals with epilepsy, and the QoL of rural versus urban living (Khoudri, Ali Zeggwagh, Abidi, Madani, & Abouqal, 2007; Mrabet, Mrabet, Zouari, & Ghachem, 2004; Sabbah, Drouby, Sabbah, Retel-Rude, & Mercier, 2003). The A-SIP has been used in the United Arab Emirates to investigate the QoL of infertile women (Khayata, Rizk, Hasan, Ghazal-Aswad, & Asaad, 2003). Following this detailed review of QoL measures it was decided to use the A-SIP as a measure of HRQoL in this thesis.

2.6 Quality of Life Assessment Measure Review

When reviewing QoL measures in neurodegenerative disease we noticed that the terms QoL and HRQoL have been used interchangeably in research. The assessment tools that have been used include generic tools, disease-specific and patient-centred measures, and qualitative research to obtain a more personal perspective of QoL. Each of these methods has both benefits and shortcomings. Generic tools lack the sensitivity for disease-specific features and are heavily weighted on the functional ability of an individual. Therefore, they may be a better assessment of health status rather than QoL (Tennant, 2008). The benefit of using such tools is that they allow for comparisons between different patient groups. Disease-specific measures usually include factors that are specific to certain diseases and are therefore a better way of capturing important elements for an individual. They usually include factors related to physical function as well as those related to social wellbeing. However, they do not allow for comparisons between different medical conditions. These factors are usually pre-set by clinicians working with a specific patient population, and the tools assume that the QoL of patients with the same medical conditions will be influenced by the same physical and psychological factors (Ramaker, Marinus, Stiggelbout, & van Hilten, 2002).

Patient-centred assessment tools represent a person's individual opinion of what constitutes their own QoL. They are difficult to use in large group studies (Jenkinson *et al.*, 2000), but they have the capacity to detect individual problems that may otherwise be ignored and are more meaningful to the patient (Ruta, Garratt, Leng, Russell, & MacDonald, 1994).

In addition to the above QoL measurement tools, qualitative research has also been used to assess QoL for patients with neurodegenerative diseases (Cruice *et al.*, 2010b; Foley *et al.*, 2007; Foley *et al.*, 2007). QoL in neurodegenerative conditions has been shown to be individual and subjective (Nordeson *et al.*, 1998), and therefore in order to have an accurate assessment of QoL a person's perspective must to be represented within the tool used. More generic measures do exist, such as the SIP (John Hopkins University, 1977; Bergner *et al.*, 1981). This is a generic 136-item HRQoL measure associated with illness-related dysfunction. It includes factors related to functional ability and factors concerned with feelings, emotional wellbeing and social functioning. These factors are sub-divided into 12 areas; work, recreation, emotion, affect, home life, sleep, rest, eating, ambulation, mobility, communication and social interaction.

The person completing the SIP is asked to tick the statements that apply to them on a given day and are related to their state of health. Examples of these statements include: 'I spend most of my day laying down in order to rest'; 'I stand up only with someone's help'; 'I am doing fewer social activities'; 'I am not going out to visit people'; 'I have attempted suicide'; 'I get dressed only with someone's help'; and 'my speech is understood only by a few people who know me well'. The SIP can provide an overall score of HRQoL on a range of 0 – 100; the lower the score, the better a person's HRQoL. In terms of disease-specific tools, the Parkinson's Disease Questionnaire (PDQ-39) (Jenkinson, Fitzpatrick, Peto, Greenhall, & Hyman, 1997) is a 39-item questionnaire with eight dimensions; mobility, activities of daily living, emotional wellbeing, stigma, social support, cognition, communication and body discomfort.

The PDQ-39 was developed following in-depth interviews with 20 individuals with PD. Similarly, the ALSAQ-40 (Jenkinson, Fitzpatrick, Brennan, Bromberg, & Swash, 1999) was developed following in-depth interviews with patients with ALS. The ALSAQ-40 is a 40-item measure of 5 areas of function; eating and drinking, communication, activities of daily living, physical mobility and emotional functioning. SEIQoL-DW (Browne, O'Boyle, McGee, McDonald, & Joyce, 1997) is a patient-centred approach that has been used with patients with various neurological conditions including ALS, MS, Alzheimer's Disease, and following a head injury, and was found to be a valid and reliable tool. It is administered in a semi-structured interview in which the patient is asked to: 1) nominate five areas in life that they consider important for their quality of life; 2) rate their current level of function in these areas; and 3) weight their relative importance on five interlocking, coloured and laminated circular disks that rotate around a central point to form a pie chart. Each disk displays a scale from 0 – 100.

Each segment is labelled with a life area nominated by the respondent. The respondent is asked to adjust the coloured disks until the size of each represents the relative importance of that area. The SEIQoL-DW allows for the calculation of an overall QoL score. For the purposes of this research it was decided to assess QoL using three different QoL measures; each has its strengths and weaknesses. This was done in an attempt to better understand the relationship between QoL and communication, and to determine if that relationship is influenced by the assessment measure used. In addition, a better understanding of what QoL really is and which test best describes it for the individual was sought. A generic HRQoL measure (A-SIP) that has been adapted into Arabic and has proven to be valid and reliable for use with individuals with chronic disease was chosen.

An individual QoL measure (SEIQoL-DW) where the person nominates the areas that they see as important in determining their QoL rather than responding to a predetermined set of statements set up by a panel of experts was also used. A single question was used to judge the person's own view of overall QoL (MQoL-SIS). This question should be easy to understand and can give an indication of QoL even for severely affected individuals. Finally, semi-structured interviews were conducted with patients to allow a more in-depth exploration of the QoL of individuals and in order to capture individual experiences.

2.6.1 Generic HRQoL Measures:

Once we had looked at the different instruments and methods of assessing QoL we needed to find methods that could be used with an Arabic speaking population and that have been developed using a method that follows the guidelines set by previous researchers for the cultural adaptation of instruments. In this section we will discuss the QoL measures available for an Arabic speaking population and reasons for selecting the A-SIP as a measure of HRQoL in this thesis. While reviewing the literature in an attempt to find a generic, valid, reliable HRQoL measure that has been adapted into Arabic, two measures were found including the Arabic version of SF-36 and the A-SIP. The Arabic SF-36 (Coons *et al.*, 1998) was adapted from the original RAND SF-36 which was developed at the Research and Development (RAND) Corporation in the USA. The scale includes 36 health status items which have been used worldwide to assess HRQoL among individuals with various medical conditions.

The aim in the development of the original SF-36 was to develop a short generic measure of subjective health status that was psychometrically sound. This measure is one of the most frequently used in health status surveys around the world (Bowling, 2005) and has been popular in investigating QoL. The validity and reliability of this measure has long been established through its use with a variety of medical conditions (Bowling, 2005).

The SF-36 scale measures eight dimensions of health: 1) physical functioning; 2) social functioning; 3) role limitation due to physical problems; 4) role limitation due to emotional problems; 5) mental health; 6) energy/vitality; 7) pain; and 8) general health perception. Coons *et al.* (1998) developed an Arabic version of the test, by translating the SF-36 into Arabic and administering it to 415 bilingual Saudi nationals working at ARAMCO. The participants were asked to respond to both the Arabic and English versions of the measure. The authors reported internal consistency and test-retest reliability; however, this assessment was validated using a restricted Saudi Arabian population – only employees of ARAMCO and only those who were bilingual. Furthermore, it was not tested with any patients, and therefore how sensitive it is to the severity of the disease process or the effects of medical treatment is not known.

The second assessment tool that was found was the A-SIP. This version was developed by Al Mansoori *et al.* (2003), and was based on the UK version of the SIP (Finlay, Khan, Luscombe, & Salek, 1990). The original purpose of the SIP was to develop a health status measure that allows the evaluation of outcomes across a wide range of health problems and diseases. It focuses on the assessment of the impact that sickness has on daily living activities and behaviours. The statements included in the SIP were generated following an extensive literature review as well as extracting statements from health care professionals and ill lay-people which describe sickness related behavioural dysfunctions (Bergner *et al.*, 1981).

The SIP includes 136 statements that measure functioning, emotional wellbeing, and social functioning. These are divided into 12 categories: 1) ambulation; 2) household management; 3) emotions; 4) eating; 5) body care and movement; 6) recreation/past time; 7) alertness; 8) communication; 9) mobility; 10) social interaction; 11) sleep/rest; and 12) work. The Arabic version of SIP was developed in 2003 at Cardiff University, UK. The aim was to develop a psychometrically sound, culturally specific generic HRQoL instrument suitable for use with an Arabic speaking population of patients with various chronic diseases. The method followed during this adaptation of the SIP follows the structure set by Guillemin *et al.* (1993) for cultural and linguistic adaptation of QoL measures. The UK version of SIP was translated and back translated by four professional bilingual translators, and a ten member panel of bilingual judges was used to evaluate the translation and back translation. The weighting process and weights were then re-calculated for the new instrument, before an examination of the applicability, practicality, reliability and validity of the new measure was evaluated with 100 participants with chronic illness and 250 healthy volunteers in the UAE. The final format included 136 items divided into the same categories as the original measure. Test-retest reliability was established for this measure, which was found to be easy to understand, took about 20 minutes to complete, and was applicable and practical for use with an Arabic speaking population.

After reviewing the adaptation process for the A-SIP and the Arabic SF-36 it was decided to use the A-SIP for several reasons. It had been adapted and trialled using a larger population of Arabic speakers which included individuals with chronic disease, and it followed linguistic and cultural adaptation standards developed by Guillemin *et al.* (1993). It was also fairly simple and straightforward to score the A-SIP, as only the statements for which the respondent answers ‘yes’ are recorded. The A-SIP can generate an overall score from 0 to 100 or can be scored by components, thereby providing both a physical and a psychological dimension. Adding the scaled value of each question checked across all the categories and dividing it by the maximum possible dysfunction and multiplying that by 100 generates the overall score. One important point to note is that the higher the A-SIP score the poorer the HRQoL.

2.6.2 Individual (Patient-Centred) QoL

Another approach used for determining a person’s QoL is to allow them to define it themselves. It is believed that those factors that determine a person’s QoL differ from one person to another and should be individually elicited. The SEIQoL-DW was developed with the key assumption that a person’s QoL is what he or she determines it to be, it is neither disease specific nor health related. The SEIQoL-DW allows the individual to nominate the areas they consider most important in their life using their own value systems when describing their functional status and the importance of each area (Browne *et al.*, 1997). It has been used with a number of medical conditions, including neurological and non-neurological, as well as with a healthy elderly population (Bowling, 2005). The SEIQoL-DW is administered in three stages. The first step involves a semi-structured interview in which the person is asked to nominate five areas in life (domains) that they consider most important in determining their overall QoL.

In the second stage, the individual rates each nominated domain on a vertical visual analogue from 0 – 100 mm anchored, at the two extremes, by the terms ‘best possible’ and ‘worst possible’. These anchors are used to allow the individual to use their own criteria when assessing their status within each domain. The proportion of the chart that each section represents can be scored from a 100-point scale on the circumference (Browne *et al.*, 1997). This procedure therefore minimises the amount of time and cognitive demand on the participant. The SEIQoL-DW has been found to demonstrate validity and stability and has been used with ALS/MND patients to quantify QoL (Clarke *et al.*, 2001; Felgoise *et al.*, 2009). The SEIQoL-DW was chosen to assess individual QoL in this research study as it was important to obtain a closer perspective on individuals' QoL, to identify which domains in life are considered to be important, and to determine if there is any relationship between these domains and the presence and severity of the dysarthria.

The SEIQoL-DW has never been used in Arabic in previous research and approval for its use had to be obtained from the developers. Since the domains and factors included in the SEIQoL-DW are generated by the individual respondent and do not depend on any set of previously generated statements, it was determined that this test has no linguistic or cultural specifications and can therefore be used across languages. In addition, the developers indicated that this measure can be used in single subject and within group designs where the respondent acts as their own control (Hickey et al., 1996).

2.6.3 MQoL-SIS

The final measure we selected was an individual item scale to allow the individual to express their view on overall QoL. The MQoL-SIS is one item in the complete MQoL questionnaire (Cohen, Mount, Strobel, & Bui, 1995) that was originally designed as a measure of subjective wellbeing in patients with cancer and HIV by reflecting the patients' experiences of QoL. The single question of the MQoL-SIS asks the respondent to rate their overall QoL on a scale of 0 (lowest possible) to 10 (highest possible) and it is used to measure the patient's own views of their QoL. Simmons *et al.* (2000) validated the measure in patients with ALS/MND using the single item scale, which they viewed as the person's overall QoL and found that it predicted subjective estimates better than other estimates. This measure was used in this study because it is inherently easy to understand in comparison to other more complex measures and can be administered even to the weakest patient.

2.6.4 Qualitative Assessment of QoL

When attempting to understand a complex phenomenon such as QoL within the context of progressive disease, it is helpful to obtain the in-depth views of the individual on factors related to their QoL through qualitative methodology, and to examine those alongside quantitative findings. With severe disability the relationship between QoL and function and communication ability may not be straightforward. In addition, since a fundamental part of QoL is that it is subjective in nature (Bernhard *et al.*, 2004) it was essential to include a semi-structured interview with patients in order to reflect their own perspective and insight into their QoL and to explore areas that may not have been covered within the SEIQoL-DW. One consideration that should be taken into account is the possible difficulties in conducting qualitative interviews with participants who have communication disorders. In addition, individuals who are verbally compromised have been included in qualitative research much less frequently than verbally non-compromised people (Lloyd, Gatherer, & Kalsy, 2006).

According to Paterson and Scott-Findlay (2002) the patterns of recruitment in published research mainly comprise those who have the ability to express their views using a clear and articulate style. Few studies that involve individuals with communication impairments have been reported and Koch *et al.* (2001) noted that the voice of individuals with intellectual disabilities is not represented in the literature. In a meta-analysis of qualitative research on chronic illness from 1980 to 1998, Thorne & Paterson (2000) reported that 'the experience of those who have trouble communicating, who have limited attention span, who are cognitively impaired, or who are in crisis are not easily accessible to researchers.' (p. 11).

However, there are studies specifically in the area of communication disorders that have included qualitative research, and this includes research on voice, aphasia, dysarthria, dysfluency, and hearing loss. The purpose of carrying out qualitative QoL research is to identify the domains that are important to the individuals with neurodegenerative disease, the factors that contribute to and detract from them, and the ways that progressive dysarthria is perceived to impact on QoL. Since there is no research evidence from the viewpoint of Arabic speaking individuals with progressive dysarthria, and to confirm the domains in life that have an impact on their QoL, it is essential to carry out qualitative research investigating QoL and communication with the focus of the interviews being on individuals' perspectives of their own QoL as it relates to changes in their communication.

2.7 Qualitative Research

Qualitative research is a term applied to research approaches that aim to provide an in-depth understanding and interpretation of the participants' world, learning about people's lives, life experiences, behaviours, emotions, and feelings as well as social movement and cultures (Straus & Corbin, 1998). When the nature of the problem is related to understanding meaning or nature of experience of people with problems such as chronic illness, addiction or divorce, qualitative research is usually selected (Straus & Corbin, 1998). Research data obtained is usually detailed, rich and extensive. The analysis results in emergent concepts, themes and ideas that produce description and classification to identify patterns related to the question of research. In this form of research data is collected in close contact with the research participants through interviews, observations, or textual and visual analysis (books and videos) (Gill, Stewart, Treasure, & Chadwick, 2008; Silverman, 2000).

Interviews are a commonly used in health care qualitative research and have been used for both communication (Dickson *et al.*, 2008; Lloyd *et al.*, 2006; Walshe & Miller, 2011; Yorkston *et al.*, 2003) and QoL research (Cahill & Diaz-Ponce, 2011; Cruice *et al.*, 2010b; Ownsworth, Turpin, Andrew, & Fleming, 2008). There are three types of interview: structured, semi-structured, and unstructured (Legard, Keegan, & Ward, 2003; Pope & Mays, 2008). Structured interviews are based on a list of predetermined questions with little or no variations and no scope for follow-up questions to responses that may need further elaboration. The semi-structured interview is used very often in health care research and consists of a key question that helps define the area that is explored while at the same time allowing the interviewer and the interviewee the space to pursue further ideas based on the responses. This approach allows the elaboration on information that is important through the use of probing questions. In the unstructured interview there are no preconceived theories or ideas. They are performed with little or no organisation and are usually carried out at the initial stages of investigating a certain issue or when nothing is known about the subject area. They start with an open question about the person's experiences and progress based on the initial response.

The purposes of the interview are to explore the views, experiences and beliefs of the participants on specific matters of the research and to provide a deeper understanding of the social phenomena. Interview schedules are usually developed prior to carrying out the semi-structured interview and generally contain open-ended questions that do not invite yes/no responses. They usually start with easy questions then proceed to more sensitive topics (Britten, 1995). Throughout the interview process probing questions such as 'can you describe a little more?' and 'Can you give me an example?' are used.

Qualitative researchers have suggested that, in qualitative research design, data collection and analysis are a continuous and simultaneous process (Bryman & Burgess, 2002). Analysis is not a separate phase as in quantitative research. Analysis of the data collected usually includes coding and indexing field-notes, transcripts, or documents collected, and represents the first step in conceptualising the data. There are different kinds of qualitative research depending on the purpose of the research including ethnographic research, phenomenology, and grounded theory. 'Framework' (Ritchie & Spencer, 1994), the analytical approach used in this research project, was developed in the context of conducting applied qualitative research. It was initiated for Social and Community and Planning Research to carry out qualitative research. It was also used by several speech and language disorders research (Parr *et al.* (2007) Pound *et al.* (2001). This method was chosen as opposed to computer software analysis since all the interviews were conducted in Arabic and it was decided to carry out the analysis in the original language of the interview and translate the final findings and interpretations into English as this may impact validity and reliability of the results (Twinn, 1997).

2.8 Caregiver Burden

Caregiver burden is defined in research as a term to describe the physical, psychological social and financial demands of care giving (George & Gwyther, 1986). The caregiver burden has been divided into two concepts. The objective burden is the events and activities associated with negative caregiver experiences, practical consequences and the behavioural changes of care receivers*.* The subjective burden is the emotional reaction of the caregiver such as worry, anxiety, frustration and fatigue (Montgomery, Gonyea, & Hooyman, 1985; Pinquart & Sörensen, 2003).

In research, care for older adults with disabilities has been described as a stressful experience that may impact physical and psychological health of the carer (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Fengler & Goodrich, 1979). Some researchers have shown that providing more care is related to a greater burden on the caregiver (Baumgarten *et al.*, 1992). Certain aspects of the care receiver's health have been linked to the degree of burden. These include the level of physical impairment (Schulz, O'Brien, Bookwala, & Fleissner, 1995), the degree of cognitive impairment (Bédard, Pedlar, Martin, Malott, & Stones, 2000), and behavioural problems (Bédard, Molloy, Pedlar, Lever, & Stones, 1997). Caregivers do not only experience stress and the negative aspects of care, they also experience positive effects such as the feeling of being needed, useful, and appreciated, the closeness to the care receiver and the feeling of pride in the ability to handle crises (Kramer, 1997).

Since individuals with progressive neurological disorders experience continuous loss of motor skills they rely on the help of others to carryout activities of daily living. Although there are no statistics on the percentage of informal helpers (caregivers: spouse, adult children, domestic workers) that provide care for older adults with chronic illness in Saudi Arabia, we know that in the USA 80 – 85% of care for older adults is given by informal helpers (Pinquart & Sörensen, 2003; Stone, Cafferata, & Sangl, 1987).

Considering the impact that communication problems play within the caregiver's burden, it was noted that communication problems have not been systematically investigated in relation to caregiver burden (Savundranayagam, Hummert, & Montgomery, 2005) even though the role that communication skills plays could be a possible factor leading to increased burden on the caregiver. Self-reported questionnaires by families caring for adults with dementia noted that breakdowns in communication were problematic and led to a decline in quality of their relationships and their interactions (Orange, 1991).

(Savundranayagam *et al.*, 2005) looked at the caregivers of patients with dementia to try and understand the part that communication problems plays with this burden. They noted that the patients' cognitive and functional status indirectly predicted problems in behaviour via communication problems. The indicators also directly predicted demand burden. In addition, behavioural problems mediated the relationship between communication problems and all forms of burden. They noted that it may be that the breakdown in communication triggers feelings of frustration and agitation that manifest themselves problems in behaviour.

In addition the burden and changes in relationships associated with changes in communication have been recognised by speech therapists for some time (Parr, Byng, Gilpin, & Ireland, 1997; Pound, Parr, Lindsay, & Woolf, 2000). Therapists have offered counselling (Rice, Paull, & Muller, 1987) and have worked with partners to improve communication between them and the patients (Kagan, 1998). Researchers have also looked at the impact that changes in communication skills have on both the patient and their caregivers through qualitative research (Hartelius *et al.*, 2010) and found that both patients and caregivers are aware of and impacted by the changes and the diminished ability to communicate.

In neurodegenerative disease research caregiver burden, depression and decrease in social life have been found within the caregivers. Some researches linked this increase I depression and burden with the functional abilities of the individual (Martínez-Martín *et al.*, 2005) others have not (Rabkin, Wagner, & Del Bene, 2000). In addition they identified that teaching the caregiver problem solving skills may help coping with the changes in their life (Murphy, Felgoise, Walsh, & Simmons, 2009).

2.9 Conclusions

To summarise, this chapter has outlined the major determinants and measures of QoL in patients with neurodegenerative disease involving dysarthria. The factors that impact on patient QoL were found to be subjective and multidimensional, and a review of the current QoL measures was found to cluster into three major categories: HRQoL, individual QoL, and overall QoL. There is no single QoL measure that adequately covers all of these important areas, and there is no single current measure validated for Arabic-speaking patients. Nevertheless, the current trend in management of individuals with neurodegenerative conditions is towards a more holistic and patient-centred approach.

This entails looking at the patient as a whole and not just at the signs and symptoms of the disease that they exhibit, thereby following the ICF model of disability. As speech and language therapists, these patient-centred standards are followed, and much progress has been made in the area of dysarthria, especially in the identification of the characteristics of speech disorders and the speech mechanism structures that are involved. Although there is knowledge in the area of communication function, this may not be fully extended to the area of dysarthria, and there is still a need to investigate the area of participation, which as previously detailed, represents the closest link to QoL measures (Cruice, 2008). The main and central goal of rehabilitation services for patients with progressive communication impairments is the improvement of QoL. Clinicians strive to identify which activities are relevant and important in the lives of their individual patients, and try to achieve some level of functional satisfaction.

In order to meet these goals, it is important to understand the complexities of what QoL really means, and the interaction between the various components (physical, psychological, social and spiritual). It must be understood that QoL is highly individualised. Clinicians need information on body function, activity and participation, as well as the personal and environmental factors which represent QoL for each individual, and to understand their needs and expectations. There is much speculation but little data on the effects and interactions between QoL and communication. By understanding the relationship between these two constructs, speech and language pathologists will be better able to serve their patients and provide them with the support they need to achieve their expectations. This is particularly true for the rehabilitation of individuals with progressive conditions where the minimum expected outcome is improvement and maintenance of a life that is worth living.

Chapter 3 - METHODOLOGY

3.1 Introduction

This chapter presents the research methodology used in this study. The first aim of the research was to develop intelligibility and a functional communication measures that is acceptable to use with an Arabic speaking population in Saudi Arabia. Part one describes the methodology employed in the development of an Arabic test to assess intelligibility and functional communication. Part two describes the methodologies employed with the participants when using the communication and QoL assessment tools in order to tackle the other aims of the research which are related to communication and how it impacts QoL in individuals with neurodegenerative disease as well as a comparison between the participants' own judgement of their QoL and functional communication and that of their caregiver. Both parts one and two outline the ethical issues, participant inclusion and exclusion criteria, and sampling strategy, as well as the obtaining of informed consent from all of the participants. Finally, details regarding the testing protocols, interviewing, and quantitative and qualitative analysis are also included.

3.2 Phase One – Development of intelligibility and functional communication measures in Arabic

Given the absence of suitable and standardised testing materials to assess communication function and intelligibility in an Arabic-speaking population, the first research step was to develop these tools.

3.2.1 Ethical Issues

Prior to participant recruitment for this study, ethical approval was obtained from both the University College London Research Ethics Committee and the Office of Research Affairs at King Faisal Specialist Hospital and Research Centre (KFSH&RC), Riyadh, Saudi Arabia, the site of data collection. The main ethical issue that was expected to arise from conducting such a study on individuals with disabilities was the potential for distress and anxiety due to the participants' vulnerability (Appendix 1). This included information about the purpose, nature and duration of the research, the expectations resulting from their participation, how data generated would be stored and analysed, and how the findings would be reported. Only those who expressed an interest in taking part in the study were approached. All participants were given the opportunity to have their questions answered, after which informed consent was obtained from all participants (Appendix 2). All participants were informed of their right to withdraw from the study and have their data destroyed at any point in time, without them having to give any reason and without any penalty or influence on the care they were currently receiving at KFSH&RC. They were also informed that declining to participate would not negatively influence the care that they were receiving at the hospital. Participation was entirely confidential, any data recorded used the participants' initials only, and all data collected was stored in compliance with the Data Protection Act.

One aspect of the research required judges to listen to a speech sample recording of the participants' speech output as they read a number of words and sentences, and these included speech language pathology students at King Saud University. These speech judges were only provided with the speech sample and the participants' initials. The primary researcher ensured that no biographical information was presented to the speech judges that might lead to identification of the participant.

As the majority of participants were being followed in the speech language pathology clinic at KFSH&RC, and in order not to potentially influence the research or the care that they were receiving, none of their speech language pathologists was involved in this research. The only information that the researcher obtained from the participants' therapists was the presence of communication disorder marked by decreased intelligibility.

3.2.2 Sampling

The participants for phase one of the research were selected from the population of patients following up in the Neurology Clinics at KFSH&RC. By reviewing previous studies looking at intelligibility assessment measures (Yorkston & Beukelman, 1978; Beukelman & Yorkston, 1979; Yorkston & Beukelman, 1981b) and studies in functional communication measures (Worral *et al.*, 2002; Ball *et al.*, 2004), the number of participants recruited ranged between 8 and 25. Therefore, the target sample size to be recruited was set at 30 participants who had a confirmed diagnosis of neurodegenerative disease with the presence of a communication disorder. This number was deemed to be sufficient to account for any participants who might withdraw from the study at a later stage. Over a period of two months 27 participants were selected who matched the inclusion criteria specified at the beginning of phase one. Two participants were excluded from the study because they were anarthric and no speech sample could be obtained for the intelligibility assessment, and a further nine participants were unable to continue (8 female and 1 male) due to difficulties in travelling to the hospital. Therefore, a total of 16 participants participated in the first phase of the research.

3.2.3 Inclusion Criteria

Inclusion criteria were as follows: the confirmed diagnosis of a neurodegenerative disease; the presence of at least a mild communication disorder marked by a decrease in intelligibility; and the ability of the participant to respond to basic yes/no questions verbally or through the use of AAC. In addition, the ability to provide independent consent was also required. A consultant neurologist at KFSH&RC confirmed the diagnosis of neurodegenerative disease, and speech and language pathologists working at KFSH&RC confirmed the presence and severity of the communication disorder in the participants.

Following approval being granted by the KFSH&RC ethics committee, a letter was sent to the Department of Neuroscience at KFSH&RC to inform them of the study, and once the department had agreed to assist with the proposed research, the researcher contacted the neurology clinical nurse coordinator via email. The nurse coordinator had access to all patients currently being followed within the neurology clinic and was able to provide the researcher with a database of all patients who matched the inclusion criteria. The medical charts of these patients were reviewed by the researcher to ensure that dysarthria was present and that there were no other medical conditions that might affect their participation in the research. Since the presence of cognitive problems and depression is common among individuals with neurodegenerative disorders, the charts were also reviewed for the presence of any cognitive or psychological disorders such as depression. It would have been useful if an assessment of cognitive skills and depression was part of the study, but that was not possible given the circumstances of the research and the fact that there are no Arabic standardised measures that the researcher is qualified to carry out on her own. The eligible participants identified were then cross-checked with the database provided by the speech language pathology clinic to determine the presence and severity of dysarthria.

Once the potential participants had been identified through the Neurology Department or the Speech Language Pathology Department (or both), their healthcare providers (speech language pathologist, physician or nurse) introduced them to the research study. Those who expressed an interest were then given information letters (Appendix 1) describing phase one of the study and provided with the contact details of the researcher. The researcher then contacted them a few days later and arranged an appointment at the hospital at the convenience of the participant.

3.2.4 Data collection

Once the participants had agreed to take part in the research, any questions they had on the assessment process were answered, and they were presented with a consent form to sign (Appendix 2). If they were unable to sign the consent form due to difficulty in motor skills, then a caregiver signed the consent form for them following the participant’s verbal consent and in the presence of a witness.

Demographic information and a medical history were collected from all participants, including age, gender, diagnosis and disease duration. Gathering this information was a way to build rapport with the participants as well as a method to obtain information on their language abilities and to ensure that they were able to answer basic yes/no questions either verbally or with the use of AAC prior to conducting the semi-structured interviews.

The phase one sample comprised of 11 men (67%) and 5 women (31%), with a mean age of 42 (range 28 – 70 years). Three of the participants had mild dysarthria (19%), seven had moderate dysarthria (44%) and six had severe dysarthria (37.5%) as reported by the speech language pathology clinical notes. The neurodegenerative conditions these participants presented with included ALS/MND (37.5%), PD (44%), and MS (12.5%). One participant had an undiagnosed neurodegenerative disease (6%). Finally none of the participants selected presented with any form of cognitive disorder or depression, as noted in their medical records.

3.2.5 Assessment of Intelligibility

Developing the assessment tool followed the same steps as the development of the Assessment of Intelligibility of Dysarthric Speech (Yorkston & Beukelman, 1981) since it was found to be a valid and reliable (Hill, Theodoros, Russell, & Ward, 2009; Sheard, Adams, & Davis, 1991).The assessment of intelligibility involved the audio-recording of participants as they produced 50 single words and a series of sentences (two sentences each of 5 to 15 words in length, total number of words 220). These words and sentences were selected by the researcher following the methodologies used in the development of the AIDS (Yorkston & Beukelman’ 1981).

3.2.5.1 ***Selection of words and sentences:***

By reviewing the AIDS (Yorkston & Beukelman, 1981) manual we noted that the researchers generated a word list that contains 50 sets of 12 similar sounding words. There words were not necessarily minimal pairs or equal in the number of syllables. For example in certain sets there are minimal pairs mixed with similar sounding words i.e., ‘form, corn, storm, torn, swarm, store’. While in other sets there are words that are not equal in the number of syllable i.e., ‘screech, each, creature, neat, sheet, beat, peach, reach’. For the development of the Arabic word list we followed a similar procedure. We took the special characteristics of the Arabic language into consideration and made sure that the words were common words used in Arabic. For the sentence intelligibility list the AIDS used a list of 5 to 15 word length sentences selected from a pool of 100 sentences. All the sentences were selected from adult level reading materials and had the following characteristics: phrases and sentences containing 5 to 15 words with contractions counted as a single word, words were chosen from 30,000 most frequently occurring (Thorndike & Lorge, 1944), phrases and sentences contain no quotations, parenthesis, proper names, or hyphenated words. For the development of the Arabic word and sentence lists we tried to take into account the characteristics set by Yorkston and Beukelman (1981) as well as adapt them to take into consideration other features of the Arabic language.

From what we know of the specific features of the Arabic language there are certain aspects that need to be considered when selecting a list of words and sentences to be used for the assessment of intelligibility. Some features of Arabic that make it unique among languages; there is a difference between the spoken and written form of Arabic for most Arabic speaking individuals (see Chapter 1). The written form is known as Modern Standard Arabic (MSA) and the spoken form in everyday life is the colloquial Arabic and depends on the dialect of the individual. One unique feature of Arabic spoken in Saudi Arabia as noted by Watson (2007) is that Arabic spoken in the Arabian Peninsula retains most of the features of MSA. In addition MSA is taught to all children in Saudi Arabia from the time they enter preschool, and all published materials such as books, newspapers, and magazines as well as the news presented on television are in MSA. Therefore, anyone who is literate and is able to read will read MSA.

In terms of phonology, there is one phoneme that is pronounced differently between MSA and colloquial Arabic in Saudi Arabia, even when reading in MSA. The majority of people in Saudi Arabia produce / dˤ/ as /ðˤ/ even it is presented by a different letter in the alphabet. Therefore the judges were instructed to accept both productions when they occurred within the sample recordings, and since they were all of Saudi Arabian origin they were familiar with this distinction in production.

a. Word selection

In order to select the word list to use within the measure, and by looking at the methodology employed within the AIDS, we noted that the most important criteria employed were that the words were familiar to the participants and that all the words within a particular set of words were similar sounding and not necessarily minimal pairs or having an equal number of syllables. Therefore when we selected our list of words we chose to find a reference with common words in Arabic since it is safe to assume that the more the common the words in the language the more familiar they will be. The basis on which the words were selected took into account the morphology of Arabic as a root and pattern morphology. Where the root is a semantic abstraction consisting of two, three, and very rarely four consonants from which nouns and verbs are derived through adding different prefixes and affixes. Therefore in the selection of the words with the categories we used the following:

- Minimal pairs root words with the same prefix and/or affix;
- The same root with different prefix and/or affix;
- The same root words with different prefix and/or affix; and
- Other similar sounding combinations.

b. Sentence Selection

For the selection of sentences we generated a pool of 20 sentences with a word length of 5 to 15 words. The same criteria that was used in the AIDS was followed, the length of the sentences was based on the number of words and not syllables, they were selected from adult level reading material (books, magazines, and newspaper articles), all the words within the sentences were present in Abdu (Abdu, 1979), and there were no proper names or quotations.

Once the words and sentences were selected 5 judges who were speech and language pathologists were asked to judge the sentence and word lists. For the word list they were asked to make sure that the words within each group were similar sounding and familiar. For the sentence list they were asked to review the lists to make sure that there were the right number of words and that the sentences were not predictable. Overall agreement was at the 95% level for the word set, with some minor recommendations being made regarding the familiarity of some of the words to the participants, and at 93% for sentence set with very minor recommendations regarding the clarity of a few of the sentence structures. Recommendations were undertaken when two or more of the reviewers agreed upon them. Once these changes had been made a final word and sentence sample was reviewed and approved by the same five speech and language pathologists, therefore the final list presentence in Appendices 3 and 5 (Arabic version) had 100% approval (Appendix 4 – presents the phonemic transcription of the words and Appendix 6 – presents a translation of the sentences in English).

3.2.5.2 Recording

Each participant was asked to produce the target utterance by reading for words and imitating for sentences. Reading skills were determined by asking participants and caregiver about the participants' reading abilities. With regards to problems with vision, participants' medical charts were reviewed to investigate the presence of any visual problems; in addition, participants and their caregivers were asked if any visual problems existed or if they needed glasses to read. This procedure took between 15 to 40 minutes depending on the severity of the dysarthria.

Recording Methodology Details:

- All recordings took place in the sound treated room in the Speech Language Pathology Clinic at KFSH&RC. This was done in order to maintain consistency between recordings as they may be affected by the environment, and the sound treated room was selected in order to decrease reverberations.
- We used a table-mounted microphone and maintained a distance of 20cm between the participant's mouth and the microphone.
- We used the same recording equipment for all the participants SONY IC recorder (ICD-UX60).

3.2.5.3 Word Intelligibility Task

For the word intelligibility assessment, participants were audio-recorded while reading 50 single words that were randomly selected from a list of twelve other similar sounding words for each item. Each participant was given the following instructions:

> *I want you to read a series of words. I will point to the word that I would like you to say. Say the word as clearly as possible so that listeners can understand the words that you are saying.*

The word list was positioned in front of each participant and the researcher introduced each item by number then identified the words to be spoken by pointing to them. Words that were obviously misread were re-recorded, thereby erasing the initial attempt.

3.2.5.4 Sentence Intelligibility Task

For the sentence intelligibility assessment participants were audio-recorded while reading a total of 22 sentences (two sentences for each word length, 5 to 15 words). The sentence samples were generated by randomly selecting two sentences from a master pool of 20 sentences of each word length. The researcher indicated the sentence that should be read by pointing to it. The researcher then read the sentence aloud once, whilst asking the participants to follow along as the sentence was being read. This was to ensure that intelligibility was not reduced due to misreading. The instruction given to participants was:

> *Follow along as I read these sentences. When I am finished I want you to read each sentence as clearly as possible.*

Each sentence was read once by the researcher and followed once by the participant. If any portion of the sentence was obviously misread, then the whole sentence was re-recorded, thereby erasing the initial attempt. All sentences were identified by length (number of words).

3.2.5.5 ***Word and sentence judges***

For both tasks there were five independent judges who were final year university students in communication disorders. The students were familiar with the word and sentence lists, but did not know the exact word or sentence to be spoken by each participant. Each judge was provided with forms for each of the tasks in order to write the words or sentences that they heard. Five judges were used at this point in the research to allow for the assessment of inter- and intra-judge reliability. We decided to use orthographic transcription of words and sentences heard as the method of assessing intelligibility sine we know from research that orthographic transcriptions are more consistent than percept estimates in assessing levels of intelligibility (Hustad, 2006).

To ensure consistency across the judges a training session was carried out with three speech samples recorded from patients following up in the Speech language pathology clinic who were not part of the study as their underlying diagnosis was not neurodegenerative diseases but rather post cerebrovascular accident. Written instructions were given to the judges (Appendix 7). The judges were asked to listen to all the samples in the speech language pathology clinic using the same headsets (beat headphones) provided by the researcher. For the word intelligibility they were given the following instructions: they were asked to familiarise themselves with the master pool of words by reading the words before they served as a judge for the first time, and then asked to transcribe the words that they heard. They were also asked to listen only once to each word.

For the sentence intelligibility they were given the following instructions: they were asked to listen to the sample and then listen to each sentence in its entirety once, then a second time, pausing when necessary to transcribe the sentence. They were encouraged to guess the words that were not completely understood and to listen to the sentence twice but not more than twice. This was done in order to ensure consistency across judges.

3.2.5.6 *Scoring*

Once the judges returned their forms to the researcher, the word intelligibility score was obtained by dividing the total number of correctly transcribed words by 50, which produced the word intelligibility score. The sentence intelligibility sample was scored by dividing the total number of correctly transcribed words by the total number of words (220) in order to obtain a sentence intelligibility score.

3.2.5.7 *Normal sample:*

Once the word and sentence intelligibility word lists were developed and approved, and since the test being developed (Arabic- Assessment of Intelligibility of Dysarthric Speech *A-AIDS*) is a new assessment tool looking at Arabic speaking individuals with dysarthria, we used the developed measure with 10 randomly selected normal Arabic speaking individuals (Table 3.1). These speech samples for both word intelligibility and sentence intelligibility were judged by three of the same student judges. Results of this normal sample are presented in Chapter 4.

Table 3-1 - Details of the normal sample participating in intelligibility assessment

Participant	Age/ years	Gender	Profession
MSM	40	F	Lab Supervisor
FAM	35	M	Engineer
SMA	27	F	Nurse
MMO	67	M	Farmer
SAS	47	F	House wife
AMA	52	M	Business man
MAY	70	M	Retired business man
AAM	72	F	House wife
HMA	25	M	Teacher
AFO	37	M	Teacher

3.2.5.8 *Analysis*

Once the judging procedure was complete, intra-judge reliability was examined through the use of Intraclass Correlation Coefficient (ICC) statistics. And inter-judge reliability was examined through the analysis of variance and ICC. These results are presented in more detail in Chapter 4 (Appendix 10 – shows SPSS results)

3.2.6 Qualitative interviews on functional communication

Another area of communication that we wanted to assess was functional communication, defined by ASHA as '… the ability to receive or convey a message, regardless of the model to communicate effectively and independently in [natural] environment" (ASHA, 1990). The purpose of the assessment was to develop a culturally acceptable tool to allow the participants a means of evaluating their own ability to communicate with others in a variety of contexts, considering environmental modifications, adaptive equipment, time required and the listeners' familiarity to the individual. Since no published research was found describing a method of assessing functional communication in an Arabic-speaking population with acquired communication disorders, qualitative semi-structured interviews were conducted to assist in the development of this measure in order to better understand the individual's own perspective on communication in everyday life situations.

Prior to developing the interview guide a number instruments that look at functional communication were reviewed in order to guide the researcher's thoughts and help in the development of the interview schedule. These instruments included: ASHA Functional Assessment of Communication Skills (Frattali & AmericanSpeech-Language-Hearing, 1995), Communication Disability Profile (Swinburn & Byng, 2006), and the Communication Effectiveness Index (Ball *et al.*, 2004). It was noted that there was a communality among these measures as they looked at communication as it occurred in everyday life, they reported on the individuals' experiences, communication partner, communication environment, and easy verses difficult experiences and circumstances. Using this information an interview schedule was developed (Table 3.2). These questions were used in the planning of the interviews rather than as a checklist to guide the progress of the interview. The questions were not always given in the same order and were not standardised across all the interviews. This allowed for the conversation to flow more like a naturally occurring conversation to simulate a real-life situation as much as was practically possible. The interviewer attempted to listen to the interviewee and used the relevant questions in the discussion in a natural manner refocusing the respondent on the relevant topics.

Table 3-2 - Interview topic guide – Functional Communication Interview

Main interview question:

Tell me about your communication experiences in a regular day?

Describe to me how you communicate?

Do you feel it has changed over time?

Describe how you ask for basic needs?

Describe your conversations and they have changed over time?

What are the communication difficulties that you face? How do you solve them?

What do you do when you are not understood?

What are the situations when communication is easier?

Are there certain situations when communication is easier or more difficult?

Has your ability to understand changed? Explain and give me examples?

Is there anything else about your communication that you would like to add regarding your communication experiences?

Probe Questions:

Can you describe a little more?

Give me an example

Give examples of certain scenarios and ask them how they would communicate. For example in social gatherings, at the market, at work, at the bank, etc.

Once participants had completed the intelligibility tasks they were given the choice of a 10-minute rest or continuing with the second task in the research protocol; the semi-structured interview. Only one of the participants requested a break, as the rest of the participants did not find the intelligibility task very tiring. The semi-structured interview was carried out in the same sound treated room in the speech language pathology clinic at KFSH&RC, so participants were not required to move. Each interview was audio-recorded using a SONY IC recorder (ICD-UX60) digital recorder and a table-mounted microphone. In addition, notes were taken during the interview.

Participants were asked to use any form of communication to respond to the interview questions, including verbal communication, augmentative communication as in communication boards and alphabet boards, gestures, and/or writing. The majority of the interviews were conducted orally and generated verbal responses from the participants. However, one of the participants with severe to profound dysarthria required the use of their personal communication boards to assist and facilitate the interview process. The average duration of each interview was 30 to 45 minutes.

Due to the presence of communication difficulties, some techniques were used to assist the researcher and the participants during the interview (Philpin, Jordan, & Warring, 2005). These included:

1. Taking time to listen carefully and encourage participants during the interview.
2. Being prepared to replay the tapes repeatedly during the transcription phase.
3. When it was apparent that the participant's speech was not sufficiently clear the interviewer made written notes of the responses verbatim and read them back to the participant to make sure they were well understood.
4. Copious field notes were also taken with each interview.
5. Written responses were permitted, kept and be included in the transcript.
6. Use of a communication board and writing down the exact selection of words, phrases, or pictures.

The researcher was also aware of the difficulty that some of the participants had with recall or with their memory due to their conditions and as such it was doubly important to be patient with the participants and to encourage them by suing prompt questions as well giving examples of certain scenarios in which they may have to communicate; for example when going to the bank, at work, in family gatherings?

Either on the same day or one day after each interview, the interviews were transcribed verbatim using the audio recording and any notes taken during the interview. Following the transcription, qualitative content analysis was used to generate the major themes and subthemes that were expressed by the participants. The 'Framework' set by Ritchie and Spencer (1994) was used since it allows a structured analysis of the Arabic transcription in the original language in addition it follows a systematic way of analysing and indexing the data. The methodology followed will be described later in Chapter 4. Once the questionnaire had been developed, peer and participant review of the questionnaire was used to add to the validity of the measure. Internal reliability was assessed using Chronbach's Alpha coefficient. Details of category development, definitions, analysis, the development of the questionnaire, validity and reliability measures are presented in more detail in Chapter 4.

3.3 Phase Two - The Relationship between QoL and Communication in Individuals with Neurodegenerative Disease

Once the Arabic communication measures had been developed and their validity and reliability confirmed (as described in Chapter 4), the second phase of the research was commenced. In this phase the main research questions asked were:

- What is the relationship between QoL and communication in adults with neurodegenerative conditions? and
- Does this relationship relate to the severity of their communication disorder?

In addition the relationship between the patient's significant caregiver's judgment of the participant's functional communication and QoL also being investigated.

3.3.1 Methodology for the research protocol

This section outlines the methodology used in phase two of this research. It includes information on the ethical issues, inclusion and exclusion criteria, and sampling procedures for participants and significant caregivers who participated in phase two of the research, together with details of the assessment protocol used. The aim was to evaluate the participants using a variety of communication and QoL measures in order to investigate whether there is a relationship between these measures for both the full sample, and separately severity of communication disorder (mild and moderate-severely decreased intelligibility based on WIS). We had to make a decision on how to best utilise our data from the intelligibility measure to divide our sample based on scores generated. We know from research that no single technique can be used and applied across all dysarthria severities (Yorkston & Beukelman, 1978). We also know that for participants with mild dysarthria sentence intelligibility on its own may not be an accurate measure for dysarthria severity index (Yorkston & Beukelman, 1981b) as the presence of contextual information may allow the listener to predict the words that were used. And therefore it requires the use of speech rate to give a more accurate estimation of severity. This was the case with our sample; 13 participants were within the normal range (97-96) on the SIS. Since we didn't carryout speech rate analysis when developing the measure and we do not have any data showing the average speech rate for normal Arabic speaking adults. That is why we preferred to use the WIS as an indication of decrease in intelligibility and not use a dysarthria severity index. In addition, word intelligibility has been shown to provide a valid and stringent measure of speech intelligibility, as they are free from fluctuation in listener responses and free from any contextual cues(Ansel & Kent, 1992; Yorkston & Beukelman, 1978; Yorkston & Beukelman, 1980). Therefore when dividing the data based on communication disorder severity we used the WIS with a cut-off of 71 – 95% for mild decrease in intelligibility and 70% and below for moderate to severe decrease. The cut-off for normal intelligibility was based on the normal intelligibility sample presented in chapter 4 as well as other clinical research (Dongilli, 1994; Yorkston & Beukelman, 1980).

In addition, patients' significant caregivers were asked to complete a communication and QoL questionnaire to investigate the relationship between a participant's and significant caregiver's judgment of the participant's QoL and functional communication.

3.3.2 Ethical Issues

Ethical issues for phase two of the research were the same as for phase one (see Section 3.2.1).

3.3.3 Sampling

Participants in phase two of the research were divided into two categories; participants and their significant caregivers.

3.3.3.1 *Participants*

The participants were selected from the same patient population as phase one. After looking at previous research in the area of psychosocial impact of communication disorders including dysarthria on QoL, it can be seen that the number of participants recruited across studies ranged from 10 – 37 (Cruice *et al.*, 2010a; Walshe, Peach, & Miller, 2008; Walshe & Miller, 2011). Therefore, the target of recruiting 40 participants was set. Data was collected at the KFSH&RC between October 2009 and January 2010 from 34 participants and their caregivers who agreed to participate in phase two of the research. This low recruitment was mainly due to the inconvenience of travelling to Riyadh, the result being that six female participants withdrew from the study. Since KFSH&RC is the main referral hospital in Saudi Arabia, and on average approximately 50% of the daily neurology clinic caseload is people who live outside Riyadh. This made it difficult for patients to return to the hospital and participate in phase two. However, the sample size of 34 was still acceptable in comparison with other studies carried out in this area. Inclusion criteria were as for phase one; and we made sure that none of the participants in phase one were contacted to participate in phase two.

All phase two participants used speech as their primary mode of communication, with the exception of one who used AAC in the form of writing. This patient was suffering from bulbar ALS/MND and had severe to profound dysarthria with adequate motor ability. He used a pen and paper to clarify his intended statements during the interview process and the SEIQoL-DW when communication breakdown occurred with the interviewer.

3.3.3.2 *Significant Caregivers*

The significant caregivers were selected by individual participants by identifying people who were important in their life, such as a spouse, family member, or close friend. For the purposes of this research participants were asked to nominate someone who was important to them, who knew them well, and who they would be comfortable with filling out a questionnaire on their behalf. This person needed to be someone who spent sufficient time with the participant to allow them the opportunity to interact and observe them while performing some of their activities of daily living. These criteria ensured that this person had sufficient perspective and knowledge about the participant’s functional communication and HRQoL. Table 3.3 summarises the relationships of the care providers selected by the participants. The main individuals selected were their spouse, children and siblings.

Table 3-3 - Frequency of significant caregiver relationship

Significant caregiver	**Frequency**
Spouse	35%
Children	29%
Sibling	20%
Parent	6%
Relative (Niece)	6%
Friend	3%

3.3.4 Data Collection

Once the participants and their caregiver had agreed to participate in phase two of the study, information sheets were given to them and to their caregivers (Appendix 1) and any questions they had were answered. They were presented with a consent form to sign; if the participant was unable to sign the consent form due to difficulties in their motor skills, their care provider would sign on their behalf after obtaining verbal consent in the presence of a witness (Appendix 2).

Demographic data and a medical history were gathered from each participant, including age, gender, diagnosis, time since onset, marital status, and employment status. In addition, medical information and functional scales for each disease were taken from the participants' medical records. The discussion of a participant's medical history was a way to build a rapport with them as well as a method to obtain informal information on their language skills and ability to answer simple yes/no questions. This was to ensure that they would be able to participate in the semi-structured interviews which are part of the research protocol.

The phase two data collection was conducted in a quiet room in the speech language pathology clinic at KFSH&RC, ensuring no distractions were present particularly during the audio recording of the intelligibility assessments and the semi-structured interviews. The participants were asked if they needed some time to rest, particularly following the intelligibility assessments since these can cause fatigue particularly for people with significant communication difficulties (Lou *et al.*, 2003; Yoshii, Takahashi, Kumazawa, & Kobori, 2006; Giovannoni, 2006). All the participants were able to complete the protocol in one session of approximately 90 minutes, except for two participants, one with ALS/MND and the other with PD, who asked to stop and return in a few days to complete the protocol. These return appointments were no more than seven days apart.

3.3.5 Research Protocol

The following research protocol was carried out in the same order for each participant:

1. **Measures of communication:**
   - Word intelligibility scale (WIS)
   - Sentence intelligibility scale (SIS)
   - Functional Communication Scale (FCS)
2. **Measure of QoL**
   - Arabic sickness impact profile (A-SIP)
   - Scheduled evaluation for individual quality of life – direct weighting (SEIQoL-DW)
   - McGill quality of life questionnaire – single item scale (MQoL-SIS)
   - Semi-structured interview

3.3.5.1 Measures of Communication

A-AIDS:

The A-AIDS is an assessment tool developed in phase one of this study and the details of its development are presented Chapter 4. The A-AIDS measures the intelligibility of a person with dysarthria and is divided into two scales: the word intelligibility scale (WIS) and the sentence intelligibility scale (SIS). This test took 20 to 30 minutes to complete. The protocol followed, judging and scoring of this task was the same as that previously described in section 3.2.5, except that judging was performed by only one independent judge.

While the participants were completing the above protocol, their significant caregiver was placed in a different room and asked to complete the FCS and the A-SIP (Al Mansoori, 2003).

Functional Communication Scale:

The Arabic FCS is a measure that was developed in phase one of this study and its development is described in Chapter 4. It is intended to be an acceptable self-assessment measure of functional communication in everyday life of Saudi Arabian adults with progressive dysarthria. The participant was asked to select on a scale from 1 to 7 (where 1 = does not, and 7 = does), how they perceive their function regarding specific statements relating to communication. The statements are divided into two categories; communication of basic needs and social communication and in total there are 31 statements in this measure. The higher a person's score the better they perceive their communication functions. Caregivers were also asked to fill in this measure based on how they observe the participants' communication function in daily life. The participants were able to complete this measure in 10 to 15 minutes.

3.3.5.2 Measures of quality of life

A-SIP:

The A-SIP is a fairly simple assessment of HRQoL. The participant is asked to place a mark next to the statements that apply to them. It is simple and straightforward to score as only the statements where the respondent answers 'yes' are recorded. The A-SIP can generate an overall score from 0 to 100 or can be scored by components providing physical, independent and psychological dimensions. The overall score is generated by totalling the scaled value of each question marked across all the categories, dividing it by the maximum possible dysfunction, and multiplying it by 100. The higher the A-SIP score, the worse the perceived HRQoL. Both participants and their caregivers were asked to complete this measure which took around 10 to 15 minutes. The participants completed the ASIP independently with the presence of the researcher in order to respond and clarify any questions that the participants may have. For the purposes of this research the overall score was determined together with the different components of the scale.

SEIQoL-DW:

The first step in carrying out the SEIQoL-DW is a semi-structured interview. The participant was asked to nominate the five areas in their life that they considered as important in determining their overall QoL. These areas were recorded via a table either by the participant or the interviewer depending on the participant's motor skills. The participant was then asked to rate each nominated domain on a vertical visual analogue from 0 – 100 mm with the terms 'best possible' and 'worst possible' anchored at the two extremes. These anchors are used to allow the individual to use their own criteria when assessing their status within each domain. Finally, the participants were asked to rotate five stacked, centrally mounted, interlocking laminated discs to reflect the weight that each domain has by the relative size of each disk. The proportion of the chart that each section represents can be scored using the 100-point scale of the disc circumference.

MQoL-SIS:

The MQoL-SIS includes a single question on overall QoL. Participants were asked to rate their overall QoL on a scale of 0 (lowest possible) to 10 (highest possible). The MQoL-SIS was used to measure the patient's own view of their QoL.

3.3.5.3 Qualitative interviews on quality of life

Little is known about the relationship between QoL and communication disorders in the presence of a neurodegenerative disease. Therefore, in addition to the use of standardised QoL measures this study wanted to investigate this relationship from the individual patient's perspective. Since there was no pre-existing theory to serve as a framework for the research question "What are the factors that influence QoL for patients with neurodegenerative disease in the presence of a communication disorder?", qualitative content analysis methodologies were used. These methodologies allow the exploration of individuals' feelings and attitudes towards their life experiences with progressive dysarthria and the influence that it may have on their QoL in daily life situations and interactions. The interview questions were designed to gain an in-depth insight into the participants' perspectives of their own QoL. The interview schedule outlined in Table 3.4 details the probing questions used during the interview.

Participants were interviewed one-to-one and the conversation was SONY IC recorder (ICD-UX60) digital recorder and a table-mounted microphone. We made sure to transcribe the interview verbatim by the interviewer on the same day that the interview took place. Notes were also taken during the interview to decrease the possibility of confusion when listening to the recording at a later time, especially with participants who had more severe forms of dysarthria. Clarification was requested from some of the participants who had more severe forms of dysarthria by repeating the exact statement as was understood by the researcher. All of the participants were asked to respond to the questions using any method of communication to relay their opinion. The same strategies noted in the phase one interviews were also used. All phase two participants used mainly speech in addition to some writing, with the exception of one participant with ALS/MND who used mainly written text to respond to the questions posed. A total of 34 participants completed the semi-structured interview; one participant with ALS/MND was too distressed to participate and therefore declined. The interview guide (Table 3.4) was used in the planning of the interviews rather than as a checklist to guide the progress of the interview. The questions were not always given in the same order and were not standardised across all the interviews. This allowed the conversation to flow more like a naturally occurring conversation to simulate a real-life situation as much as was practically possible. The interviewer attempted to listen to the interviewee and used the relevant questions in the discussion in a natural manner refocusing the respondent on the relevant topic. In addition prompt questions were used to encourage the participant to give more details particularly since the participants reported that they were not used to these kinds of questions and that for some of them they were asked these questions for the first time. In addition due to the fact that some participants may have some difficulties in recall and memory examples of different life situations were given to see if there has been a change in their experiences and if these changes had an impact on their QoL. Once transcribed, framework methodology was used to analyse the transcripts (Ritchie & Spencer, 1994) and details of the analysis are discussed in section in Chapter 6.

Once the research protocol had been completed and the scores calculated for each of the measures statistical analysis was performed to examine the correlations between different measures using SPSS software.

Table 3-4 - Schedule for quality of life interviews

How has your life been since the diagnosis?
Share your experiences about what is it like living with the neurodegenerative disease?
What things have changed over time?
What are the things that you do to enjoy your day?
What are the things that are important to you?
What are the things that help you cope with your day?
Did you have to make any adjustments at work to cope with the disease? What are these adjustments?
How has it affected you?
How have speech difficulties or changes affected you life?
Share your experiences about your social life with the presence of the speech disorder?
How has the neurological disease impacted your life?
What could be done to improver your life?
Is there anything that you would like to add?

3.3.6 Research Objectives

The objectives of the research are as follows:

1. To investigate the relationship between communication and QoL in the Saudi Arabian individuals suffering from different forms of neurodegenerative conditions;
2. To explore and examine the role that communication plays in the QoL of individuals with the neurodegenerative conditions;
3. To determine and comprehend if there is an association between the severity of the communication impairment and the QoL of people;
4. To compare the patients' judgement of health related QoL and functional communication and that of their caregivers; and
5. To explore participant generated themes and domains related to their QoL as it related to their communication through a semi-structured interview.

3.3.7 Variables

Due to the number of variables used in this study, it was necessary to identify those employed in this study, including both independent and dependent variables (Table 3.5).

3.3.8 Phase Two: Quantitative Data Analysis

Data was analysed using SPSS software and all statistical tests were set at a significance level of α = 0.05. Descriptive statistics (median, interquartile range), and ANOVA were conducted to profile the sample of participants and to examine any significant differences between the three patient groups in terms of demographic and medical history characteristics, severity of decrease in intelligibility, disease duration, communication and QoL. Spearman Correlation was carried out to answer questions one and two of the research, and interclass correlations were carried out to answer questions 3 and 4 (Appendix 18 shows SPSS output for this chapter).

Table 3-5 - Independent and dependent variables used in this study

Decreased Intelligibility	The decrease in intelligibility was based on WIS, mildly decreased intelligibility (WIS = 97-71) and moderate-severe decreased intelligibility (WIS = 70 and bellow)	Independent
Disease Duration	Calculated in months from the time of disease onset until the date of the assessment	Independent
SEIQoL-DW	Scheduled evaluation for individual QoL-Direct Weighting	Dependent
ASIP	Arabic Sickness Impact Profile[1]	Dependent
ASIP-physical score	Includes ambulation, mobility, and body care	Dependent
ASIP-psychological score	Includes measures emotion, affect, social interaction, communication	Dependent
ASIP–independent score	Includes rest, eating, work, home management, and recreation	Dependent
MQoL-SIS	A single item scale to measure QoL	Dependent
Diagnosis	The type of disease that the participant is diagnosed with (ALS-MND, MS or PD)	Independent
WIS	Word intelligibility score	Dependent
SIS	Sentence intelligibility score	Dependent
FCS	Functional Communication Score	Dependent
SigOtherFCS	Caregivers score in FCS	Dependent
SigOtherASIP	Caregiver Score in ASIP	Dependent

3.3.8.1 *Qualitative Analysis: QoL in neurodegenerative disease*

Qualitative content analysis was used to analyse the interview transcriptions and the framework described by Ritchie and Spencer (1994) was employed. This is a highly systematic method for the analysis of qualitative data developed by the Social and Community Planning Research Organization UK. It has also been used by other researchers in the field of communication disorders (Parr *et al., 2007*; Pound, *et al.,* 2001; Walshe and Miller, 2011) This method was used in preference to computer

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[1] This score is a reversed score so the higher the score, the lower the QoL.

software analysis since all the interviews were conducted in Arabic and it was decided to undertake the analysis in the original language of the interview and then translate the final findings and interpretations into English thereby preserving any cultural context in which the interview took place. This method of analysis includes the following stages: (1) Familiarisation; (2) Identifying a thematic framework; (3) Indexing; (4) Charting; and (5) Mapping and interpretation. The details of this Analysis are presented in Chapter 6.

3.4 Summary

This chapter has covered in detail a description of the methods used throughout this thesis. It includes information on the development of the measures and assessments, the obtaining of ethical approval, participant selection and inclusion criteria and research protocols. It has introduced the different assessments that were used in the two phases and has covered the data analysis procedures used. In the next three chapters the development of the A-AIDS and the analysis of data from the assessments and measures will be discussed in more detail in order to answer the research questions set out in Chapter 1.

Chapter 4 - PHASE 1: DEVELOPMENT OF INTELLIGIBILITY AND FUNCTIONAL COMMUNICATION MEASURES IN ARABIC

4.1 Introduction

In the absence of suitable standardised testing materials to assess communication function and intelligibility in an Arabic speaking population, one of the first tasks in this research project was to develop tools to answer one of the questions posed in this thesis; ‘Is there a relationship between communication and QoL for people with progressive dysarthria?’ The proposed method of answering this question was through the assessment of both functional communication and intelligibility of the dysarthric speaker and determining whether there was a correlation between more severely dysarthric speech and poor QoL. In order to develop these measures, existing measures in English were reviewed and then adapted for an Arabic speaking population taking into consideration the linguistic and cultural properties of the new population. This chapter includes a detailed description of the methods used to develop the Functional Communication Scale (FCS) and the Arabic Assessment of Intelligibility of Dysarthric Speech (A-AIDS). An overview of participant selection methods is included, as well as the development of the two assessment tools, data collection and analysis procedures. The suitability of using the tools developed for this research project, and the validity and reliability of them are also addressed within this chapter.

4.2 Development of the Arabic Assessment of Intelligibility of Dysarthric Speech

A-AIDS was developed to provide the researcher with a way of measuring the intelligibility of Arabic speaking individuals with neurodegenerative disease associated with changes in speech production and communication. Specifically, the A-AIDS was used to assess the ability to understand the speech of Arabic individuals with dysarthria. Establishing a standard protocol with specific speaking tasks and judgment methodologies allowed the collection of communication intelligibility measures that could then be used to obtain an index for the severity of dysarthria as indicated by Yorkston and Beukelman (1981).

In the assessment of dysarthria several practices have been followed by speech therapists over the years. These include perceptual assessments, component assessment, and overall assessments as discussed in Chapter 1. The overall assessment includes assessment of intelligibility. Sarno, (1968) suggested using “functional intelligibility ratings” to show how well the speaker can make themselves understood.

Speech intelligibility has been broadly defined as the accuracy with which the listener is able to decode the acoustic signal produced by the speaker (Kent, Weismer, Kent, & Rosenbek, 1989; Yorkston & Beukelman, 1980; Yorkston *et al.*, 1996). Reduction in intelligibility is a common feature among the various types of dysarthria regardless of the underlying aetiology (Hustad, 2006) and its assessment is a well-established practice in the management and assessment of the condition. As argued by Yorkston and Beukelman (1981b), the use of measures of intelligibility as an index of severity contains face validity, since the more understood a person is the better he or she is as a functional communicator.

The review of the literature revealed that there are various methods of assessing intelligibility. Usually the speaker is asked to read or imitate a word, sentence or paragraph and the listener is asked to write down what they have heard, or select it from a group of possible words or sentences. Results reveal that clinical measures of intelligibility that use orthographic transcriptions may be more consistent than the use of subjective percept estimates (Hustad, 2006). One of the most commonly used methods of intelligibility assessment in dysarthric speakers is the Assessment of Intelligibility of Dysarthric Speech (AIDS) (Yorkston and Beukelman, 1981). Therefore, it was decided to use the same methodology and adapt it to be used with an Arabic speaking dysarthric population.

4.2.1 Development of the assessment material

The development of this tool was based on the standards set by Yorkston and Beukelman (Yorkston & Beukelman, 1981a) in the development of the AIDS and the steps taken are described in Table 4.1.

Table 4-1 - Description of the steps taken to develop the A-AIDS

Steps	Process
Step 1: Development of the word intelligibility scale (WIS).	Generated from Abu's (1979) "Most Common Words in the Arabic Language" to develop the word list.
Step 2: Development of the sentence intelligibility scale (SIS).	From adult level popular reading material (books, newspapers and magazines).
Step 3: Review of the WIS and the SIS	Review of the word and sentence lists by 5 independent speech language pathologists.
Step 4: Testing the WIS and WIS with normal speaking population	The WIS and SIS were used with a 10 participants who did not have any neurological or communication problems.
Step 5: Piloting	The WIS and the SIS was used with 16 participants with progressive dysarthria to assess validity and reliability of the measure.

The process of word and sentence selection was describes in detail in Chapter 3. Once the word and sentence lists had been developed, they were then reviewed by five independent Arabic speaking speech and language pathologists who were recruited from clinics in Riyadh, Saudi Arabia. Agreement was at the 95% level for the word set with some minor recommendations being made regarding the familiarity of some of the words to the participants, and at 93% agreement level for sentence set with very minor recommendations regarding the clarity of a few of the sentence structures. Recommendations were accepted when they were agreed upon by two or more of the reviewers. Once these changes had been made a final word and sentence sample was reviewed and had a 100% agreement among the same five speech and language pathologists (Appendices 3, 4, 5, and 6).

4.2.2 Normal Sample and Piloting of the Arabic assessment of intelligibility of dysarthric speech

The WIS (word intelligibility scale) and the SIS (sentence intelligibility scale) were used with a total of ten Saudi Arabian participants (4 women, 6 men) with no communication or neurological disorders with an age range of 25 to 72 years. Details are presented in Table 4.2

Table 4-2 - Details of the normal sample participating in intelligibility assessment

Participant	Age/ years	Gender	Profession
MSM	40	F	Lab Supervisor
FAM	35	M	Engineer
SMA	27	F	Nurse
MMO	67	M	Farmer
SAS	47	F	House wife
AMA	52	M	Business man
MAY	70	M	Retired business man
AAM	72	F	House wife
HMA	25	M	Teacher
AFO	37	M	Teacher

In total, 16 people participated in piloting of the word intelligibility (WIS) scale and 12 patients participated in sentence intelligibility (SIS) scale (Table 4.3). The four participants who did not participants in the SIS scale were NYA, NAD, JMS, and AAA; this did not impact the analysis carried out since the two measures (SIS and WIS) were not compared to each other. The participants had a variety of underlying conditions including ALS/MND (6 participants; 4 men, 2 women), MS (2 participants; 1 man, 1 woman), PD (7 participants; 6 men, 1 woman) and one had an undiagnosed neurodegenerative disease (1 woman). The participant with undiagnosed neurodegenerative disease mainly presented with bulbar symptoms including severe dysarthria and dysphagia and at the time of this research this particular patient was being considered for the placement of a G-tube. The age of the patients ranged from 28-70 years old, this wide age range was expected particular with the different characteristics of the selected diseases and typical age of onset. In addition, this age range is similar to that seen with the normal sample. The severity of dysarthria reported was based on the documentation in the patients' records made by speech and language pathologists following them at KFSH&RC. Six participants had severe dysarthria (3 with ALS/MND, 2 with PD, and 1 with undiagnosed neurodegenerative disease), 7 participants had moderate dysarthria (2 with ALS/MND, 3 with PD and 2 with MS) and 3 had mild dysarthria (1 with ALS/MND and 2 with PD).

Table 4-3 - Demographic and medical history characteristics of the participants

Participant Code	Age	Gender	Diagnosis	Severity of Dysarthria
NYA	40	F	ALS/MND	Severe
HAD	51	M	ALS/MND	Moderate
AMS	44	M	ALS/MND	Mild
NAD	70	F	ALS/MND	Severe
MSJ	60	M	ALS/MND	Severe
IBA	42	M	ALS/MND	Moderate
OMH	70	M	PD	Mild
MAA	60	M	PD	Moderate
JMS	70	M	PD	Severe
MJS	40	M	PD	Moderate
LAA	42	F	PD	Moderate
AAA	65	M	PD	Severe
NSA	31	M	PD	Mild
AAZ	40	M	PD	Moderate
LMS	28	F	PD	Moderate
HHH	34	F	Undiagnosed Neurodegenerative Disease	Severe

4.2.3 Data Analysis of the A-AIDS pilot study

The WIS and the SIS were performed following the instructions and methods described in Chapter 3. Statistical analysis was then undertaken using SPSS software to determine the validity and reliability of the A-AIDS to test speech intelligibility for an adult Arabic speaking Saudi Arabian population with neurodegenerative disease.

*4.2.3.1 **Normal Sample Analysis:***

To assess the WIS and SIS with the normal sample, the same instructions were used as with the participants with dysarthria. We had three speech language pathology students listen to the sample of words and sentences produced by the normal speaker and transcribe what they heard. For the sentence intelligibility scale the score was obtained by dividing the total number of correctly heard words by the total number of words spoken (220) and multiplying it by 100. Similarly for the word intelligibility scale the score was obtained by dividing the total number of correctly heard words by the total number of words spoken (50) and multiplying it by 100. We expected the scores to be 100 to 95 for the normal sample (Appendix 10- presents that raw scores).

Intraclass Correlation Coefficient (ICC) was carried out to determine the inter-judge reliability on the WIS. As presented in Table 4.4 there was a high correlation of ratings among the team of judges with average measure ICC (0.85) indicating a strong agreement between the judges.

Table 4-4 - Intraclass Correlation Coefficient for Word Intelligibility of the normal speaking sample

		95% Confidence Interval		F Test with True Value 0			
	Intraclass Correlation	Lower Bound	Upper Bound	Value	df1	df2	Sig
Single Measures	.65	.29	.888	6.204	9	18	.001
Average Measures	.85	.55	.960	6.204	9	18	.001

Intraclass Correlation Coefficient (ICC) was carried out to determine the inter-judge reliability on the SIS. As presented in Table 4.5 there was an acceptable correlation of ratings among the team of judges with average measure ICC (0.7) indicating that the agreement between the judges had a 30% chance of being due to random variations.

Table 4-5 - Intraclass Correlation Coefficient for Sentence Intelligibility of the normal speaking sample

	Intraclass Correlation	95% Confidence Interval		F Test with True Value 0			
		Lower Bound	Upper Bound	Value	df1	df2	Sig
Single Measures	.44	.079	.790	3.636	9	18	.009
Average Measures	.70	.20	.919	3.636	9	18	.009

4.2.3.2 Reliability of the measure:

In assessing the reliability of the A-AIDS a variety of reliability measures were used for both single word and sentence intelligibility tasks. The procedures used to obtain the reliability of the A-AIDS for both word and sentence intelligibility are described in the succeeding section.

Word Intelligibility Scale

For this task five independent judges were asked to transcribe 50 words produced by the 16 selected patients with dysarthria. Seven samples were randomly selected and scored twice by the same judge, and these two transcriptions were carried out one month apart. The scores that were calculated from the judge were in the form of percentages. That is, total number of intelligible words transcribed correctly by the judges divided by the total number of possible words (50) multiplied by 100.

The Intra-judge reliability was assessed by comparing test-retest scores for seven randomly selected samples from the 16 participants. Intraclass Correlation Coefficient (ICC) was carried out to determine the intra-judge reliability for WIS. As presented in Table 4.6 there was a high correlation of ratings among the two judges with average measure ICC (0.96) indicating high agreement between the judges on both times they heard the WIS.

Table 4-6 - Interclass correlation coefficient for intra-judge correlation of the WIS

	Intraclass Correlation	95% Confidence Interval		F Test with True Value 0			
		Lower Bound	Upper Bound	Value	df1	df2	Sig
Single Measures	.92	.59	.987	33.994	6	6	.000
Average Measures	.96	.74	.993	33.994	6	6	.000

The Inter-judge difference compares how different judges rated the speech samples of the same participant. To analyse inter-judge rating, a one-way analysis of variance (ANOVA) was carried out on each of the judging tasks to determine the presence of any inter-judge differences. Table 4.7 presents the ANOVA results and it shows that there are no significant differences were found between the five judges for each of the subjects (F = 0.94, p > 0.05).

Table 4-7 - Judge-by-speaker ANOVA results (single word inter-judge)

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	3503.520	4	875.880	.914	.461
Within Groups	67050.800	70	957.869		
Total	70554.320	74			

Intraclass Correlation Coefficient (ICC) was carried out to determine the inter-rater reliability on the WIS across the 16 judges. As presented in Table 4.8 there was a high correlation of ratings among the team of judges with average measure ICC (0.99) indicating agreement between the five judges in scoring of the WIS.

Table 4-8 - Intraclass Correlation Coefficient for inter-judge reliability

	Intraclass Correlation	95% Confidence Interval		F Test with True Value 0			
		Lower Bound	Upper Bound	Value	df1	df2	Sig
Single Measures	0.95	0.90	0.980	98.781	15	60	0.000
Average Measures	0.99	0.97	0.996	98.781	15	60	0.000

Sentence Intelligibility Scale

For this task five independent judges were asked to transcribe sentences produced by 12 patients with dysarthria. The judges were asked to score seven samples twice, with the two transcriptions being carried out one month apart. The scores that were calculated from the judge were in the form of percentages. That is, total number of intelligible words transcribed correctly by the judges divided by the total number of words read (220) multiplied by 100.

The Intra-judge reliability for SIS was assessed by comparing test-retest scores for seven randomly selected samples from the 12 participants. The Intraclass correlation coefficient was used to measure consistency of judges scores on SIS when repeated one month apart. The ICC showed a high correlation of ratings among the two judges with average measure ICC (0.99) indicating high agreement between the judges on both times they heard the SIS (Table 4.9).

Table 4-9 - Interclass correlation coefficient for intra-judge correlation of the SIS

	Intraclass Correlation	95% Confidence Interval		F Test with True Value 0			
		Lower Bound	Upper Bound	Value	df1	df2	Sig
Single Measures	.99	.950	.999	408.182	6	6	.000
Average Measures	.99	.974	.999	408.182	6	6	.000

The Inter-judge difference compares how different judges rated the speech samples on the same participant. To analyse inter-judge rating, chi-square test was used since the Levene's test for testing a homogeneous population was below the significance level of 0.05. Table 4.10 presents that chi-square test results and these results revealed that there are no significant differences on how the five judges rated the 12 speech samples (Chi-square = 2.2, p > 0.05).

Table 4-10 - Judge-by speaker Chi-square test

Chi-Square	2.222
Df	4
Asymp. Sig.	0.695

To further investigate the reliability of measurements or ratings of the five judges across the 12 participants, an Intraclass Correlation Coefficient (ICC) was conducted. There was a high correlation of ratings among the team of judges with average measure ICC (0.99) indicating agreement between the judges in scoring the SIS (Table 4.11).

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Table 4-11 - Intraclass Correlation Coefficient

		95% Confidence Interval		F Test with True Value 0			
	Intraclass Correlation	Lower Bound	Upper Bound	Value	df1	df2	Sig
Single Measures	0.984	0.963	0.995	301.744	11	44	0.000
Average Measures	0.997	0.992	0.999	301.744	11	44	0.000

*4.2.3.3 **Item-by Item Analysis:***

In addition to the statistical analysis of the WIS a descriptive analysis of the WIS word list was carried out. After looking at all the words it was noted that all the vowels of Arabic were represented in both their long and short forms. The consonants were all present in initial and medial position, however there were seven consonants missing from the final position /j, k, w, χ, ʁ, ð, ðˤ/. In addition a profile of the WIS word groups was carried out (Appendix 11) based on number of syllables, consonant and vowel representation, the main sound structure of the words, and the presence of minimal pairs. It was apparent that most of the groups had a mixed number of syllables as well as different consonant and vowel representations. In addition, the groups were not always perfectly matched in acoustic features making them not equally similar sounding. Although some of the groups had very distinct features such as the presence of certain vowels, starting or ending with the same phoneme or having the same phonemes in different positions (initial, medial, and final). Some of the groups did have one or more sets of minimal pairs. They were also sometimes based on either one or more similar sounding root words with different prefixes and suffixes. A contrast of acoustic features likely to be vulnerable to dysarthria was not conducted.

Since the words were randomly selected from a pool of 12 similar sounding words, we looked at the words that were repeated; out of the 600 words 50 words were repeated between three and six times. None of these 50 words were misheard or heard correctly 100% of the time. In addition we looked at the words as a group to see if there were any groups of words that were constantly heard or misheard. As indicated in Figure 4.1 the groups were heard correctly between 70% and 40% of the time. The most misheard was group 1 and the least misheard was group 27. Group 1 from WIS profile, included one and two syllable words, long and short vowels and was based on three sets of similar sounding minimal pairs. While in group 27 all the words had two syllables, the same first and second vowel, and they all started with the phoneme /m/.

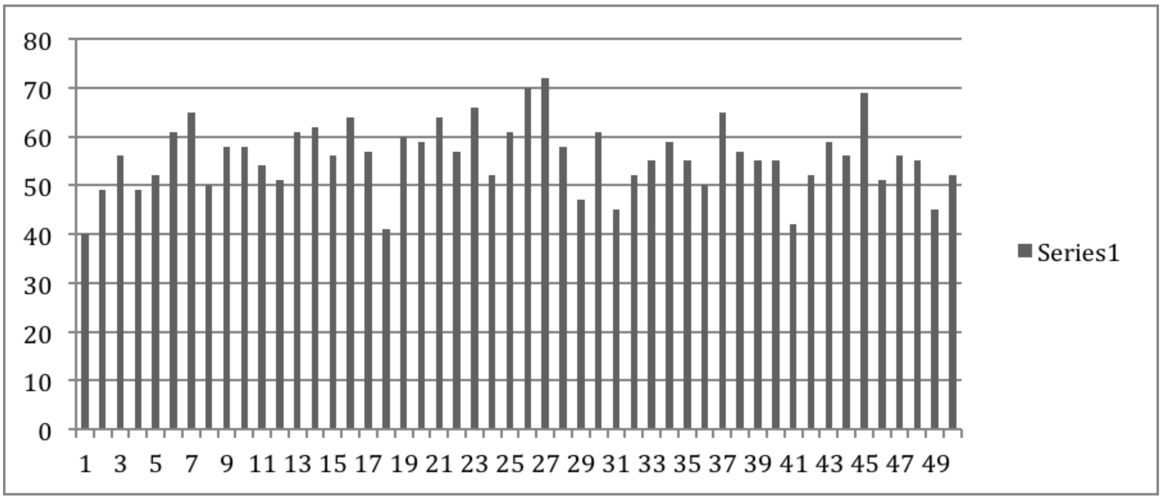

Figure 4-1– Percentage of word groups correctly heard by the five judges

4.2.3.4 *Validity of the measure:*

A valid measure is defined as: ‘one which can measure whatever it is supposed to, and achieve the purpose wanted’ (Wade, 1992). The A-AIDS was developed with the purpose to assess intelligibility and we followed steps of development that were carried out for the development of the original AIDS (Beukelman & Yorkston, 1981). It could be reasonable to assume that the A-AIDS has face validity as a measure of overall dysarthric speech since it measures the listener's ability to accurately decode the acoustic signal produced by the speaker since this is in essence the definition of intelligibility. In addition, many speakers with dysarthria experience reduction in intelligibility and therefore measures of intelligibility provide important information. However, the validity of an intelligibility measure does not only relies on the listener decoding of the acoustic message, it also depends on other factors such as the message itself, the response format, and the transition system.

For the A-AIDS we used orthographic transcriptions was the only form of responding , rather than the option of multiple choice that has been used with severely dysarthric patients in both clinical settings and in research. This decision was made to control for the judging methodology since it could have an impact on the results. Transmission systems were controlled for; the A-AIDS was recorded and scored in controlled settings with similar acoustic and environmental factors during the piloting of the test stage as well as later on in the second part of this research. This brings us to the message transmitted. Even though the standards for test development that were set by Beukelman and Yorkston during the development of the original AIDS were followed there may be some factors that were not considered during the development of the Arabic version of the measure.

The message formats that were used included connected speech in the form of sentences and individual words that were placed in groups of similar sounding words. These two formats were selected since we know from research that no single technique which measures intelligibility can be applied across all dysarthria severities (Yorkston & Beukelman, 1978). For example, participants who are at the higher end of the scale have speech close to normal with both SIS and WIS (Yorkston & Beukelman, 1981a), and therefore the speech rate must be taken into account to differentiate normal speakers from mildly dysarthric speakers. We have not carried out any measures looking at speaking rates in Saudi Arabia in general or more specifically on the SIS sample that we have. This is considered a shortcoming in the test and caution should be taken when discussing SIS measures, particularly for participants with mild dysarthria.

Furthermore, in the development of the WIS word lists we followed the same steps as the AIDS and a 100% agreement from five independent judges was sought in order to generate the final list. However, and as indicated from the WIS profile (Appendix 11) there are certain word groups that share more acoustic features than others. The fact that we did not contrast for certain acoustic features diminishes our ability to determine the features specific to Arabic that may be more vulnerable to dysarthria. Therefore, the interpretation of the WIS in its present state needs to be done with caution since we currently do not have all necessary information to determine if certain acoustic features were the reason behind some of the words not being heard. Nevertheless, the WIS is still a test of intelligibility as indicated by the definition of intelligibility “the accuracy with which an acoustic signal is converted by the speaker and recovered by the listener” (Yorkston and Beukelman, 1980; Yorkston et al., 1996). So when a judge is able to transcribe a higher number of words produced by one speaker versus another it is a reflection of the acoustic signal that they were able to convert correctly.

Familiarity with the message is an important factor to be considered. Therefore, a randomised sample selection process was used to ensure general familiarity with the word and sentence pool, but the judge did not know the exact word or sentence spoken. In addition, the examiner who was involved in the selection, recording and scoring of the sample was not in any way involved in the judging process. Another point on familiarity is the fact that the judges were allowed to hear the sentences twice; this may have had an effect on the results. The effect of familiarisation on intelligibility has shown inconsistent findings while some research has found an effect that, providing the listeners were provided a written transcript of the target production, there was a significant increase in intelligibility (Spitzer, Liss, Caviness, & Adler, 2000). Other research results contradicted previous ones and showed no difference between groups of participants who did not receive any familiarisation and those who did (Yorkston & Beukelman, 1983).

4.2.3.5 ***Summary***

The A-AIDS showed reliability in the results of the inter-judge and intra-judge statistical analysis. Caution should be used when interpreting the results of the A-AIDS particularly at the two ends of the scale (those with very mild dysarthria, and those with very severe dysarthria) since further analysis of the messages (words and sentences) needs to be carried out before the A-AIDS can be determined as a valid test of intelligibility.

Due to this fact and for the purpose of this research we decided not to use the results of the A-AIDS as an index of severity until further testing can be carried out to investigate the acoustic features of Arabic that are most affected by dysarthria as well as the inclusion of speech rate analysis with the SIS.

We are going to be looking at the percentage of intelligibility on the SIS and WIS in the group of participants in part two of this research. In defining what we meant by mild, moderate and severe decrease in intelligibility we looked at our normal sample of participants and saw that they had an intelligibility score between 98 and 100 for both WIS and SIS on the A-AIDS. We also looked at research and found that there was a cut off between normal and mild intelligibility at 95% (Dongilli, 1994; Yorkston & Beukelman, 1981a). For the purposes of this research mild was considered 95% to 71%, moderate 71% to 50% and anything below 50% was considered severe.

Focusing only on the assessment of intelligibility does not provide a complete perspective on the communication skills and experiences that an individual may have in everyday life experiences. Intelligibility measures alone do not predict the individual's communication in everyday life. The purpose of developing the Functional Communication Scale was to have an acceptable tool to allow an Arabic speaking population of Saudi Arabian patients to rate their functional communication in everyday life. This tool was required to assess functional communication as this study aimed to also investigate if there was a difference in the relationship between QoL and intelligibility, and the relationship between QoL and functional communication.

4.3 Development of the Arabic Functional Communication Scale

Functional communication is "the ability to receive and convey a message, regardless of the mode, to communicate effectively and independently in a natural environment" (Association, 1990). In order to assess communication function the different environments in which communication occurs, communication partners, their familiarity with the message and the speaker, adaptive equipment, environmental modification, and the efficiency of the communication act, all need to be taken into consideration. It is an instrument to assess functional communication measures, communication and the use of communication in functional everyday life situations (Hustad *et al.*, 1998). It is not an instrument to measure of the perceived change in communication and the impact that it has on overall life satisfaction or QoL

The optimum way to develop an Arabic functional communication scale was carefully considered and it was decided that it was inappropriate to translate or adapt any of the measures already published in English, since communication is a complex factor that is highly individualised and highly influenced by the linguistic and cultural background of an individual. Therefore, it was decided to take a closer look at an individual's own perspectives when developing this tool. In addition, to increase the reliability and validity of this assessment tool a panel of experts, including individuals with dysarthria, and speech language pathologists with extensive experience working with patients with dysarthria, were also recruited to review and give feedback on the assessment tool developed.

The stages involved in the development of the Arabic FCS are outlined in Table 4.12.

Table 4-12 - Outline of the stages involved in the development of the Arabic FCS

Stage	Process
1: Review of the published functional communication measures (ASHA FACS[2], CDP[3], CES[4]).	To familiarise the researcher with the different methodologies used for functional assessment of communication and the different themes they tap into.
2: Conduct semi-structured interviews exploring communication in everyday life.	Interview 13 participants with progressive dysarthria associated with various neurodegenerative diseases.
3: Transcribe and analyse the interviews using quantitative content analysis.	Use the 'framework' analysis approach[5] to analyse the interviews and help develop the themes for testing in the FCS.
4: Review the scale prior to pilot testing.	Review of the scale by experts in the field -5 speech language pathologists and 7 individuals with dysarthria.
5: Pilot testing	Test the developed FCS with 16 participants with dysarthria to assess its reliability and internal consistency.

4.3.1 Semi-structured interviews with people suffering from dysarthria

The same 16 individuals who participated in the intelligibility assessment described in Section 4.2.2 were asked to participate in the semi-structured interviews to help develop the FCS and 13 agreed to take part. The interviews were carried out

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[2] ASHA Functional Assessment of Communication Skills (Frattali & AmericanSpeech-Language-Hearing, 1995)

[3] Communication Disability Profile (Swinburn & Byng, 2006)

[4] Communication Effectiveness Index (Ball *et al.*, 2004)

[5] Qualitative data analysis for applied policy research (Ritchie & Spencer, 1994)

individually in a quiet room in the speech language pathology clinic at KFSH&RC, Riyadh, and the interviews were audio-recorded using a SONY IC recorder (ICD-UX60) digital recorder. In addition, notes were taken during the interview. The participants were asked to use any form of communication to respond to the research questions including verbal communication, augmentative communication via communication boards and alphabet boards, and gestures. The majority of the interviews were presented orally and generated verbal responses from the subjects. However, one of the participants with advanced ALS/MND required the use of their personal alphabet boards to assist and facilitate the interview process. The average duration of the interviews lasted 45 minutes. It was noted that some of the participants were not familiar with interviews for research purposes and were reserved about sharing some of their personal information. The interviewer assured them that all the shared information during the interview will be recorded anonymously and no personal data would be revealed, this seemed to relieve some of their uneasiness. In addition some of the participants reported that it was the first time for them to be asked such questions in relation to speech and communication.

To develop the interview schedule, research in the area of functional communication was reviewed. Functional communication assessment tools usually consist of a list of items that are scored or rated based on the effectiveness of the communication in certain situations or acts. These items usually represent communication in everyday activities. Items included in these assessment tools have usually been generated through: (a) a panel of experts, for example speech language pathologists participated in the development of the ASHA Functional Assessment of Communication Skills (Frattali & ASHA, 1995); (b) interviewing individuals with communication disorders regarding their experiences with communication in everyday activities, as used in the development of the Communication Effectiveness Index (Lomas *et al.*, 1989); and (c) observation of individuals with communication disorders in their natural environment together with interviewing family members, such as in the development of Communication Activities of Daily Living (Holland *et al.*, 1999). Topics that are usually covered include changes in communication ability that take place in different environments and may depend on the communication partner and how well the patient is able to communicate in these situations. In addition, coping strategies that the person might use to make the communication experience a successful one are also covered, as well as factors that may make communication better or worse. The therapist, while observing the patient communicate in natural settings sometimes completes the functional communication instruments. Following the review of the above measures the interview schedule presented in Table 4.13 was developed.

The participants were asked to describe their communication function in everyday life situations in order to gain an understanding of communication as it occurs in context. The interview guide (Table 4.13) was used in the planning of the interviews rather than as a checklist to guide the progress of the interview. The questions were not always given in the same order and were not standardised across the interviews. This allowed for the conversation to flow more like a naturally occurring conversation to simulate a real-life situation as closely as was practically possible. The interviewer attempted to listen to the interviewee and used questions in the discussion in a natural manner, refocusing the respondent on the relevant topics.

The interviews were transcribed verbatim during or immediately following the interview. This was important since the speech of some of the participants was somewhat unintelligible in certain parts and it was easier to transcribe while there was a better recollection of what had been said. Notes taken during the interview were also used to help in the transcription. A standard transcription notation was used and can be found in (Appendix 12).

The Framework described by Ritchie and Spencer (1994) was used for the analysis of the 13 interviews. This is a highly systematic method for the analysis of qualitative data developed by the Social and Community Planning Research Organization UK and has been used by researchers in the field of communication disorders (Parr *et al.,* 2007; Pound *et al.,* 2001). This method was chosen as opposed to computer software analysis since all the interviews were conducted in Arabic and it was decided to carry out the analysis in the original language of the interview and translate the final findings and interpretations into English to preserve any cultural context in which the interview took place.

4.3.1.1 *Familiarisation*

Once all the interviews were transcribed, this stage of the analysis involved familiarisation with the interviews by reading and re-reading all 13 interviews and this stage allowed the identification of any recurring themes. It was necessary during this stage to go over all the transcripts and listen to the interviews repeatedly in order to clarify the statements. The data from this familiarisation stage was used for the next stage of the analysis.

4.3.1.2 *Identifying a thematic framework*

This stage involved setting up a thematic framework, which was later used to sort and code the interviews. The thematic framework was generated using notes from the familiarisation stage, *a priori* knowledge from the functional communication measures reviewed, and the interview guide described in Table 4.13. A sample of five transcripts was taken and coded using this framework and this lead to further revisions to the framework and finally the formulation of an index (Table 4.14). This index covered five broad areas related to functional communication and included communication activities, communication of basic needs, emotions and feelings, communication environment and communication partner.

Table 4-13 - Interview topic guide

Main interview question:

Tell me about your communication experiences in a regular day?

Describe to me how you communicate?

Do you feel it has changed over time?

Describe how you ask for basic needs?

Describe your conversations and they have changed over time?

What are the communication difficulties that you face? How do you solve them?

What do you do when you are not understood?

What are the situations when communication is easier?

Are there certain situations when communication is easier or more difficult?

Has your ability to understand changed? Explain and give me examples?

Is there anything else about your communication that you would like to add regarding your communication experiences?

Probe Questions:

Can you describe a little more?

Give me an example

Give examples of certain scenarios and ask them how they would communicate. For example in social gatherings, at the market, at work, at the bank, etc.

The ‘framework’ includes five stages: familiarisation; identifying a thematic framework; indexing; charting; and mapping and interpretation

Table 4-14 - Index used to chart interviews (Development of the Functional Communication Scale)

Index used to chart the interviews:

1. Communication activities
    - 1.1 Speaking
    - 1.2 Understanding others
    - 1.3 Conversation
    - 1.4 Initiating a conversation
    - 1.5 Correcting communication errors
2. Communication of basic needs
    - 2.1 Requests for basic needs
    - 2.2 Requesting help
    - 2.3 Expressing agreement and disagreement
3. Emotions and feelings
    - 3.1 Changes in communication ability when angry or frustrated
    - 3.2 Changes in communication ability when emotional
4. Communication environment
    - 4.1 At home
    - 4.2 At work
    - 4.3 On the phone
    - 4.4 One-to-one conversations
    - 4.5 In a group
5. Communication partner
    - 5.1 Family
    - 5.2 Familiar person (friend or neighbour)
    - 5.3 Stranger

4.3.1.3 *Indexing*

Indexing is the process of applying the index or thematic framework to the interview transcript and it involves recording the index number on the margins of all the interview data. Completing this stage requires the continuous review of all the interview transcripts repeatedly. Some statements were assigned two different codes as they fitted into two themes. All the data from the interviews were assigned to an index number, thereby resulting in every piece of data being accounted for.

An independent Arabic-speaking observer re-coded a sample of six interview transcripts to increase the reliability of the indexing process. No differences were observed in this re-coding process. In addition, all the interview transcripts were rechecked one month later before the charting stage. This allowed some time away from the data but no further changes were made.

4.3.1.4 *Charting*

Once the thematic framework had been applied to the transcripts, a picture of the data as a whole needed to be built up by considering the range of attitudes and experiences for each issue. This is achieved by lifting data from the original text and rearranging it according to the appropriate thematic reference. Charts were drawn up using a thematic approach for each theme across respondents and involved drawing a chart for each of the five key themes with the interviewees listed on the left hand column of each chart. The order of the interviewees was kept to that recommended by Ritchie and Spencer (1994) for ease of comparison across and between participants. Appendix 13 contains an example of the charts generated.

4.3.1.5 *Mapping and Interpretation*

Once all the data was charted, themes relating to functional communication emerged. This provided an overview of the experiences of participants in everyday functional communication. These themes were then used to help develop the FCS and are presented in the following section.

4.3.2 Themes emerging from interviews

Five key themes emerged from the analysis of the interview transcripts. These were communication activities, communication of basic needs, emotions and feelings, the communication environment, and finally communication partner. Each will be discussed separately in the next section. All the interview transcript analysis and theme development were carried out in Arabic then translated once mapping and interpretation had been completed. This was done in order to preserve the contextual and cultural aspects of the language. The researcher carried out the translation from Arabic into English and two bilingual, Arabic and English speaking speech language pathologists performed a back translation with no significant differences observed.

4.3.2.1 Communication Activities

People with progressive dysarthria discussed several aspects of communication activities including speaking, understanding others, holding a conversation, initiating a conversation and correcting communication errors. The frequency of mentioning these different aspects of communication were calculated and are presented in Table 4.15.

Table 4-15 - Number of mentions of communication activities

Communication Activity	Number of Mentions
Speaking	11
Understanding Others	12
Holding a Conversation	13
Initiating a Conversation	7
Correcting communication errors	11

When asked to describe communication and how it has changed over time, six of the participants described either a change or no change in speaking and speech output.

Extract 1: LMS (MS):

> Speaking is very difficult for me […] it used to be very easy now [long pause] it is difficult and distorted. The person in front of me is not able to understand me.

Extract 2: AMS (ALS/MND):

> The way I speak has changed a lot, especially with some letter pronunciations. I don’t think anyone has noticed but I notice it myself.

Extract 3: HHH (Undiagnosed neurodegenerative Disease):

> Everything is my speech has changes. It is very very hard.

Extract 4: OMH (PD):

> There has not been that much change in the way I speak. At least I haven’t noticed it.

Four of the participants described changes in the amount and frequency of communication that they used. They reported that they do not communicate as often and have more restricted communication opportunities.

Extract 1: IBA (ALS/MND):

> I get the intention to speak […] but then I change my mind […] I

> think what is the point.

Extract 2: AMS (ALS/MND):

> I do not speak as often as I used to […] it has become more difficult. Before I used to start conversations and liked to discuss many things, now I am more reserved and choose what I really want to talk about and talk only when it is really necessary.

Extract 3: LAA (PD):

> Often I think I am going to say something and then I stop especially if I know it will be difficult […] you know depending on the timing of the medication. I feel what I was going to say is not important.

Only one participant reported the use of augmentative and assistive communication in the form of an alphabet board.

Extract 1: NYA (ALS/MND):

> Everything changed in my communication, I use an alphabet board now.

There were no significant difficulties reported in the ability to understand others; nine out of the 13 participants reported that they are able to understand others with no difficulties. However, five participants reported some change, such as the need to pay more attention, concentrate more or needing to be in a quiet environment.

Extract 1: HAD (ALS/MND):

> I have to concentrate more to understand others. But I can […] usually I can.

Extract 2: IBA (ALS/MND):

> If there are too many people […] like in a group and they are all taking it becomes noisy. It’s harder than it used to be to understand what they are saying.

Extract 3: MAA (PD):

> I have no problems at all with understanding others.

The participants reported most difficulties with holding a conversation e.g. having to concentrate more than they used to. Some even reported that having a conversation was something that they tried to avoid.

Extract 1: HAD (ALS/MND):

> When I have a long conversation and speak a lot my articulation becomes very difficult […] really difficult.

Extract 2: NSA (PD):

> I avoid having long conversations because I know I cannot keep up.

Extract 3: AAZ (MS):

> I avoid any topic that will require a lot of talking.

Extract 4: AMS (ALS/MND)

> When having a long conversation it is impossible for people to understand me.

In addition, some reported that the ease of having a conversation depended on the communication partner and the environment.

Extract 1: MAA (PD):

> I can have a conversation but not as I used to. If the timing is right, I mean for the medication then it is OK.

Extract 2: MSJ (ALS/MND)

> I can have a conversation with someone familiar […] someone who knows me like my children.

Extract 3: LMS (MS)

> I try to talk and start a conversation at home as often as I can.

Participants also spoke about initiating a conversation on their own. Some reported that they did not start a conversation except when directed to, whilst others continued to initiate conversations even if they experienced some communication misunderstandings.

Extract 1: IBA (ALS/MND):

> I get the intention to speak […] but then I change my mind […] I think what is the point.

Extract 2: HAD (ALS/MND):

> I only like to speak when I have to […] since I got the disease and my speech got affected I so not talk a lot. Only when someone speaks to me.

Extract 3: LMS (MS):

> I try to talk and start a conversation at home as often as I can.

Extract 4: AMS (ALS/MND):

> I do not speak as often as I used to […] it has become more difficult. Before I used to start conversations and liked to discuss many things, now I am more reserved and choose what I really want to talk about and talk only when it is really necessary.

Extract 5: MSJ (ALS/MND):

> I am constantly trying to speak with others. But when there is a lot to say I always rely on my son especially with a large group or with strangers.

The final theme discussed under communication activities was communication misunderstandings and how they were corrected. The participants were asked about the communication difficulties they were faced with and how they resolved them. All reported that breakdowns occurred when the person they were speaking to was unable to understand them. With regards to what they did to resolve this breakdown; the main responses were repetition, gesturing, using a communication board and finally relying on a familiar person to explain what was intended.

Extract 1: LMS (MS):

> When someone isn't able to understand me I repeat what I said or I gesture [long pause] but when this happens it frustrates me. It frustrates me a lot.

Extract 2: LAA (PD):

> I feel when the person in front of me is not able to understand what I am saying. I can see it in their face. Sometimes they ask me to repeat or clarify what I said. Other times I just do it myself […] I know they didn't get it.

Extract 3: NYA (ALS/MND):

> I use a letter board to help people understand me.

In addition, participants reported feelings of frustration and being upset when the person they were speaking to was not able to understand them.

Extract 1: IBA (ALS/MND):

> I do not like it when the person in front of me doesn't understand. That really upsets me [long pause] but when they do not understand I repeat myself.

Extract 2: HHH (undiagnosed neurodegenerative disease):

> I don't like it when I am not understood. It's so frustrating and I feel insulted when someone asks me to write down what I said because they can't understand me.

Finally, some reported certain situations where their speech was less understood such as when speaking on the phone or with a stranger.

Extract 1: HAD (ALS/MND):

> I have to repeat myself for others especially strangers to

> understand what I say.

Extract 2: OMH (PD):

> My errors are more obvious on the phone. I now because people often ask me to clarify what I said.

4.3.2.2 *Communication of basic needs*

The second key theme that emerged from the qualitative analysis of the interview transcripts was the participants' ability to communicate basic needs. The participants were asked if they would ask for things that they needed and their responses were divided into three subthemes; requests for basic needs, requests for help and expressing agreement and disagreement. The frequency of mentions is presented in Table 4.16 with the highest frequency being observed for requesting basic needs.

Table 4-16 - Number of mentions of communication of basic needs

Communication Activity	Number of Mentions
Requesting basic needs	9
Requesting for help	6
Expressing agreement and disagreement	3

The first subtheme to be discussed is requesting for basic needs. Some of the participants reported that requesting for basic things had become what their communication was about "the only thing that they can do". This included requesting for help using speech or other methods such as gestures.

Extract 1: IBA (ALS/MND):

> I use speaking just to ask for things that I need, for what I need. It is rare that I talk in other things. I was never a talkative person […] this has always been my nature and it increased now.

Extract 2: HHH (undiagnosed neurodegenerative disease):

> My speech is limited to short conversations when I have to […] and ask for basic things and help.

Extract 3: NYA (ALS/MND):

> I mainly use speaking or gesturing to ask for basic things and needs. But my family know my routine so I don't have to ask for much.

Some reported that asking for basic needs was something that they could do without experiencing any difficulties.

Extract 1: HAD (ALS/MND):

> I can ask for basic things around the house. Things that I need which is often since my movement has gotten worse.

Extract 2: MAA (PD):

> I can speak normally ask for everything that I need.

Extract 3: OMH (PD):

> Asking for things using short words is easy.

It was noted that the participants specified who they made their requests to and where. The majority talked about asking a family member for help (mother, son) and this usually occurred at home.

Extract 1: HAD (ALS/MND):

> I can ask for basic things around the house. Things that I need which is often since my movement has gotten worse.

Extract 2: MSJ (ALS/MND):

> My son is always there to help me with what I need I wither gesture or ask for it.

Extract 3: LMS (MS):

> I can ask my mother to help me with things. I used to be the one to help her, but now I have to ask for help moving around the house, getting in and out of my wheel chair.

The second subtheme was requesting help. The majority of the participants reported that requesting help in activities of daily living, such as eating, moving around, going to the bathroom.

Extract 1: LMS (MS):

> I can ask my mother to help me with things. I used to be the one to help her, but now I have to ask for help moving around the house, getting in and out of my wheel chair.

Extract 2: NYA (ALS/MND):

> If I need to go to the bathroom or help with something I can get their attention.

Extract 3: OMH (PD):

> I am able to ask for help to go to the bathroom or help to transfer from my chair or bed.

The third subtheme under communicating basic needs was the expression of agreement and disagreement. Only three participants talked about expressing agreement and disagreement using either speech or nodding and gestures.

Extract 1: HAD (ALS/MND):

> Communication has become very restricted to asking for help to do things like change, go to the bathroom and saying yes and no.

Extract 2: NYA (ALS/MND):

> I use my hands and nod to agree or disagree.

Extract 3: AAZ (MS):

> I try to express agreement or disagreement and avoid long arguments.

The participants were later asked about situations during which communication was easier or more difficult. Their responses were categorised into the remaining three key themes: communication environment, communication partner and the emotions or feelings they have at the time of the communication.

4.3.2.3 *Emotions and Feelings*

Participants did not frequently discuss their emotions and feelings as they related to communication as demonstrated by the frequencies presented in Table 4.17. Some specified the feeling of being angry or upset, whilst others reported feeling emotional or down.

Table 4-17 - Number of mentions of feelings and emotions

Communication Activity	Number of Mentions
Anger and frustration	4
Emotional	1

Extract 1: AAZ (MS):

> When I am upset my speech errors are more obvious, or at least that is what I am told.

Extract 2: NSA (PD):

> When I am upset, frustrated or nervous people tell me that my speech becomes less clear, this has been a problem especially at

> university when I have to present in front of a group.

Extract 3: HHH (Undiagnosed neurodegenerative disease):

> When I am happy I am able to speak and express myself. But when I am emotional or feel down like I am a burden on everyone then I can get nothing out.

4.3.2.4 *Communication Environment*

Participants discussed different environments where communication occurred that either made the communication experience easier or more difficult. These included home, work, communicating over the phone, one-to-one conversations and communicating in a group. Table 4.18 shows the frequency of mentions for each of these subthemes. The subthemes that were most frequently mentioned as being the most difficult were using the phone followed by having a conversation in a group, with the easier communication experiences usually taking place at home and when conducting a one-to-one conversation.

Table 4-18 - Number of mentions of communication environment

Communication Activity	Number of Mentions
At home	4
At work	5
On the phone	10
One-to-one conversation	4
In a group	7

The following extracts include one extract to represent each of the subthemes under communication environment. These subthemes were generated in response to the questions “are there situations when communication is easier?” and “are there situations when communication is more difficult?”

Extract 1 HHH (Undiagnosed neurodegenerative disease):

-conversation at home:

> At home I feel so comfortable communicating with my family. They are supportive and give me the time I need.

Extract 2 LAA (PD):

- conversation at work

> I am a teacher, when my speech started to get affected work has become more difficult [long pause] I am not as fluent and I keep discussions to a minimum.

Extract 3 NYA (ALS/MND):

- on the phone

> I used to love speaking on the phone. I could talk for hours especially since my family live far away. Now it is the most difficult thing for me. I can only say a few words.

Extract 4 IBA (ALS/MND):

- one-to-one conversations

> It is so much easier to speak to one person, when you speak to a group it requires so much more effort.

Extract 5 HAD (ALS/MND):

- in a group

> In a group I avoid speaking, I prefer to stay quit or speak to the person closest to me […] speaking with a group of people is hard.

4.3.2.5 *Communication Partner*

The final key theme is communication partners. Again this theme was generated from responses to situations that make communication easier or more difficult. The participants' responses were categorised into three subthemes; family, familiar person (friend or neighbour) and stranger. Table 4.19 presents the number of mentions for each subtheme.

Table 4-19 - Number of mentions of communication partner

Communication Activity	Number of Mentions
Family	10
Familiar person	5
Stranger	12

The majority of participants reported that communicating with a family member made communication easier; however, two of the participants reported the opposite and either that they tried to avoid communication at home or that their family members were unable to understand them, which they found frustrating and upsetting.

Extract 1: LAA (PD):

> My husband is not able to understand me all the time and it frustrates him, it has affected our relationship.

Extract 2: AAZ (MS):

> I restrict speaking at home to the minimum.

Extract 3: LMS (MS):

> My family, I mean my parents are able to understand me [long pause] I think it is because I spend so much time with them and I rely on them. But others can't like my aunt and cousin they need some help to be able to understand what I said.

Extract 4: IBA (ALS/MND):

> Communication is so much easier with my family, particularly with my daughter I rely on her a lot for communication.

Only five of the 13 participants discussed communicating with a familiar person such as a friend or neighbour. All the participants except one reported that communication with a familiar person made communication an easier experience. The one who disagreed reported that communicating with someone who was familiar made them more aware of the changes that had taken place with regards to their speech*.*

Extract 1: HAD (ALS/MND):

> I feel comfortable when talking with someone who I know and familiar with.

Extract 2: HHH (undiagnosed neurodegenerative disease):

> For someone who lives with me […] they know me well and can understand what I need and what I am saying. But for a stranger they need to see my mouth move and I have to keep repeating myself [long pause] sometimes I have to get someone else to explain what I am saying.

Extract 3: LAA (PD):

> When I have to speak with a stranger I feel pressured and I sometimes plan what I want to tell them in advance. For example if I go to get something, go to an appointment or the bank.

Finally, communicating with a stranger was the subtheme that was most frequently mentioned by the participants when they discussed situations that made communication more difficult.

Extract 1: HAD (ALS/MND):

> I have to repeat myself for others to understand me especially with strangers.

Extract 2: LMS (MS):

> Strangers are not aware of my communication errors and mistakes, however with my friends and colleagues who are used to the way I used to speak […] there is a difference between how I used to speak and now.

4.3.2.6 *Summary*

The themes that emerged from the analysis of the interview transcripts related to five key themes concerned with communication activity, communicating basic needs, the impact that emotions have on communication behaviour, and relating to the environment in which communication occurs and with whom. In the next section the use of these themes will be discussed together with their hierarchy of difficulty in order to develop an Arabic FCS.

4.3.3 Development of the functional communication scale

When looking at all the themes discussed above, a FCS could be devised with 23 statements divided into two main areas; communication of basic needs and social communication. The statements were placed within a hierarchical order from easiest to most difficult communication activity, and also for communication partner, as described by the majority of the participants in the interviews (Figure 4.2). A 7-point visual analogue Likert scale was adapted from the one used in the ASHA FACS (Table 4.20).

Table 4-20 - Rating Key for the FCS

7	Does	The participant performs the communication behaviour, needing no assistance and/or prompting.
6	Does with minimal Assistance	The participant performs the communication behaviour, rarely needing assistance and/or prompting.
5	Does with minimal to moderate assistance	The participant performs the communication behaviour, occasionally assistance and/or prompting.
4	Does with moderate assistance	The participant performs the communication behaviour, often needing assistance and/or prompting.
3	Does with moderate to maximal assistance	The participant performs the communication behaviour, very frequently needing assistance and/or prompting.
2	Does with maximal assistance	The participant performs the communication behaviour only with constant assistance and/or prompting.
1	Does not	The participant does not perform the communication behaviour, even maximal assistance and/or prompting.
N	Not applicable	Not applicable.

Figure 4-2-Communication difficulty hierarchy

Communication Activity		Communication Partner	
Express Agreement and Disagreement	↓	Family	↓
Request basic needs – Ask for help		Someone familiar	
Have a conversation		Stranger	
Initiate a conversation		In a group	

4.3.4 Reviewing, piloting and amending the proposed functional communication scale

To review the questionnaire five speech and language pathologists with experience of working with individuals with dysarthria were asked to review the first version of the FCS. They agreed with the main areas and themes that were being assessed as well as the hierarchy used, and also made a number of suggestions:

1 Adding a statement about the ability to communicate strong likes and dislikes.
   - it was felt that it was important to have such a statement especially for those who have a more severe form of dysarthria

2 Division of the statement regarding ‘exchanging information over the phone’
   - this was to specify who they are communicating with (i.e., family member, familiar person, or a stranger).

3 Adding a number of statements regarding ‘understanding’
   - this was to specify a familiar person, family member, stranger, in a group situation and on TV or radio.

4 The statement regarding work should be more specific
   - to include professional conversations vs. the exchange of basic information.

Taking these suggestions into consideration a final version of the FCS was developed (Appendix 14 – Arabic Version and Appendix 15 – English version) with 31 statements divided into two main areas; communication of basic needs and social communication. This scale was piloted on 16 participants with progressive dysarthria associated with neurodegenerative disease. The details of the participants are presented in Table 4.21. In total, 16 patients participated in piloting of the functional communication scale. The participants had a variety of underlying conditions including ALS/MND (6 participants; 4 men, 2 women), MS (3 participants; 1 man, 2 woman), PD (7 participants; 6 men, 1 woman). The participants had an age range from 30 to 70 years. Dysarthria severity was based on the speech language pathology report two participants presented with profound dysarthria, four with severe dysarthria, six with moderate dysarthria and finally four with mild dysarthria.

Table 4-21 - Details of Participants in FCS Pilot Study

Participant Code	Age	Gender	Diagnosis	Severity of Dysarthria
SMJ	70	M	PD	Severe
MSJ	40	M	PD	Moderate
SMA	44	M	ALS/MND	Mild
DAN	70	F	ALS/MND	Profound
MJS	60	M	ALS/MND	Severe
BAI	42	M	ALS/MND	Moderate
YAN	40	F	ALS/MND	Profound
AAM	60	M	PD	Moderate
DAH	51	M	ALS/MND	Moderate
ALA	42	F	PD	Moderate
HOM	70	M	PD	Mild
SML	30	F	MS	Moderate
AAA	56	M	PD	Severe
HAM	43	F	MS	Severe
ANS	31	M	PD	Mild
AAS	50	M	MS	Mild

These participants were asked to report any difficulties in understanding the statements in the questionnaire or if they found any of the items confusing. They were given the following written instructions with each FCS:

- Functional communication is the ability to receive and convey a message, regardless of the mode, in order to communicate effectively in your everyday natural environment.
- We would like you to consider carefully while responding to the following questions on your ability to communicate at this moment. You should pay attention to how much help you need and the different compensations you or someone else needs to make in order for a successful exchange of information to take place.

- Please try and respond to all the statements.

None of the 16 participants reported any difficulties with understanding the scale items or in completing the scale. In addition, a Cronbach's alpha coefficient was calculated to measure the internal consistency and reliability of the scale. The coefficient for the multi-item scale was calculated as 0.97, indicating an excellent result (George & Mallery, 2003) (Table 4.22). In addition to internal consistency, the FCS had face validity since individual with dysarthria were involved in its development (Lomas *et al.*, 1989).

Table 4-22 - Cronbach's alpha coefficient for the internal consistency and reliability of the FCS developed

Cronbach's Alpha	Number of Items
0.974	31

Therefore the FCS is considered a valid test to assess the functional communication in the everyday life of participants in this study. However, further assessment is required to be able to generalize the results to other populations of adults with communication disorders. In addition, the differences between the patients completing the assessment measure, the caregiver completing the measure and/or the clinician completing it while observing the patient in a real life situations needs to be investigated before the measure can be used reliably in clinical settings. Some similarities may be noticed between the FCS and the ASHA FACS (ASHA, 1995) (Appendix 16) these similarities may be due to the fact that they both measure functional communication, we asked about areas that were covered within our interview, and finally the therapists that reviewed the test were familiar with the ASHA FACS. The FCS is still considered a valid, reliable, and acceptable test to be used with a Saudi Arabian population of participants with neurodegenerative disease since it was generated, reviewed, and piloted on the same population.

4.3.5 Summary

In this chapter the development of tools to measure intelligibility and functional communication for an Arabic speaking population in Saudi Arabia was discussed. Attempts were made to decrease the variability between the patients who participated in the standardisation of the measures and those for whom the measures will be used. This was achieved by following the same recruitment protocol and approaching the same population of patients, i.e., patients with progressive dysarthria associated with neurodegenerative diseases being followed up in the neurology or speech therapy clinic at the KFSH&RC, Riyadh. In addition, the various methods employed used both quantitative and qualitative data in order to ensure the validity and reliability of the A-AIDS and the FCS. Reliability and internal consistency for both measures was examined through the use of multiple statistical analyses. Some factors on validity of both measures were discussed and will be looked at further in Chapter 7. Finally, these measures will be used in the next part of the research looking at communication and QoL for individuals with neurodegenerative disease.

Chapter 5 - THE RELATIONSHIP BETWEEN QOL AND COMMUNICATION IN INDIVIDUALS WITH NEURODEGENERATIVE DISEASE

5.1 Introduction

Following the development of tools used in the assessment of communication (functional communication and intelligibility) within an Arabic speaking population of Saudi Arabian adults with neurodegenerative disease, the research now moved on to investigate the relationship between QoL and communication in individuals with neurodegenerative diseases. As noted in the methodology chapter, the results of this research are divided into quantitative and qualitative, this chapter will focus on the quantitative results and is divided into two parts. The first part of the chapter describes the results concerning communication assessments and QoL for 34 patients diagnosed with neurodegenerative disease involving progressive dysarthria in Saudi Arabia. The second part of the chapter is devoted to profiling four randomly selected participants using SEIQoL-DW individual patient profiles based on their disease type and dysarthria severity.

The results relating to the quantitative analysis of data and the SEIQoL-DW profiles are presented within this chapter, beginning with the communication assessments and QoL measures for 34 participants with either MS, PD or ALS/MND. Following this an analysis of the relationships between communication assessments and QoL measures is undertaken. The second section is devoted to reporting a detailed profile of four randomly selected participants based on their disease type and dysarthria severity, using SEIQoL-DW individual patient profiles.

Prior to discussing the quantitative analysis of the research and the descriptive statistics we will present an outline of how the raw scores of the instruments used was obtained:

> Arabic Sickness Impact (ASIP) profile and its subcategories (psychological, independent, and physical): the score for the ASIP can generate a score from 0 to 100. Totalling the scaled value of each question marked across all the categories, dividing it by the maximum dysfunction and multiplying it by 100 generate the overall raw score. This can be done for the overall score or for each of the categories. One thing is since the ASIP looks at negative impact in

HRQoL the higher the score the more severely impacted the HRQoL i.e., the lower the health related QoL.

Scheduled Evaluation of Individual QoL – Direct Weighting (SEIQoL-DW): this measure is obtained through a semi-structured interview as described in Chapter 3 (Methodology) the participants are asked to rate their five nominated areas on a vertical disk analogue from 0 to 100mm for best possible and wors possible anchored at the two extremes. This is followed by asking the participant to rotate a five stacked, centrally mounted, interlocking laminated discs to reflect the weight that each domain has by the relative size of the disc. To calculate the SEIQoL Index, having obtained the wights and levels for each of the five cues, for each cue the index is measured by multiplying the level by the weight then sum these products across the five cues.

McGill Quality of life – Single Item Scale (MQoL-SIS): is a simple single question scale where the person is asked to rate overall QoL from 0 (lowest possible) and 10 (highest possible).

Functional Communication Scale (FCS): participants are asked to select from a scale from 1 to 7 (1=does not, 7 = does) on how they perceive their function in regards to communication in everyday life situations. A total of 31 statements are included in this measure. The raw score is calculated by dividing the total of the selected scales (1 to 7) by 31. The higher the score the better the person perceives their own QoL.

Word Intelligibility Scores (WIS): the scores for these measures are obtained by dividing the total number of correctly heard words by 50 and multiplying it by 100 to get the percentage of WIS intelligibility

Sentence Intelligibility Score (SIS): the scores for these measures are obtained by dividing the total number of correctly heard words in the sentences by 220 and multiplying it by 100 to get the percentage of SIS intelligibility

To decide how to best use the intelligibility scores to look at our sample and carryout the quantitative data we know from research that no single technique can be used and applied across all dysarthria severities (Yorkston & Beukelman, 1978). We know that for participants with mild dysarthria sentence intelligibility on its own may not be an accurate measure for dysarthria severity index (Yorkston & Beukelman, 1981b) as the presence of contextual information may allow the listener to predict the words that were used. Therefore it requires the use of speech rate to give a more accurate estimation of severity. In our sample 13 participants had SIS scores within the normal range (97-96) on the SIS. Since we did not carry out speech rate analysis when developing the measure and we do not have any data showing the average speech rate for normal Arabic speaking adults we preferred to use the WIS as an indication of decrease in intelligibility and not use a dysarthria severity index. In addition, word intelligbiliy has been shown to be a valid of intelligibility excluding any contextual cues (Ansel & Kent, 1992; Yorkston & Beukelman, 1978; Yorkston & Beukelman, 1980). Therefore when the participants based on WIS we used a cut-off of 95 - 71 for mild decrease in intelligibility and 70 and below for moderate to severe decrease. The cut-off for normal intelligibility was based on the normal intelligibility sample presented in Chapter 4 as well as other clinical research (Dongilli, 1994; Yorkston & Beukelman, 1980).

5.2 Profile of Participants

Thirty-four eligible participants with a neurodegenerative disease (23 men, 11 women) volunteered to complete the functional communication, intelligibility and QoL assessments. Judgements of each participant's functional communication and A-SIP QoL were also collected from each participant's caregiver. Table 5.1 presents a profile of the 34 patients who participated in this study, in terms of gender, age, marital status, employment status, and if unemployment was related to health. Table 5.2 presents the descriptive statistics for disease duration, severity of intelligibility based on WIS, functional communication, intelligibility (SIS, WIS), and QoL. Disease duration (in months) was calculated as the length of time from date of diagnosis to the date of the interview.

Table 5-1 - Demographic characteristics of 34 patients with neurodegenerative disease

Study variable	Total Sample *N* = 34 (100%)	ALS-MND *n* = 9 (26%)	MS *n* = 6 (18%)	PD *n* = 19 (56%)	ANOVA Tests of Group differences	*p*-value
Gender	*N* (%)	*n* (%)	*n* (%)	*n* (%)		
Male	23 (68%)	8 (89%)	2 (33%)	13 (69%)	*F* = 2.728*	0.079
Female	11 (32%)	1 (11%)	4 (67%)	6 (31%)		
Age (years)						
Median (Mdn)	51 (12.5)	51	34	55	*F* = 11.121*	0.000
Interquartile Range (IR) (25, 50, 75)	39, 51, 60	39, 51, 56	29, 34, 36	47, 55, 64		
Age bands						
20-29 years	1 (3%)	0 (0%)	1 (17%)	0 (0%)		
30-39 years	9 (26%)	2 (22%)	5 (83%)	2 (11%)		
40-49 years	5 (15%)	2 (22%)	0 (0%)	3 (17%)		
50-59 years	10 (29%)	4 (44%)	0 (0%)	6 (33%)		
60-69 years	7 (21%)	1 (11%)	0 (0%)	6 (33%)		
70-79 years	1 (3%)	0 (0%)	0 (0%)	1 (6%)		
Marital status						
Married	28 (82%)	8 (89%)	3 (50%)	17 (89%)	*F* = 2.830*	0.074
Never Married	6 (18%)	1 (11%)	3 (50%)	2 (11%)		
Employment status						
Retired	8 (24%)	2 (22%)	0 (0%)	6 (32%)	*F* = 1.788*	0.184
Unemployed	12 (35%)	4 (44%)	2 (33%)	6 (32%)		
Part-time	6 (18%)	2 (22%)	1 (17%)	3 (16%)		
Full-time	8 (23%)	1 (11%)	3 (50%)	4 (21%)		
Unemployment is related to health						
Yes	12 (35%)	4 (44%)	1 (17%)	7 (37%)	*F* = 0.597*	0.557
No	22 (65%)	5 (56%)	5 (83%)	12 (63%)		

Notes: SD = Standard deviation. ALS-MND = Motor Neurone Disease; MS = Multiple Sclerosis; PD = Parkinson's Disease. [1] SEIQoL-DW = Individual QoL (higher scores = higher QoL) [2] A-SIP = Health related QoL (lower scores=higher QoL) [3] MQoL-SIS = Single Item Scale QoL (higher scores = higher QoL). *F* = For ANOVA test. *Sig. < .05, **Sig. < .01, *** Sig. < .001.

Table 5-2 - Patients' disease duration, dysarthria severity, communication, intelligibility and QoL

Study variable	**Total Sample N=34 (100%)**	**ALS-MND n=9 (26%)**	**MS n=6 (18%)**	**PD n=19 (56%)**	**ANOVA Tests of Group Differences**	***p*-value**
Disease duration						
Months Mean (SD)	16 (66.3)	16	78	96	*F* = 6.667*	0.004
Interquartile Range	3-312	12, 16, 37	37, 78, 90	60, 96, 132		
Severity of Intelligibility in WIS						
Mild	26 (76%)	4 (44%)	6 (100%)	16 (84%)	*F* = 4.469*	0.020
Moderate to severe	8 (24%)	5 (56%)	0 (0%)	3 (16%)		
Communication assessments	Mdn (IR)	Mdn (IR)	Mdn (IR)	Mdn (IR)		
Word Intelligibility	87 (72,87,92)	70 (60,70,83)	88 (79,88,94)	90 (80,90,93)	*F* = 6.184*	0.005
Sentence Intelligibility	95 (91,95,96)	25 (42,65,96)	28 (95,96,97)	18 (94,95,96)	*F* = 8.812*	0.001
Functional Communication	7 (5,7,7)	6 (4,6,7)	7 (5,7,7)	7 (6,7,7)	*F* = 1.384	0.266
QoL measures	Mdn (IR)	Mdn (IR)	Mdn (IR)	Mdn (IR)		
SEIQoL-DW Index Score[1]	60 (42,60,70)	63 (49,63,77)	41 (34,41,65)	61 (47,61,71)	*F* = 1.689	0.202
A-SIP Total [2]	25 (15,25,37)	35 (19,35,47)	20 (8,21,35)	22 (15,22,30)	*F* = 0.851*	0.437
MQoL – SIS[3]	6 (5,6,8)	7 (4,7,8)	7 (6,7,8)	7 (5,7,9)	*F* = 7.369*	0.002

Notes: SD = Standard deviation. ALS-MND = Motor Neurone Disease; MS = Multiple Sclerosis; PD = Parkinson's Disease. [1] SEIQoL-DW = Individual QoL (higher scores = higher QoL) [2] A-SIP = Health related QoL (lower scores=higher QoL) [3] MQoL-SIS = Single Item Scale QoL (higher scores = higher QoL).

F = For ANOVA test. *Sig. < .05, **Sig. < .01, *** Sig. < .001.

Nine participants had a confirmed diagnosis of ALS/MND (8 men, 1 woman), 6 had MS (2 men, 4 women), and 19 participants had PD (13 men, 6 women). An ANOVA analysis found that the participants with MS were significantly younger than those with ALS/MND and PD (F = 11.121, $p < 0.05$). The participants with ALS/MND also demonstrated significantly lower disease duration than those with MS or PD (F = 6.667, $p < 0.05$). All 6 participants with MS were found to have mildly decreased intelligibility, whereas those with ALS/MND and PD had a mix of mild and moderate to severe decrease in intelligibility (F = 4.469, $p < 0.05$).

The majority of the sample had mild decrease in intelligibility (76%, n = 26) and a minority had moderate to severe decreased in intelligibility (24%, n = 8). Among the subgroups, participants with ALS/MND were more likely to have moderate to severe decrease in intelligibility (56%) than mild (44%); whereas the participants with PD were more likely to have mild decrease in intelligibility (84%) than moderate to severe (16%). As discussed earlier, all of the participants with MS patients had only mild decrease in intelligibility (100%).

5.3 Normality Testing

Before conducting inferential statistics, normality tests were conducted, as the normal distribution is an assumption for parametric tests (Brace, Kemp, & Snelgar, 2003). These tests included a visual examination of all variable histograms and boxplots to examine skew and the presence of any outliers, followed by a number of statistical tests including skewness, kurtosis, and a Shapiro-Wilk test of normality. The Shapiro-Wilk test is appropriate for small sample sizes of around 30. All the histograms showed varying degrees of left or right skew, and five of the distributions had outliers visible on the boxplots, which is inconsistent with a normal distribution. Furthermore, 10 of the 16 distributions were found to be non-normally distributed using the Shapiro-Wilk test, as they had a p-value of less than 0.05 (Appendix 17).

5.4 Correlation Analysis

5.4.1 Testing the relationship between communication, intelligibility and QoL

Research Question 1. How does QoL (as measured by SEIQoL-DW, A-SIP the three components of A-SIP and MQoL-SIS) relate to communication *assessments (as measured by word intelligibility, sentence intelligibility and functional communication) in patients with neurodegenerative disease?*

Initially the entire sample of 34 patients was examined. Table 5.3 presents the Spearman correlations between QoL and communication and it was found that functional communication and total A-SIP scores were significantly negatively correlated (*rho* = -0.458, *p* < 0.01, two-tailed). According to Cohen's (1988) guidelines, there is a medium association between total A-SIP and functional communication. This result indicates that participants who scored higher on functional communication also reported higher A-SIP HRQoL.

Table 5-3 - Spearman correlations between patients' measures of communication and measures of QoL

Total Sample (N=34)	WIS	SIS	FCS	A-SIP Total	A-SIP[1]	A-SIP[2]	A-SIP[3]	SEIQoL -DW
(SIS)	0.843**							
(FCS)	0.419*	0.330						
A-SIP Total QoL	-0.183	-0.041	-					
A-SIP Physical[1] QoL	-0.252	-.081	-0.221	0.822**				
A-SIP Independent[2] QoL	-0.241	-.076	-	0.886**	0.646**			
A-SIP Psychological[3] QoL	-0.048	0.060	-	0.801**	0.462**	0.672**		
SEIQoL-DW Index QoL	0.288	0.127	0.341	-0.182	0.003	-0.233	-0.192	
MQoL- SIS QoL	0.308	0.325	0.338	-0.424*	-0.319	-	-	0.272

Notes:

Measures of Communication – WIS (Word Intelligibility Scale), SIS (Sentence Intelligibility Scale) and FCS (Functional Communication)

[1] A-SIP Physical Score (measures ambulation, mobility, and body care)

[2] A-SIP Independent Score (measures rest, eating, work, home management, and recreation)

[3] A-SIP Psychological Score (measures emotion, affect, social interaction, communication)

** Correlation is significant at the 0.01 level (2-tailed)

* Correlation is significant at the 0.05 level (2-tailed)

The subscales within the A-SIP were examined and it was found that functional communication and the independent component of the A-SIP HRQoL were also significantly, negatively correlated (*rho* = -0.520, *p* < 0.01, two-tailed). This medium association indicates that participants who scored higher on functional communication also reported higher levels on the independent components of the A-SIP. Functional communication and the psychological component of the A-SIP were significantly negatively correlated (*rho* = -0.605, *p* < 0.01, two-tailed). This strong association indicates that patients with neurodegenerative disease who scored higher on functional communication also reported higher levels on the psychological components of A-SIP QoL. No other correlations were found to be statistically significant.

Since the groups of patients were not equal in number based on type of disease, severity of decrease in intelligibility, disease duration, and age. We wanted to have a closer look at these differences to determine how they may impact the results. Therefore, we divided the sample based on the type of disease and the severity of decrease in intelligibility to determine if that has an impact of the correlation results.

5.4.2 Type of Neurodegenerative Disease

> *Research Question 2. Does the type of neurodegenerative disease (ALS-MND, MS and PD) influence the relationship between communication assessments (as measured by word intelligibility, sentence intelligibility and functional communication) and QoL (as measured by SEIQoL-DW, A-SIP and MQoL-SIS) in participants who have neurodegenerative diseases?*

Table 5.4 presents the Spearman correlations between the communication assessments and the QoL measures separately for the disease groups. The data was grouped by diagnosis (ALS/MND, MS and PD), and a Spearman correlation was performed to examine whether the relationship between the communication assessments (as measured by word intelligibility, sentence intelligibility and functional communication) and QoL measures (as measured by SEIQoL-DW, A-SIP, the three A-SIP subscales and MQoL-SIS) was significant.

5.4.2.1 *Participants with ALS-MND*

Sentence intelligibility and SEIQoL-DW index scores were significantly positively correlated (*rho* = 0.802, $p < 0.05$, two-tailed). This strong association indicates that participants with ALS-MND, who scored higher on sentence intelligibility, also reported higher SEIQoL-DW index scores. No other correlations were statistically significant.

5.4.2.2 *Participants with MS*

Functional communication and overall A-SIP scores were significantly negatively correlated (*rho* = -0.941, $p < 0.01$, two-tailed). This strong association indicates that participants with MS who scored higher on functional communication also reported higher overall HRQoL on the A-SIP scale. Functional communication and the psychological component of A-SIP QoL scale were also significantly, negatively correlated (*rho* = -0.893, $p < 0.05$, two-tailed). This strong association indicates that participants with MS who scored higher on functional communication also reported higher levels on the psychological components of the A-SIP. Word intelligibility and the physical component of A-SIP were significantly negatively correlated (*rho* = -0.829, $p < 0.05$, two-tailed). This strong association suggests that participants with MS who scored higher on word intelligibility also reported higher levels on the physical component of A-SIP. No other correlations were statistically significant.

5.4.2.3 **Participants with PD**

Functional communication and the independent components of A-SIP QoL showed a negative significant correlation (*rho* = -0.577, $p < 0.05$). This moderate association reveals that participants with PD, who scored higher on functional communication, reported higher levels on independent components of the A-SIP. Functional communication and psychological components A-SIP were also negatively significantly correlated (*rho* = -0.590, $p < 0.01$). This moderate association reveals that participants with PD who scored higher on functional communication reported higher levels on independent components of the A-SIP QoL.

Table 5-4 - Spearman correlations for functional communication, intelligibility, and QoL by disease group

ALS-MND (n = 9)	WIS	SIS	FCS	A-SIP Total	A-SIP[1]	A-SIP[2]	A-SIP[3]	SEIQoL -DW
SIS	0.714*							
FCS	0.718*	0.475						
A-SIP Total QoL	-0.159	0.126	-0.109					
A-SIP Physical[1] QoL	-0.008	0.345	0.168	0.887				
A-SIP Independent[2] QoL	-0.227	-0.092	0.168	0.577	0.433			
A-SIP Psychological[3] QoL	-0.294	-0.004	-0.571	0.795	0.550	0.160		
SEIQoL-DW Index QoL	0.323	0.802*	0.240	0.381	0.524	0.048	0.503	
MQoL- SIS QoL	0.198	0.482	0.025	-	-0.506	-0.221	-0.278	0.408
MS (n = 6)	WIS	SIS	FCS	A-SIP Total	A-SIP[1]	A-SIP[2]	A-SIP[3]	SEIQoL-DW
SIS	0.828*							
FCS	0.395	0.000						
A-SIP Total QoL	-0.600	-0.207	-					
A-SIP Physical[1] QoL	-	-0.414	-0.577	0.714				
A-SIP Independent[2] QoL	-0.714	-0.414	-0.880*	0.943	0.771			
A-SIP Psychological[3] QoL	-0.232	0.000	-0.893*	0.783	0.232	0.696		
SEIQoL-DW Index QoL	0.029	0.000	0.516	-	0.143	-0.371	-0.725	
MQoL- SIS QoL	0.522	0.525	0.678	-	-0.377	-	-0.662	0.464
PD (n = 19)	WIS	SIS	FCS	A-SIP Total	A-SIP[1]	A-SIP[2]	A-SIP[3]	SEIQoL-DW
SIS	0.841*							
FCS	0.289	0.110						
A-SIP Total QoL	0.076	0.105	-0.374					
A-SIP Physical[1] QoL	-0.112	-	-0.242	0.797				
A-SIP Independent[2] QoL	0.057	0.206	-0.577*	0.882	0.563*			
A-SIP Psychological[3] QoL	0.049	0.176	-0.590**	0.828	0.483*	0.853*		
SEIQoL-DW Index QoL	0.418	0.094	0.450	-	-0.261	-0.322	-0.340	
MQoL- SIS QoL	0.158	0.082	0.275	-	-0.076	-0.457	-	0.311

Notes: WIS = Word Intelligibility Scale, SIS = Sentence Intelligibility Scale, FCS = Functional Communication

[1] A-SIP Physical Score (measures ambulation, mobility, and body care)

[2] A-SIP Independent Score (measures rest, eating, work, home management, and recreation)

[3] A-SIP Psychological Score (measures emotion, affect, social interaction, communication)

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

Once we looked at the sample by disease group we wanted to see if the severity of communication disorder based on WIS scores impacted the relationship.

5.4.3 Mild versus Moderate to Severe Decrease in intelligbility

> *Research Question 2. Does the severity in decrease of intelligibility based on WIS (mild, moderate-severe) influence the relationship between the communication assessments (word intelligibility, sentence intelligibility and functional communication) and the QoL measures (SEIQoL-DW, A-SIP and MQoL-SIS) in neurodegenerative patients?*

Table 5.5 presents the Spearman correlations between the communication assessments and QoL measures separately for the mild and moderate to severe decrease in intelligibility. The data was grouped by severity of WIS (mild and moderate to severe), and Spearman Rho correlations were used to examine the possibility of group differences in the strength of the relationships between functional communication, intelligibility and QoL scores.

5.4.3.1 ***Participants with mild decrease in intelligibility***

Total A-SIP and functional communication scores were significantly negatively correlated (rho = -0.586, $p < 0.01$, two tailed). This moderate association suggests that participants with a mild decrease in WIS who scored higher on the functional communication assessment also reported better HRQoL on the A-SIP scale. Physical components of the A-SIP and functional communication were significantly negatively correlated (rho = -0.435, $p < 0.05$, two-tailed). This medium association suggests that participants with mild decrease in intelligibility who scored higher on the functional communication assessment also reported better physical components of the A-SIP. Independent components of A-SIP and functional communication were also significantly negatively correlated (rho = -0.639, $p < 0.01$, two-tailed). This strong association suggests that participants with mild decrease in intelligibility who scored higher on the functional communication assessment also reported better independent components of the A-SIP scale. Psychological components of A-SIP and functional communication were significantly negatively correlated (rho = -0.691, $p < 0.01$, two-tailed). This strong association suggests that participants with mild decrease in intelligibility who scored higher on the functional communication assessment also reported better psychological components of the A-SIP HRQoL scale. SEIQoL-DW index score and functional communication were significantly positively correlated (rho = 0.421, $p < 0.05$, two-tailed). This moderate association suggests that participants with mild decrease in intelligibility who scored higher on the functional communication assessment also reported better SEIQoL-DW index scores.

5.4.3.2 Participants with moderate to severe decrease in intelligibility

Total A-SIP and word intelligibility scores were significantly negatively correlated (*rho* = -0.881, *p* < 0.01, two-tailed). This strong association indicates that participants with moderate-severe decrease in intelligibility who scored higher on the word intelligibility assessment reported better overall A-SIP scores. Psychological components of the A-SIP HRQoL and word intelligibility were significantly negatively correlated (*rho* = -0.790 < 0.05 two-tailed). This strong association suggests that participants with moderate to severely decreased intelligibility who scored higher on the word intelligibility assessment also reported better psychological components of the A-SIP HRQoL scale.

Table 5-5 - Spearman correlations among functional communication, intelligibility, and QoL by severity of intelligibility disorder based on WIS

Mild Decrease in intelligibility (n = 26)	WIS	SIS	FCS	A-SIP Total	A-SIP[1]	A-SIP[2]	A-SIP[3]	SEIQoL –DW
SIS	0.779**							
FCS	0.409*	0.326						
A-SIP Total QoL	-0.110	-0.077	-					
A-SIP Physical[1] QoL	-0.243	-0.195	-0.435*	0.801**				
A-SIP Independent[2] QoL	-0.221	-0.114	-	0.937**	0.747**			
A-SIP Psychological[3] QoL	-0.130	-0.094	-	0.911**	0.569**	0.823**		
SEIQoL-DW Index QoL	0.307	0.043	0.421*	-0.172	0.042	-0.254	-0.272	
MQoL- SIS QoL	0.231	0.125	0.281	-0.583**	-0.473*	-0.717**	-0.565**	0.258

Moderate-severe decrease in intelligibility (n = 8)	WIS	SIS	FCS	A-SIP Total	A-SIP[1]	A-SIP[2]	A-SIP[3]	SEIQoL –DW
SIS	0.524							
FCS	0.467	0.443						
A-SIP Total QoL	-	-0.595	-0.168					
A-SIP Physical[1] QoL	-0.506	-0.145	0.327	0.771*				
A-SIP Independent[2] QoL	-0.790*	-0.623	-0.187	0.862**	0.479			
A-SIP Psychological[3] QoL	-0.410	-0.434	-0.442	0.205	-0.183	0.127		
SEIQoL-DW Index QoL	0.036	0.536	-0.288	-0.286	-0.234	-0.162	0.346	
MQoL- SIS QoL	0.013	0.651	0.263	-0.294	-0.155	-0.225	0.032	0.355

Notes: WIS = Word Intelligibility Scale, SIS = Sentence Intelligibility Scale, FCS = Functional Communication

[1] A-SIP Physical Score (measures ambulation, mobility, and body care)

[2] A-SIP Independent Score (measures rest, eating, work, home management, and recreation)

[3] A-SIP Psychological Score (measures emotion, affect, social interaction, communication)

* *p*< 0.05 level (2-tailed). ** *p*<0.01 level (2-tailed).

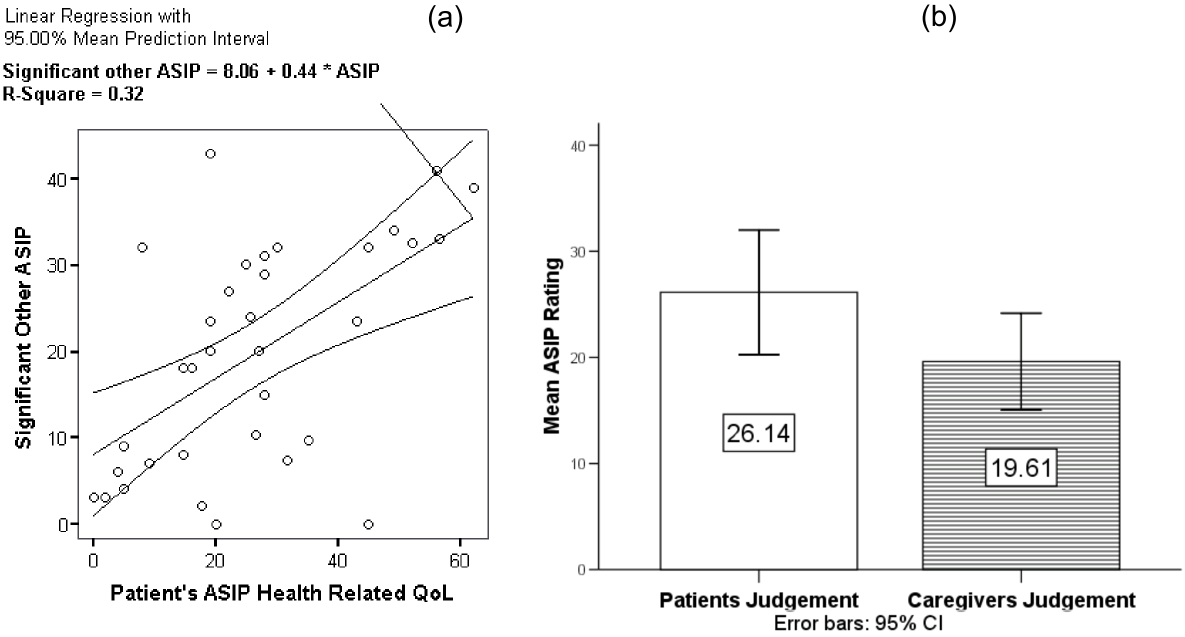
5.4.4 Patients versus Caregivers Judgements of FCS and ASIP

> *Research Question 3. Is there a relationship between the participants' judgment of their own total A-SIP HRQoL and their caregivers' judgment? If so how do they relate to each other?*

To investigate this question a Spearman correlation was performed to examine whether the relationship between participants' judgment of their own total A-SIP and their caregivers' were significantly related. The results found that participants and caregivers' judgments were significantly positively correlated (*rho* = 0.567, $p < 0.05$, two-tailed). This moderate association indicates that patients and caregivers reported similar judgments of the patients' total A-SIP HRoL. Figure 5.1 (a) illustrates this positive relationship and Figure 5.1 (b) shows that patients' judgment of their own HRQoL was higher (*M* = 26.14, range: 0-62. *SD* = 16.8), when compared to their caregivers judgement (*M* = 19.61, range: 0-43, *SD* = 13.0), by 6.53 points.

Figure 5-1- Comparison of patients' and caregiver's judgment of total A-SIP.

(a) Scatterplot of participants and caregivers total A-SIP judgments showing the positive linear relationship and 95% confidence intervals. (b) Bar chart of participants vs. caregivers total A-SIP judgments.



Intraclass Correlation Coefficient (ICC) shows how similar the ratings in two groups resemble each other to determine the caregiver and participant inter-rater reliability on the ASIP total score as well as the individual components (physical, independent and psychological). As presented in Table 5.6, ICC for the ASIP was not high (0.67).

However, when looking at each of the individual components of the ASIP it seems that the rating of the caregivers and the participants resemble each other more in the physical component with a high intraclass correlation (.80) and psychological component (0.78) as compared to independent component (measures rest, eating, work, home management, and recreation) with lower ICC (0.55)

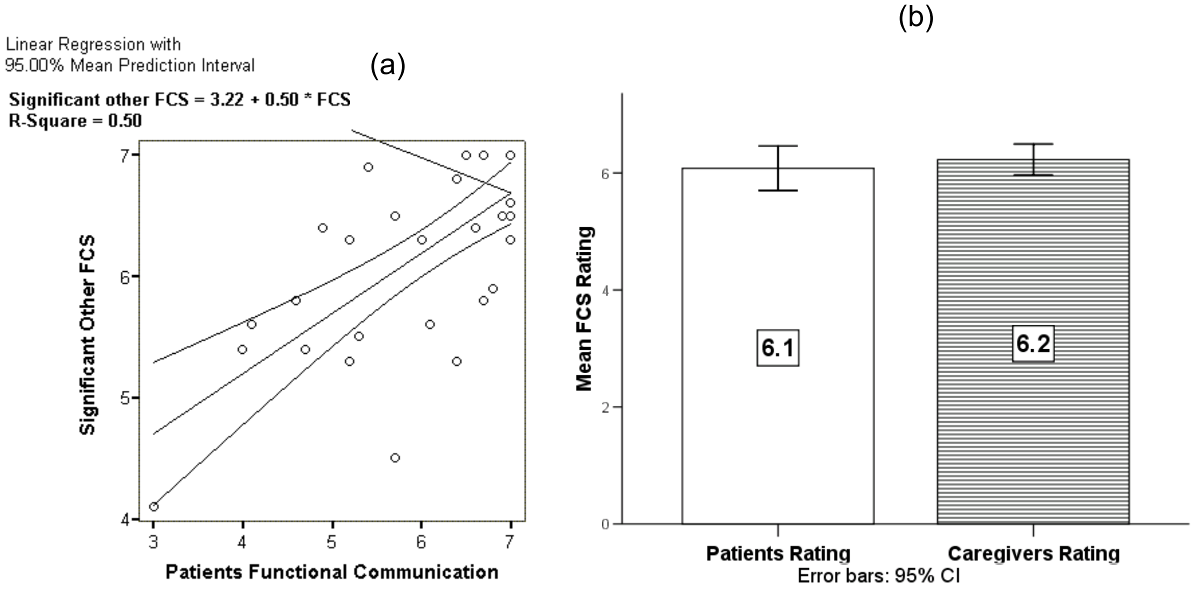
Table 5-6 - Intraclass Correlation Coefficient for ASIP ratings

		Intraclass Correlation	95% Confidence Interval		F Test with True Value 0			
			Lower Bound	Upper Bound	Value	df1	df2	Sig
Overall ASIP	Single Measures	.51	.20	.722	3.451	33	33	.000
	Average Measures	.67	.34	.83	3.451	33	33	.000
Physical ASIP	Single Measures	.66	.43	.818	5.242	33	33	0.000
	Average Measures	.80	.60	.900	5.242	33	33	.000
Independent ASIP	Single Measures	.38	.07	.635	2.329	33	33	.009
	Average Measures	.55	.13	.777	2.329	33	33	.009
Psychological ASIP	Single Measures	.64	.31	.817	5.670	33	33	.000
	Average Measures	.78	.47	.900	5.670	33	33	.000

Research Question 4. Is there a relationship between the participants' judgment of their functional communication scores and their caregivers' judgment of their functional communication? And if so how do they relate to each other?

To investigate this question a Spearman correlation was performed to examine whether the relationship between the participants' judgment of their own functional communication and their caregivers' judgment were significantly related. The results showed that patients' and caregivers' judgments were significantly positively correlated (*rho* = 0.725, p < 0.01, two-tailed). This strong association suggests that patients and caregivers expressed similar judgments about the patients' level of functional communication. Figure 5.2 (a) illustrates this positive relationship and Figure 5.2 (b) shows that participants' and caregivers' judgments of patients' functional communication were almost identical (*M* = 6.08, range: 3-7. *SD* = 1.0; and *M* = 6.23, range: 4-7, *SD* = 0.7, respectively).

Figure 5-2 Comparison of pateints' and caregivers' jugement of functional communication
(a) Scatterplot of participants and caregivers functional communication judgments showing the positive linear relationship and 95% confidence intervals. (b) Bar chart of participants vs. caregivers functional communication judgments.



The relationship of the scores of participants' and caregivers' judgment of functional communication, the Intraclass Correlation Coefficient (ICC) was conducted and as presented in Table 5.7 there was a high ICC (0.79) indicating that the participants high agreement between the participants and their caregivers in scoring the FCS.

Table 5-7 - Intraclass Correlation Coefficient

		95% Confidence Interval		F Test with True Value 0			
	Intraclass Correlation	Lower Bound	Upper Bound	Value	df1	df2	Sig
Single Measures	.66	.42	.814	4.927	33	33	.000
Average Measures	.79	.59	.89	4.927	33	33	.000

5.5 SEIQoL Individual Quality of Life Profiles

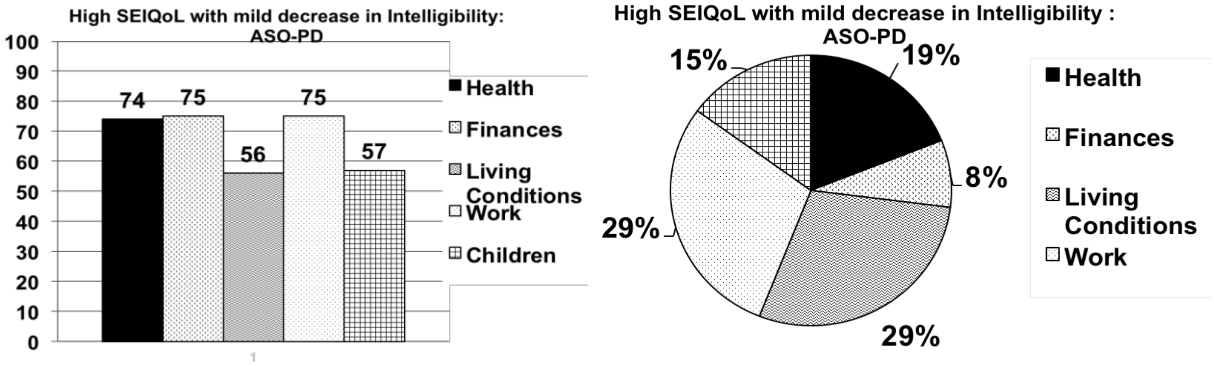
The SEIQoL-DW was completed by 33 patients. The index score of the SEIQoL-DW is the sum of the individual cue levels by cue weight. However, since each may vary independently then looking at the index score alone may not truly reflect the selection and rating of the individual cues. Four individual SEIQoL-DW profiles of participants with neurodegenerative disease will therefore be discussed in depth. These profiles were selected to represent one participant in each of the following categories: high SEIQoL-DW index score and mild decrease in intelligibility; low SEIQoL-DW index score and moderate-severe decrease in intelligibility; high SEIQoL-DW index score and moderate-severe decrease in intelligibility; and low SEIQoL-DW index score and mild decrease in intelligibility. For the purposes of this research anyone with a SEIQoL-DW of above 50 was presumed to have a high score and those below 50 a low score. The frequency of the areas/domains nominated by the participants and the range of weights they were given will then be discussed.

5.5.1 The Four SEIQoL-DW Participant Profiles

5.5.1.1 *Profile 1*

The first SEIQoL-DW individual profile is for a male patient with PD and mild decrease in WIS, who had a high SEIQoL-DW score (67). At the time of the interview he was 50 years old, had a disease duration 132 months (11 years), was married, and in full-time employment. This participant seems to be satisfied with his life and nominated the areas of health, finances, living conditions, work, and children as having the most impact on it. As Figure 5.3 demonstrates, he rated three areas (health, finances and work) as being very good (above 70) and the two other areas (living conditions, children) were lower (56 and 57, respectively). The pie chart in Figure 5.3 shows the weight that the participant indicated for each of the nominated domains. Living conditions (29%) and work (29%) were clearly of greatest importance, followed by health (19%), and children (15%), with finances (8%) ranked as lowest in importance. The high level of functioning and high importance weight given to living conditions and work may be what is mostly driving the high SEIQoL-DW index score. Overall, this participant appears to be highly satisfied with his individual QoL. His word intelligibility (98), sentence intelligibility (99), and functional communication (7) scores were above average, with corresponding low scores for total A-SIP HRQoL (28) and A-SIP subscales, physical (24), independent (29), and psychological (38), indicating reasonably high HRQoL. In addition, he had an average MQoL-SIS QoL score (6).

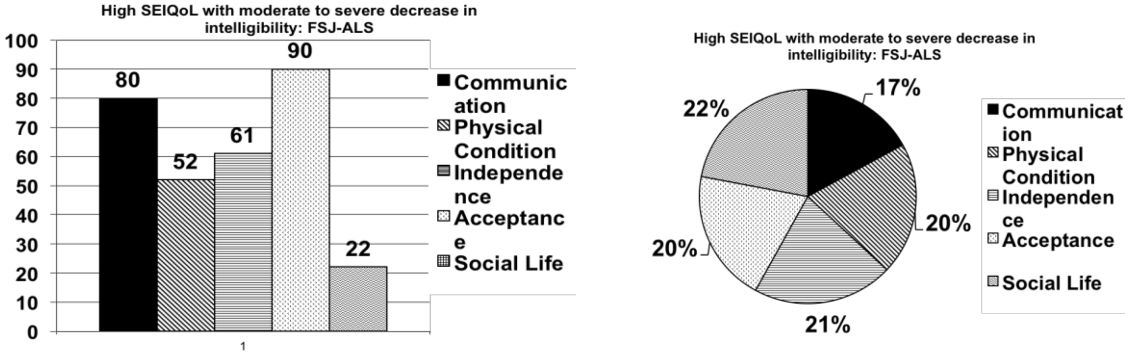
Figure 5-3 Profile 1- SEIQoL-DW levels of importance and weightings



5.5.1.2 *Profile 2*

The second profile is of a male participant with ALS/MND and moderate-severe decrease in WIS score with a high SEIQoL-DW score (60). At the time of the interview he was 51 years, had a disease duration of 12 months, was married, and employed part-time. This participant seems to have a high level of individual QoL despite scoring low on the ALSFRS (16 out of a possible 40). As Figure 5.4 demonstrates, the overall index score may be influenced by the significantly high rating he gave both acceptance and communication (90, 80 respectively) with a weight (20) for acceptance and (17) for communication. The worst rating was given to social life (22, Figure 5.4). It is demonstrated by this profile that despite a low level of function (ALSFRS = 16) and moderate-severe decrease in intelligbility (WIS = 74, SIS = 64) this participant's perception of his individual QoL and functional communication (FCS = 6) is reasonably high. He has an equally high HRQoL; total A-SIP health-related QoL (20) and A-SIP subscales of physical (20), independent (19), and psychological (15). However, his MQoL-SIS (5) was considerably low.

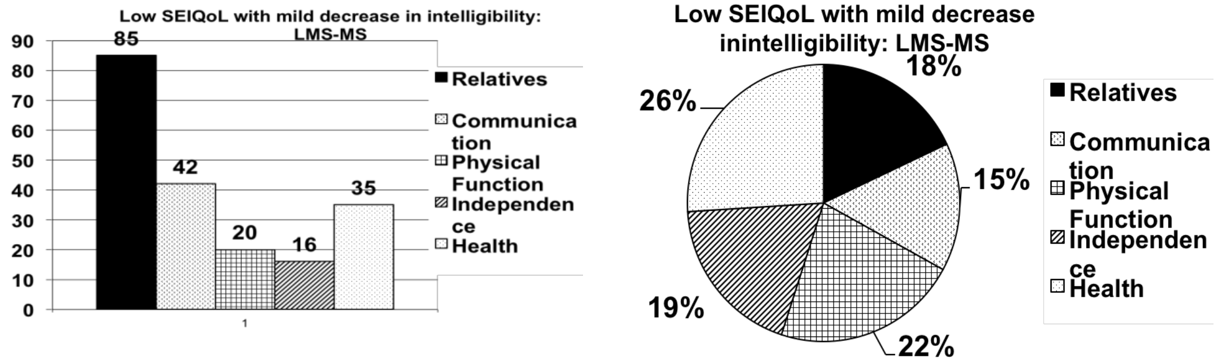
Figure 5-4 Profile 2- SEIQoL-DW levels of importance and weightings



5.5.1.3 *Profile 3*

The third profile is that of a female participant with MS and mild decrease in intelligibility, who had a low SEIQoL-DW score (38). At the time of the interview she was 30 years old, had a disease duration of 7 years, had never married, and was unemployed. The domains that she nominated as having the highest impact on individual QoL were relatives, communication, physical function, independence, and health. The domain of relatives is the only factor the participant rated as being good with the other factors being rated as poor (below 50, Figure 5.5). The index score was negatively influenced by poor satisfaction with communication and physical as they were rated at low levels of function with high weights (26, 22 respectively, Figure 5.5). Even though, the participant rated relatives' support at a high level of satisfaction, the weight that was given was low compared to the other domains (Figure 5.5). This participant appears to be functioning reasonably well on communication measures (WIS = 74, SIS = 98); however, her perception of her communication skills was below average for this group of participants (FCS = 5). Other QoL measures were also low; HRQoL was also low; A-SIP total score (57), A-SIP physical (60), independent (45), and psychological (65). Finally, she had an average MQoL-SIS score (6).

Figure 5-5- Profile 3- SEIQoL-DW levels of importance and weightings

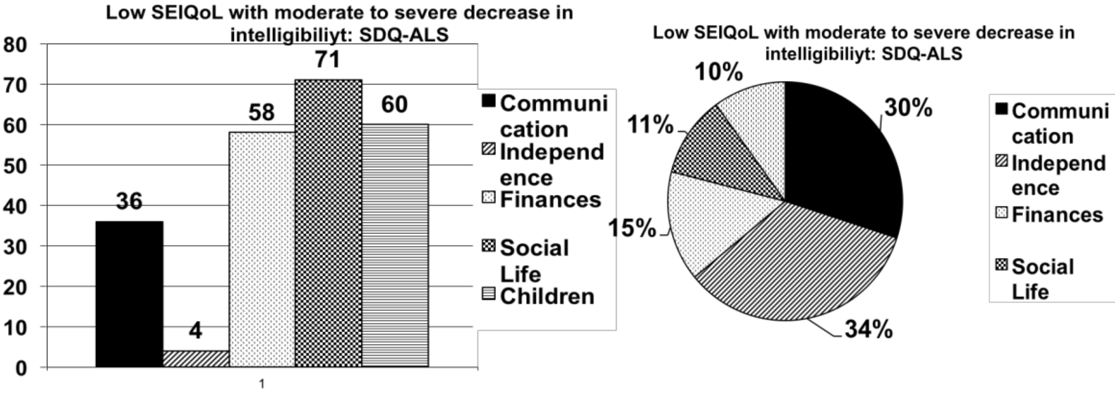


5.5.1.4 *Profile 4*

The final profile presented is that of a male participant with ALS/MND and moderate-severe decrease in intelligibility with a low SEIQoL-DW score (35). At the time of the interview he was 65 years old, had a disease duration 4 years, was married, and retired. As Figure 5.6 demonstrates, this patient rated one SEIQoL-DW domain (social life) as being very good (71), finances and children were a little lower (58 and 60 respectively) but still considered as good. However, the levels of functioning for communication and independence were low (36, 4 respectively). These last two domains appear to be negatively driving the index score for individual QoL as they were given the highest weights; communication (30) and independence (34, Figure 5.6). Overall, this participant appears to be poorly functioning in his word intelligibility

(72), sentence intelligibility (20) and ALSFRS (15). However, his perception of his own communication was high, FCS (7). His other measures of QoL were; total A-SIP (35), A-SIP physical (44), independent (55), and psychological (10), which are matched by a very low MQoL-SIS score (2).

Figure 5-6 - Profile 4- SEIQoL-DW levels of importance and weightings



5.5.2 Identifying the most frequent SEIQoL domains and the range of weights they were given by participants

After looking at individual participant profiles for the SEIQoL-DW categories attention will now be focussed on the frequency with which each domain was nominated and the range of weights given. These results are divided into two groups based on the severity of the decrease in intelligibility. SEIQoL-DW categories were ranked using the frequency value for each category in the interview. Relative category rankings were determined on the basis of the frequency value for each SEIQoL-DW category.

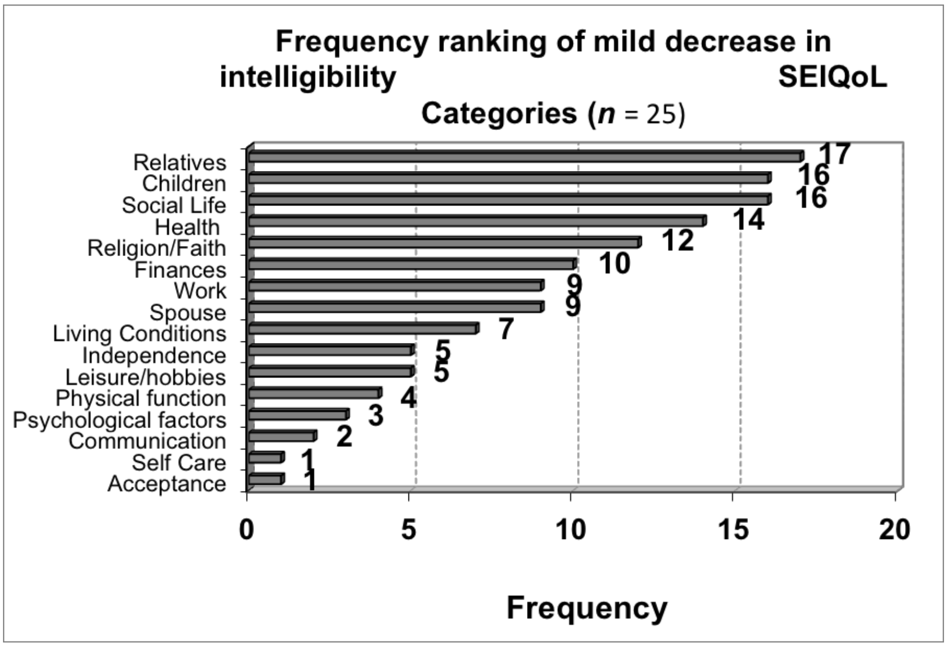
5.5.2.1 *Participants with mild decrease in intelligibility based in WIS:*

As Table 5.8 shows, the highest frequency and therefore the most important SEIQoL domain for the 25 patients with mild decrease in intelligibility was relatives (17), followed by the need for a social life (16), children (16), health (14), religion/faith (12) and finances (10). Less important SEIQoL-DW domains were spouse (9), work (9), living conditions (7), leisure/hobbies (5), independence (5), physical function (4), psychological factors (3), and communication. The least important domains for participants with mild decrease in intelligibility were acceptance and self-care, both scoring a frequency of 1. A graphical presentation (Figure 5.7) further illustrates the most important SEIQoL-DW domains as they were nominated and ranked by participants with mild decrease in intelligibility.

Table 5-8 - Frequency and weight ranking of mild decrease in WIS score SEIQoL-DW domains (n = 25)

Factor Ranking	SEIQoL Domains	Frequency	Range of weights
1	Relatives	17	0.12 to 0.53
2	Social Life	16	0.02 to 0.7
3	Children	16	0.1 to 0.26
4	Health	14	0.06 to 0.32
5	Religion/Faith	12	0.12 to 0.58
6	Finances	10	0.08 to 0.24
7	Spouse	9	0.13 to 0.34
8	Work	9	0.09 to 0.29
9	Living Conditions	7	0.06 to 0.29
10	Leisure/hobbies	5	0.05 to 0.18
11	Independence	5	0.13 to 0.47
12	Physical function	4	0.1 to 0.22
13	Psychological factors	3	0.09 to 0.2
14	Communication	2	0.15 to 0.27
15	Acceptance	1	0.18
16	Self-care	1	0.22

Figure 5-7 Frequency and weight ranking of mild decrease in intelligibility SEIQoL domains (n = 25)



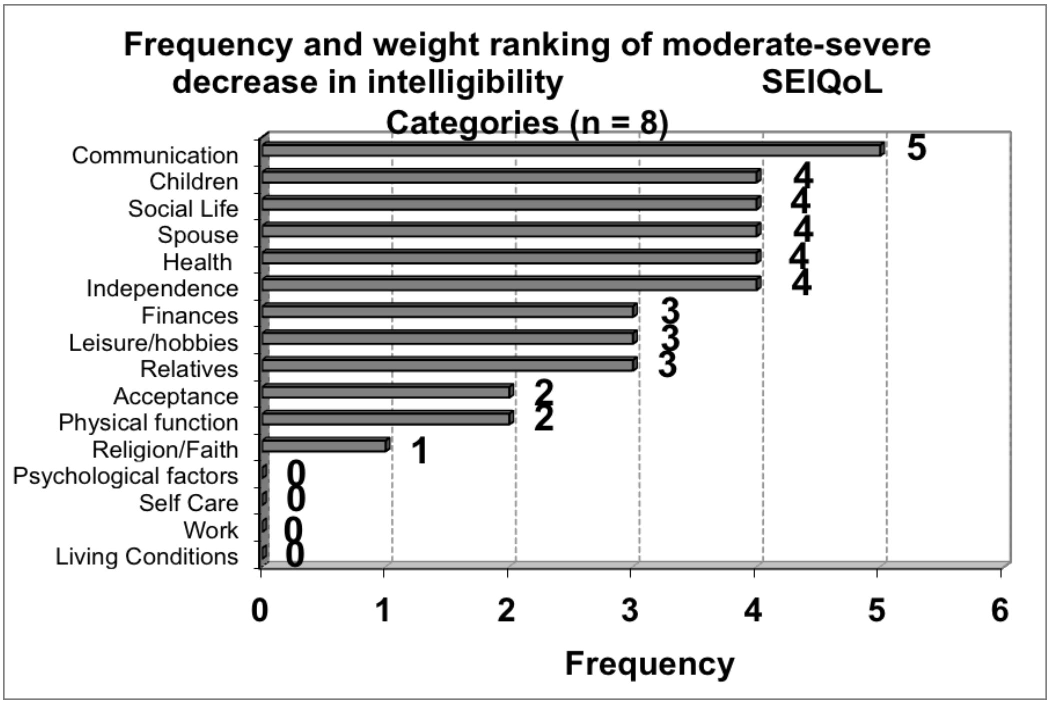
5.5.2.2 *Participants with moderate-severe decrease in intelligibility*

As Table 5.9 shows, the highest frequency and therefore the domain most important to the 8 participants with moderate-severe decrease in intelligibility was communication (5) followed by the need for independence (4), health (4), spouse (4), social life (4) and children (4). Less important SEIQoL-DW domains included relatives (3), leisure/hobbies (3), finances (3), physical function (2), and acceptance (2). The least important domain for participants with moderate-severe decrease in intelligibility is having religion/faith in their lives scoring a frequency of just 1. Living conditions, work, self-care and psychological factors were not rated by any as important. A graphical presentation (Figure 5.8) further illustrates the most important SEIQoL-DW domains nominated by participants with moderate-severe decrease in intelligibility

Table 5-9 - Frequency and weight ranking of moderate-severe decrease in WIS score SEIQoL domains (n = 8)

Factor Ranking	SEIQoL domains	Frequency	Range of weights
1	Communication	5	0.17 to 0.3
2	Independence	4	0.15 to 0.34
3	Health	4	0.14 to 0.38
4	Spouse	4	0.12 to 0.23
5	Social Life	4	0.11 to 0.22
6	Children	4	0.1 to 0.25
7	Relatives	3	0.09 to 0.4
8	Leisure/hobbies	3	0.09 to 0.18
9	Finances	3	0.12 to 0.21
10	Physical function	2	0.1 to 0.2
11	Acceptance	2	0.2 to 0.23
12	Religion/Faith	1	0.34
13	Living Conditions	0	0
14	Work	0	0
15	Self-Care	0	0
16	Psychological factors	0	0

Figure 5-8- Frequency and weight ranking of moderate-severe decrease in intelligibility SEIQoL domains (n = 8)



5.6 **Summary**

Initially the influence of demographic factors and disease history differences between the three disease groups were looked at, and it was found that there were some significant differences between the disease groups in terms of their age (MS patients were significantly younger than other groups), disease duration (ALS/MND patients reported significantly lower disease duration than other groups), and severity of decrease in intelligibility (MS patients reported only mild decrease, whereas PD patients were more likely to report mild decrease in intelligibility, and ALS/MND patients were more likely to report moderate to severe decrease in intelligibility). These significant differences may be related to the attributes of each individual neurodegenerative disease and/or to cultural constraints in Saudi Arabia and these potential reasons will be discussed in Chapter 7.

For the entire sample it was observed that FCS and ASIP scores showed a medium level negative correlation, suggesting that the more impaired a patient's functional communication is, the worse they rate their HRQoL as measured by the ASIP scale. This negative correlation seems to be influenced by both the independent and psychological components of the ASIP which respectively showed medium and strong correlations with the FCS scores.

The entire sample was then analysed by type of neurodegenerative disease (i.e., MS, PD, and ALS/MDS functional scales) to examine if the type of disease influences the relationship that was seen between QoL and the communication measures. Within the MS and PD groups the negative correlation between FCS and ASIP scores were again observed with the independent and psychological ASIP components of the disease influencing the results. Within the ALS/MND group there was no significant correlation between FCS and ASIP scores. However, for the ALS/MND group there was a strong positive correlation between the MQoL-SIS and SEIQoL-DW QoL scores, suggesting that as their sentence intelligibility increases, so does their individual QoL, and vice versa.

Relationships between the communication and QoL measures were examined next by separating the total sample by severity of intelligibility based on WIS (mild and moderate to severe). A moderate negative correlation was again seen between the ASIP and FCS scores in the mild group, with the strongest influence coming from the psychological component of the ASIP, then the independent component, and the weakest influence from the physical component. These results suggest that for the mild group, high functional communication is most strongly related to high psychological QoL. In addition, the group with mildly decrease intelligibility also showed a moderate positive correlation between FCS and SEIQoL-DW QoL.

In the moderate to severe group, there were no significant correlations between the ASIP QoL scores and FCS scores as noted above. The moderate to severe decrease in intelligbility group showed strong positive correlations between WIS and total ASIP QoL and the independent component of ASIP. Due to the small number of participants with moderate-severe decrease in intelligibility we cannot conclude that the correlation is significant and caution must be taken.

Finally, the relationship between the participants' judgement of their QoL and communication as measured by ASIP and FCS, versus the judgements of their caregivers was investigate. This was investigated with two statistical analyses (Spearman correlation and Intraclass correlation coefficient). The results from the spearman correlation showed that the patients' and caregivers' ratings of both overall ASIP and FCS, in particular their judgment of the patients' HRQoL was almost identical, although the caregivers gave a slightly more positive assessment of the patients' ASIP HRQoL, than the patient did themselves. However when this was further investigated through the use of ICC analysis to explore the agreement between the caregivers and the participants on ASIP, as well as the individual components of ASIP (physical, independent and psychological) and the FCS. The results showed that there was a significant and high ICC between the ratings on the FCS. However in the case of the ASIP there was a larger correlation among the two for the physical and psychological components but not amongst them on the independent component of the test. Physical component of the measure measures ambulation, mobility, and body care. The psychological component, measures emotion, affect, social interaction, and communication. Finally, the independent component measures rest, eating, work, home management, and recreation.

The second section of this chapter looked at four SEIQoL-DW profiles on individual QoL. According to the administration manual for the SEIQoL-DW (O'Boyle, Browne, Hickey, McGee, & Joyce, 1993) care should be taken when interpreting the overall index score since it is the sum of the products of the individual cue levels by their weights and this may vary significantly between individuals. Therefore it was decided to look more closely at individual differences in QoL, using SEIQoL-DW profiles of four neurodegenerative patients who were selected to represent the following profiles: (1) mild decrease in WIS score with a high SEIQoL-DW score (above 50); (2) mild decrease in WIS score with a low SEIQoL-DW score (below 50); (3) moderate-severe decrease in WIS score with a high SEIQoL-DW score (above 50); and (4) moderate to severe decrease in WIS score with a low SEIQoL-DW score (below 50).The frequency of nominating each SEIQoL-DW cue in the entire sample of 34 participants was the final set of data to be analysed. The results for participants with mild decrease in WIS score showed that they rarely mentioned communication as an important factor in their QoL; however, over 50% of patients in the moderate to severe group mentioned communication as their most important weight ranking. In contrast, for the mild group, the most important weight rankings were social factors, including relatives, social life and children. These social factors had dropped down to seventh, fifth and sixth indicating that different factors are important for individual QoL between patients with both mild and moderate-severe decrease in intelligibility. For patients with moderate to severe decrease in intelligibility, individual QoL is now driven by communication, independence and health.

From the four individual profiles it can be seen that the ratings of individual QoL are highly individual and subjective to each participant. The way that the participants rate their cues is not always related to the level of function as measured by the communication measures or scales of overall function. The nature of QoL required investigating QoL from an individual's perspective through the use of semi-structured interviews, as discussed in chapter 6.

Chapter 6 - PHASE 2: THE RELATIONSHIP BETWEEN QOL AND COMMUNICATION IN INDIVIDUALS WITH NEURODEGENERATIVE DISEASE - QUALITATIVE RESULTS

6.1 Introduction

In this chapter the individual perspectives of people with progressive dysarthria associated with neurodegenerative disease and the impact it has on their QoL was investigated. Through the qualitative analysis of interview transcripts, the experiences of these individuals as they deal with the disease and the impact it has on their QoL was explored first hand. Qualitative methodology was used to explore this research question since it is the person living with the condition who is the expert on their own situation and the best able to describe their experiences in detail (Yorkston *et al.*, 1999). In addition, the literature shows that in the area of progressive disease, the relationship between the social context, emotional adaptation and the continuous changes in the individual perspectives represents a complex process that is often not represented by measures of QoL (Foley *et al.*, 2007). As stated by Hirsch and Holland (2000), quality of life includes various domains of life, i.e. physical functioning, economic status, social environment, and spiritual status, being filtered through the personal opinions and perspectives of individuals facing problems. The problem of dysarthria is usually an outcome of physical dysfunction weaknesses, paralysis, incoordination of the speech musculature, or due to neurological problems (Darley, Aronson, and Brown, 1969a)

Relevant features of the 34 participants who took part in the interviews will be described, followed by the content analysis of the transcripts and the findings, and finally the emerging themes and subthemes will be presented. The participants were divided into two groups; those with mildly decreased intelligibility and those with moderately-severely decreased intelligibility.

A demographic portrait of the 34 patients who agreed to participate in the interviews is presented in Tables 6.1 and 6.2 to provide context for the narratives. Table 6.1 presents the socio-demographic characteristics, and Table 6.2 contains the medical history, split by severity of dysarthria.

6.1.1 Socio-demographic characteristics

Among the moderate to severe group with moderate-severe decrease in intelligibility, the majority were male (88%), aged 50-59 (50%), or 60-69 (36%), married (100%), and retired (38%). The majority of the mildly decreased intelligibility group were also male (62%), but younger aged 30-39 years (36%), and 50-59 years (24%), also married (77%), and unemployed (35%) or employed full-time (31%).

6.1.2 Medical History

Table 6.2 shows that 8 of the participants with mild decrease in intelligibility had a diagnosis of ALS/MND, 6 had a diagnosis of MS and 19 had a diagnosis of PD. Twenty-six of the patients had a mild decrease in intelligibility (16 male and 10 women), and eight of the patients had moderate-severe decrease in intelligbility (7 men and 1 woman). On average, the mildly decrease intelligibility group had been living with neurodegenerative disease for 35 months (2.9 years) longer than the moderate-severe group of participants.

Table 6-1- Sociodemographic data by severity of dysarthria (N = 34)

Variables	Values	Mildly decreased intelligibility (n = 26)	Moderate-Severely decreased intelligibility (n =	Total (N=34)
Gender	Men	16 (62%)	7 (88%)	23 (68%)
	Women	10 (38%)	1 (12%)	11 (32%)
Age (Years)	Mean (SD)	45.52 (12.32)	57.14 (6.14)	48.23
	Range	25-66 years	51-65 years	25-66
Age Groups	20-29 years	1 (4%)	-	1 (3%)
	30-39 years	9 (36%)	-	9 (26%)
	40-49 years	4 (16%)	1 (12%)	5 (15%)
	50-59 years	6 (24%)	4 (50%)	10 (29%)
	60-69 years	4 (16%)	3 (36)	7 (21%)
	70-79 years	1 (4%)	-	1 (3%)
Marital Status	Never Married	6 (23%)	-	6 (18%)
	Married	20 (77%)	8 (100%)	28 (82%)
Employment	Retired	5 (19%)	3 (38%)	8 (24%)
	Unemployed	9 (35%)	3 (37%)	12 (35%)
	Part-time	4 (15%)	2 (25%)	6 (18%)
	Full-time	8 (31%)	-	8 (24%)

Table 6-2 - Medical data by severity of dysarthria (N = 34)

Variables	Values	Mildly decreased intelligibility (n = 26)	Moderate-Severely decreased intelligibility (n = 8)	Total (N = 34)
Diagnosis	ALS/MD	4 (15%)	5 (63%)	9 (26%)
	MS	6 (23%)	-	6 (18%)
	PD	16 (62%)	3 (37%)	19 (55%)
Disease Duration	Mean (SD)	90.48 (68.58)	55.43 (60.28)	82.30 (67.43)
In months	Range	3-312	12-168	3-312
ASIP QoL	Low	22 (85%)	8 (100%)	30 (88%)
(Health-Related)	High	4 (15%)	-	4 (12%)
SEIQoL-DW Index	Low	15 (58%)	6 (86%)	21 (64%)
(Individual)	High	11 (42%)	1 (14%)	12 (36%)
MQoL	Low	11 (44%)	6 (75%)	17 (52%)
(All Parts of Life)	High	14 (56%)	2 (25%)	16 (48%)
[1]ASIP Total	Mean (SD)	27.57 (17.96)	21.07 (10.42)	26.05 (16.58)
[1]ASIP Physical	Mean (SD)	29.24 (22.25)	25.00 (21.84)	28.25 (21.85)
[1]ASIP Psychological	Mean (SD)	29.80 (21.69)	13.64 (3.41)	26.03 (20.19)
[1]ASIP Independent	Mean (SD)	24.24 (14.86)	23.50 (18.76)	24.07 (15.51)
SEIQoL-DW Index	Mean (SD)	27.06 (19.11)	55.60 (12.46)	26.72 (17.59)
MQoL	Mean (SD)	6.52 (2.19)	5.57 (2.44)	6.30 (2.24)
FCS	Mean (SD)	6.35 (0.86)	6.10 (0.85)	6.29 (0.85)
WIS	Mean (SD)	90.09 (8.58)	73.71 (8.90)	86.27 (11.03)
SIS	Mean (SD)	97.74 (2.34)	70.71 (24.73)	91.43 (16.30)

Note: [1] Higher scores on the ASIP scale indicate lower HRQoL

6.1.3 Communication and QoL

The groups varied considerably in their communication ability and QoL. Table 6.2 shows that the majority of both groups perceived their QoL to be low, but the moderate-severe group reported lower ASIP HRQoL (100%), lower SEIQoL-DW individual QoL (86%), and lower MQoL-SIS overall QoL (75%); whereas more of the patients with mildly decreased intelligibility reported higher ASIP HRQoL (15%), high SEIQoL-DW individual QoL (42%), and high MQoL-SIS QoL (56%). As expected, the patients with moderate-severely decreased intelligibility also had lower scores on functional communication (Mean = 6.10 vs. 6.35), word intelligibility (Mean = 73.71 vs. 90.09), and sentence intelligibility (Mean = 70.71 vs. 97.74).

6.2 Semi-structured Interviews

Prior to developing the interview schedule and determining what topics should be explored a number of published research looking at qualitative research of quality of life in neurodegenerative disease and/or communication disorders was reviewed. It was noted that questions posed focused on understanding the nature of the disease and the changes that have taken place overtime as well as the emotional impact that these changes have had on the interviewee. Research on impact of communication changes on life has focused on the perceived changes in communication and how has it impacted communication interaction, as well as the emotional consequences of these changes. Specific factors that may influence communication either negatively or positively have also been explores (Hartelius *et al.*, 2010; Miller *et al.*, 2006; Walshe & Miller, 2011). In other research that looked specifically at QoL the interview schedules include questions that look at overall QoL and how it is perceived by the individual, how it has changed over time, and factors that contribute or detract from it (Foley *et al.*, 2007). If communication needs to be explored as it relates to QoL then specific questions related to communication are added (Cruice *et al.*, 2010b).

Based on the review of the research, the interview schedule presented in Table 6.3 was developed. The intent of the questions was to understand what it was like living with a neurodegenerative disease, the life domains that were important for individuals with neurodegenerative disease, the factors that contributed to QoL, the factors that detracted from QoL, and how progressive dysarthria was perceived to impact QoL. An additional aim was to explore if the severity decreased intelligibility based on WIS scores made a difference to how a person experienced daily living. The interview schedule was used to plan, rather than as a checklist, to guide the progress of the interview. The questions were not always given in the same order and were not standardised across all the interviews. The interviewer listened to the interviewee and used the relevant questions in the discussion in a natural manner, refocusing the respondent to the relevant topics when necessary, as in a natural conversation. This helped keep the participants relaxed and calm and helped them to make sense of the conversation. The researcher was also aware that the participants may have memory and recall problems therefore probing questions and examples of different life situations were presented. In addition some of the participants were reluctant to engage at the beginning as they noted that, for some of them, it was the first time that they had been asked such questions. However, confidence was established when the researcher assured them that the information they provided would be kept confident and that it will help understand what they go through in everyday life.

Table 6-3 - Interview of QoL and communication topic guide

How has your life been since your diagnosis?

Share your experience about what it’s like living with the neurodegenerative disease?

What things have changed over time?

What are the things that you do to enjoy your day?

What are the things that are important for you?

What are the things that help you cope with your day?

What makes life better?

What makes life worse?

Has your role at home changed? How has that affected you?

Did you have to make any adjustments at work to cope with the disease? What are those adjustments?

How has it affected you?

How have speech difficulties or changes affected your life?

Share your experience about your social life with the presence of speech disorders?

How the neurodegenerative disease has impacted your social life?

What could be done to improve your life?

Is there anything that you would like to add?

The interviews were tape recorded and then transcribed verbatim immediately following the interview. This was important since the speech of some of the participants was somewhat unintelligible and it was easier to transcribe while there was a more recent recollection of the content and process of the interviews. Notes taken during the interview were also used to help in the transcription and standard transcription notation was used (Appendix 12). For one participant (KMW) his responses were handwritten, as although he had bulbar ALS/MND he still had good hand function, but his speech was unintelligible. The extracts taken for the analysis represented a translation of his exact written responses.

6.3 Qualitative Content Analysis

The framework described by Ritchie and Spencer (1994) was used for the analysis of the 34 interviews. The five stages of the framework are:

1. Familiarisation
2. Identifying a thematic framework
3. Indexing
4. Charting
5. Mapping and interpretation

6.3.1 Familiarisation:

Once all the interviews had been transcribed verbatim, the first stage of the analysis involved familiarisation with the interviews by reading and re-reading all 34 interviews. This allowed the identification of any recurring themes and it was necessary during this stage to go over all the transcripts and listen to the interviews again to clarify the statements made.

6.3.2 Identifying a thematic framework:

This stage involved setting up a thematic framework which was later used to sort and code the interviews. The thematic framework was generated using notes from the familiarisation stage, i.e. *a priori* knowledge from the functional communication measures reviewed (Figure 6.1), and the interview guide (Table 6.3).

Seventeen transcripts were coded for use in the framework and this led to further revisions to the framework, and finally the formulation of the index as shown in Table 6.4. This index covered 11 broad areas related to QoL, including emotional and psychological wellbeing, desire to maintain identity, physical function, search for control, social life, family, communication, faith and spirituality, overall perception of

QoL, factors that help with coping and acceptance, and the impact of the disease on life.

6.3.3 Indexing

Indexing is the process of applying the index or thematic framework to the interview transcript and involves recording the index number on the margins of all the interview data. Completion of this stage requires the continuous review of all the interview transcripts repeatedly. Some statements had two different codes as they fitted into two themes.

An independent Arabic-speaking observer re-coded a sample of 10 interview transcripts to increase the reliability of the indexing process and no differences were observed in this re-coding process. In addition, all the interview transcripts were re-checked two weeks later before the charting stage, but no further changes were made.

Figure 6-1 - Development of the interview index using interview guide and notes

Interview Guide:

1. How has your life been since your diagnosis?
2. Can you tell me what it's like living with the neurodegenerative disease?
3. What things have changed over time?
4. What are the things that you do to enjoy your day?
5. What are the things that are important for you?
6. What are the things that help you cope with your day?
7. What makes life better?
8. What makes life worse?
9. Has your role at home changed? How has that affected you?
10. Did you have to make any adjustments at work to cope with the disease? How has that affected you?
11. How have speech difficulties or changes affected your life?
12. Talk to me about your social life and how the neurodegenerative disease has impacted it?
13. Is there anything that could be done to improve your life?
14. Is there anything that you would like to add?

Research Notes (Extract)

- Depression
- Anxiety
- Self-image
- Social isolation
- Mobility
- Verbal communication
- In/dependence
- Activities (Home, work, hobbies)
- Change of role (home, work, relationship)
- Perception of others
- Importance of family
- Faith
- Acceptance

Index (Extract)

1. Emotional and psychological wellbeing:
    - 1.1. Depression
    - 1.2. Sadness
    - 1.3. Anxiety
    - 1.4. Fear
    - 1.5. Sense of loss
    - 1.6. Worry
2. Desire to maintain identity
    - 2.1. Self image
    - 2.2. Others' perception
    - 2.3. Need to maintain activities (work, home, hobbies, travel, sports)
3. Physical function:
    - 3.1. Mobility
    - 3.2. Fatigue
4. Search for control
    - 4.1. Need for control
    - 4.2. Feeling vulnerable or dependent on others
    - 4.3. Need for independence
5. Social Life
    - 5.1. Restricted due to physical disabilities
    - 5.2. Restricted due to communication disability
    - 5.3. Restricted due to feelings of embarrassment
    - 5.4. More selective
6. Family
    - 6.1. Importance for coping
    - 6.2. Financial concerns about family
    - 6.3. Feeling like a burden
7. Communication
    - 7.1. Change in speech (voice and articulation)
    - 7.2. Interaction
    - 7.3. Emotions when not understood

Table 6-4 - Index used to chart interviews

1. **Emotional and psychological wellbeing:**
    - 1.1. Depression
    - 1.2. Sadness
    - 1.3. Fear
    - 1.4. Worry
    - 1.5. Happy
2. **Desire to maintain identity**
    - 2.1. Self-image
    - 2.2. Others perception
    - 2.3. Need to maintain activities (work, home, hobbies, travel, sports)
3. **Physical function**
    - 3.1. Mobility
    - 3.2. Fatigue
4. **Search for control**
    - 4.1. Need for control
    - 4.2. Feeling vulnerable or dependent on others
    - 4.3. Need for independence
5. **Social Life**
    - 5.1. Restricted due to physical disabilities
    - 5.2. Restricted due to communication disability
    - 5.3. Restricted due to feelings of embarrassment
    - 5.4. More selective/limited
    - 5.5. Enjoy doing
6. **Family**
    - 6.1. Importance for coping and enjoy life
    - 6.2. Concern about family (Financial or emotional)
    - 6.3. Feeling like a burden
7. **Communication**
    - 7.1. Change in speech (voice and articulation)
    - 7.2. Interaction
    - 7.3. Emotions and communication
    - 7.4. Impact of the communication disorder
8. **Faith and Spirituality**
    - 8.1. Accept disease and cope
    - 8.2. Despite disability still grateful for things they can do
9. **Perceived QoL**
10. **Factors that help in coping and acceptance**
    - 10.1. FaithPeople
    - 10.2. Health (medication or information)
    - 10.3. Learn to live with disease
11. **Impact of disease on life**
    - 11.1. Change role at home
    - 11.2. Change role at work
    - 11.3. Changes in activities and hobbies
    - 11.4. Future goals

6.3.4 Charting

Once the thematic framework had been applied to the transcripts, a picture of the data as a whole needed to be built by considering the range of attitudes and experiences for each issue. Data was lifted from the original text and rearranged according to the appropriate thematic reference. A thematic approach such as this involves drawing a chart for each of the 11 key themes and the entries made for several respondents on each chart. Appendix 19 illustrates an example of these charts which include the translated quote as well as abstraction and synthesis of that quote.

6.3.5 Mapping and Interpretation

Once all the data had been charted, key characteristics were used to map and interpret the data as a whole, comparing experiences of the participants with mildly decreased intelligibility to those with moderate-severely decreased intelligibility. This provided an overview of the experiences of participants in everyday life and how they coped with changes that were associated with neurodegenerative disease with a focus on changes in their communication.

6.4 Key Themes and Subthemes

In the next section the content analysis of the interview transcripts is discussed. The results will be presented based on 11 main themes and subthemes that reflect the participants' experiences related to QoL and to neurodegenerative disease. The number of mentions reported within each theme represents the frequency of items mentioned within each of the groups of participants. However, since the groups were not equal in number it was important to consider the number of mentions within each group rather than the number of mentions between groups. It should also be noted that a higher frequency of items mentioned may indicate that the particular item is more frequently experienced, but not that it is more important.

6.4.1 Emotional and psychological wellbeing

Within this first theme, participants with mild decrease in intelligibility spoke mainly about negative feelings including depression, sadness, fear, and worry. The exception was one participant with PD who had a more positive attitude and reported feelings of happiness; "I am always happy, my children tell their mother, 'why are you not more like our father? he is always happy’. I wake up happy and I go to bed happy” (GBD/PD/male/64 years).

Five of the 26 participants with mild decrease in intelligibility reported depression. Feelings were associated with the lack of independence; “increase in isolation and decrease in taking care of oneself, the constant need for others makes me feel of misery and sadness. There is not much change, but the need for others makes you feel depressed” (AAA/ALS/MND/male/59 years). Another who has been medically diagnosed with depression for which medication is being taken said “My children tried to encourage me a lot but I prefer to stay at home - I do not like to see or talk to anyone. I have depression; I was referred to a doctor and was given medication that helped a little” (FAB/PD/female/53 years). Depression was also mentioned as a side effect of the medication or disease; “the medication has affected my life. It causes depression and this is from the side effects of the medication” (ATK/PD/male/58 years).

Three participants within the mild group reported the feeling of sadness. This was reported to be mainly associated with remembering loss and with the lack of independence, “I participate in conversations and in joking when meeting with friends and family in large groups. But when I need to drink, eat, or leave I get a moment of sadness, I remember the past, but thank god I do not spend all my day depressed and sad” (AAA/ALS-MND/male/59 years).

One participant reported fear; he reported a fear of falling and always thinking of the worst case scenario “now I am afraid from everything. When I was in university I was braver, for example if my mother asked me to go do something in the morning I do not sleep at night. I put the worst-case scenarios in my head. I am afraid of falling and everything” (NSM/Juvenile PD/male/30 years).

Finally, three participants reported worry. They expressed that their worry has restricted their ability to carry out certain activities such as driving, walking, and travelling.

Extract 1 (travel)	“The disease has affected a lot of things in my life. It has made a lot of things very difficult. Things that I used to like doing. I used to like to travel with my husband and now I worry a lot. This upsets me a lot. I worry about everything.” (KOM/PD/female/42 years)
Extract 2 (driving)	“My social life has changes. I worry and driving the car and fatigue plus I have no interest. I only leave the house for things that are important.” (ASO/PD/male/50 years)
Extract 3	“….will get tired, so I let him go out with the children or alone.”

(walking) (NSB/PD/female/47 years)

Of the seven participants in the moderate to severe group, only two mentioned emotional and psychological wellbeing. They reported being more emotional, especially with regards to the speech difficulty "I have become very emotional I cannot express my feelings and emotions. My speech doesn't help" (FSJ/ALS-MND/male/51 years), and also being more anxious when speaking "I have become a very anxious person. If I even speak to someone I get anxious" (MAM/PD/male/60 years).

6.4.2 Desire to maintain identity

Desire to maintain identity includes self-image, the need to be able to maintain activities and roles. Participants also reported that they are aware of others perceptions of their disabilities. Table 6.5 presents the number of mentions within each group.

Table 6-4 - Number of mentions for the desire to maintain identity

	Mild decrease in intelligibility (N=26)	Moderate-severe decrease in intelligibility (N=8)
Self-image	6	3
Others Perception	10	1
Need to Maintain Activities	16	3

As indicated in Table 6.5, the most frequent item mentioned by participants within the mild group was the need to maintain activity. They emphasised the importance of this item and the impact of not being able to do so has on their sense of identity. The activities they mentioned include travel, leisure and hobbies, sports and exercise, independence, and household activities.

Extract 1 (travel)	"I go on trips and visits with other retirees. Thank god I do not feel my life is empty." (SSG/PD/male/55 years)
Extract 2 (hobbies)	"I try to work around the house - I like gardening. I try to maintain this hobby to spend time at home since my activities are more restricted." (SHK/PD/male/50 years)
Extract 3 (work)	"Work has changed significantly. I do not go to work regularly. This has affected my achievements and my satisfaction with work." (AMB/PD/male/66 years)

Extract 4 (exercise) “I would love to go back to exercising. I used to go daily to the gym - I really miss that.” (ATK/PD/male 58 years)

Extract 5 (independence) “I participate in conversations and joking when meeting with friends and family in large groups. But when I need to drink, eat, or leave I get a moment of sadness, I remember the past but thank god I do not spend all my day depressed and sad.” (AAA/ALS-MND/male/59 years)

Extract 6 (household activities) “If I have the energy to go into the kitchen and cook I feel that I have accomplished something. I like to embroidery it was one of my hobbies that I sometime still do” (NSB/PD/female/47 years)

Three of the seven participants within the moderate group expressed the need to maintain activities. They spoke mainly about the impact that the loss of not being able to maintain such activities had on their QoL. They also spoke about how much they would love to be able to go back to their usual activities. Finally, they reported that despite their disabilities they tried to maintain some of the activities that they used to carry out before the disease.

Extract 1 “I give my life quality 2 or 3 because the things that I used to live for are not available. I used to be the person people came to for advice and opinions. I used to write and read poetry. I was responsible for our family funds and now I have no more responsibilities.” (SDQ/ALS/MND/male/65 years).

Extract 2 “I would love to be able to go back to playing sports. It used to be an important part of my life before the disease.” (IAJ/PD/female/55 years).

Extract 3 “I like being able to go out on road trips. I do not like staying in the city all the time. I can still do that sometimes [go on trips] the only thing that is not good is my speech.” (MRS/ALS-MND/male/52 years).

The second item within this theme is the desire to maintain identity including self-image. Participants within the mild group expressed changes in the way they perceive themselves; they reported changes in appearance, the need to maintain image as they used to before the disease, and the need for others not know that they have a disability.

Extract 1 “I feel that I move like a machine. Even patients with cancer can move easily- they do not look like they are sick. But for me I feel disabled, I feel tied up and do not have any independence.” (FAB/PD/female/53)

Extract 2 “The fatigue and muscle spasticity in my face is restricting. Not like before the disease. My face and general image were normal.” (MNM/MS/female 25 years)

Extract 3 “I used to fix my hair on my own, put my makeup on my own, now I have to wait for someone to come comb my hair. My hands are tied; dependent on others. I used to enjoy cooking; now I cannot even go into the kitchen.” (KOM/PD/female/42 years)

Extract 4 “Weakness in one leg has affected my movement and climbing the stairs. I go out less often. I do not want to walk with a cane, I do not want people to see that I need help.” (SAG/MS/male 39)

Participants within the moderate to severe group reported specific changes associated with their conditions that affected their image especially in public places such as uncontrolled laughter; “The [uncontrolled] laughter is what affects my life the most. It is embarrassing especially in the mosque during prayer. So I started praying at home. They tell me are you a religious man and you laugh during prayer!” (KMW/familial ALS-MND/male/44 years).

Similar to the mild group, they also did not want others to know that they had any disabilities; “my friends come to visit me but I do not want them to know that I am sick” (KMW/familial ALS-MND/male/44 years).

The final item within the desire to maintain identity is the perception of others. Participants within the mild group reported that they were aware of people’s perception and that on some occasions they were kinder to them, however this was not always positive since it made them feel different.

Extract 1 “People’s kindness and help has increased significantly but this hurts me a lot, it reminds me that I am different.” (FAB/PD/female/53 years)

Extract 2 “People have become kinder, but this is not a good thing. For example, you do not want your parents to worry about all the time and treat you differently from the other members of your family. My family do not live here they live in Madina [different city], whenever they come to visit they always say ‘let her sleep, let her rest’ this may affect other members of the family.” (SGS/PD/female/39 years)

They also reported that the perception of others has affected their work and families as well as their social lives.

Extract 1 “The disease has affected my job a lot any my relationship with my

(work)	students. I feel that they think that I am afraid or nervous [due to tremor in hands].” (SGS/PD/female/39 years)
Extract 2 (family)	“Everything is worse. I see my children hurting for my pain. They try to take me out with them, but I refuse. I feel that people stare at me so I do not like to go out.” (SHK/PD/male/50 years)
Extract 3 (social life)	“My relationship with people has decreased. Actually it hasn’t decreased I started feeling that I am a burden on society and I am the kind of person who doesn’t want to be a burden on anyone. I try to avoid embarrassment in any way possible.” (NSM/Juvenile PD/male/30 years)

Only one participant in the moderate to severe group expressed an opinion regarding others’ perception, he reported that he felt that people looked at him in a different way than they used to: “One feels that others look at him in a certain way. They do not look at him in the same way as before. Or maybe these are my feelings in reality. It may be an unrealistic view or the disease makes me feel this way” (MAM/PD/male/60 years).

6.4.3 Physical function

Participants in both groups expressed the changes in their physical function in terms of changes in mobility and fatigue. They also reported the impact these changes have on socialising, activity, wellbeing and QoL, and finally independence. The number of mentions is reported in Table 6.5.

Table 6-5 - Number of mentions for physical disability

	Mild decrease in intelligibility (N=26)	Moderate-severe decrease in intelligibility (N=8)
Mobility	6	2
Fatigue	2	1

Participants in the mild group reported that changes in mobility had led to less socialisation: “movement and walking make me upset. Before I used to get around visit people go out of the house and now I am stuck at home. I cannot go anywhere without the wheelchair and dependent on another person” (MHM/ALS-MND/male/52 years). They reported that it affects their overall wellbeing and QoL; “what would make me happy is to be cured from the disease. It is the cause of tension at home. Movement has decreased and a lot of things in life have decreased with it. Sometimes you want to have some quality in your life, but it is not up to you” (TSJ/ALS-MND/male/40 years).

The impact it has on their independence was also stated "… for me, I feel disabled, I feel tied up and do not have any independence […] then worst thing in my life is movement. When you are able to move you feel like a human being not tied up like a corpse" (FAB/PD/female/53).

With regards to fatigue, participants within the mild group worried about fatigue restricting their activities and social life; "my going out with friends and family has decreased by about 75% because of fatigue" (SAG/MS/male/39 years) and "my social life has changed. I worry about driving the car and fatigue, plus I have no interest. I only leave the house for things that are important" (ASO/PD/male/50 years).

Similar comments were reported by participants with moderate to severe decrease in intelligibility when expressing the impact that restricted mobility had on their social life and overall wellbeing: "because I cannot climb the stairs, go outside or go to stores and different places all the things in my life have diminished" (SDQ/ALS-MND/male/65 years). Fatigue was also reported as being a consequence of the disease "My body is all fatigued, I am always tired" (MMZ/PD/male/65 years).

6.4.4 Search for control

Comments concerning the search for control ranged from the search for control to feelings of less control and choices in life, feeling vulnerable and dependent on others, and the need for more independence. Table 6.6 presents the number of mentions within each group.

Table 6-6 - Number of mentions for search for control

	Mild decrease in intelligibility (N=26)	Moderate-severe decrease in intelligibility (N=8)
Need for Control	2	1
Feeling Vulnerable and dependent on others	6	2
Need for independence	6	0

Participants in the mild group expressed a lack of control over life and therefore avoiding making future plans; "I do not want to make future plans that I cannot control. I want to be in control of my life. I want to have the choice whether to build it or destroy it" (SAG/MS/male/39 years), and "I am sitting and watching my life go by I have no control over it" (FAB/PD/female/53 years). One participant with moderate-severe decrease in intelligibility reported that the need for control over life was required to make him happy and content, “I would be happy if I was cured from this disease. But on a daily basis I am happy when things around me are organised and I can control them” (SDQ/ALS-MND/male/65 years).

Feeling vulnerable and dependent on others was an item reported by participants in both groups. They reported this dependence on others as upsetting and a source of negative feelings.

Extract 1 (mild decrease in intelligibility)	“Sitting for a long time is very tiring. I cannot leave the house on my own anymore, I have to have someone with me. This has affected my independence.” (AMB/PD/male/66 years)
Extract 2 (mild decrease in intelligibility)	“…the worst thing is my disability and my health. I cannot go anywhere without the help of others and I get upset because my speech is not normal.” (LMS/MS/female/30 years)
Extract 3 (Moderate-severe decrease in intelligibility)	“The most important effect the disease has had on my life is movement and taking care of myself. I cannot even feed myself, someone has to do it for me.” (FSJ/ALS/MND/male/51 years)
Extract 4 (Moderate-severe decrease in intelligibility)	“Movement is one of the negative things in my life. Not being able to dress myself, feed myself, not going to the toilet alone is very hard. Not being independent as well as speech and communication difficulties.” (FSJ/ALS/MND/male/51 years)

The final item identified within this theme was the need for independence. This item was not expressed by any of the participants with moderate-severe decrease in intelligibility. However, participants in the mild group reported the need to regain their independence; they reported having started to accept this loss and learning to live with it; “I would like to be able to become independent again instead of someone dressing me. Initially I used to get upset from asking for help but now I see these things have become a reality. Now I cannot be independent anymore” (TSJ/ALS-MND/male/40 years).

They also reported that the changes in speech output affected their independence in carrying out activities which had an impact on their overall QoL: “I would like to be able to go back to speaking as I used to. My movement has improved after the surgery. The biggest problem is that I cannot speak well. They do not understand my speech if I need to go to a government agency, for example, the police station I have to take my son with me and if he is not available then I have to find someone else to speak for me.

Even for private visits I have to take my son with me to speak for me. My QoL is (2) speech is difficult" (MAJ/PD/male/70 years).

It has also restricted their activities such as driving; "I used to be independent in everything, I go to the market, get the groceries of the house independent in everything. I like being independent. Now I can't even drive my children around or take them to school. (SHK/PD/male/50year).

6.4.5 Impact of disability on social life

Participants spoke a lot about their social life and how it was affected by the disease and disability. The majority reported that their social life had become more restricted due to physical or communication disabilities or embarrassment and shame. They also reported that they tried to continue doing things they enjoyed despite their disabilities, but that sometimes they had to be more selective. Table 6.7 represents the number of mentions.

The highest frequency item for participants with mild decrease in intelligibility were having a restricted social life due to physical disabilities. The participants expressed that this restriction was as a result of difficulties in movement and getting around: "because of movement difficulties and difficulties in going to the toilet, I do not like going to public places. The obstacle that hinders me is the need to use the rest room" (AMB/PD/male/66 years).

Table 6-7 - Number of mentions for social life

	Mild decrease in intelligibility (N=26)	Moderate-severe decrease in intelligibility (N=8)
Restricted due to physical disability	11	2
Restricted due to communication disability	4	2
Restricted due to shame and embarrassment	3	1
More selective	4	2
Things they continue to enjoy	2	5

Not wanting to be faced with disability and difficulties or have others see their disabilities was also noted: "I do not like to go out so I am not faced with my problem and I am afraid of falling” (SAG/MS/male/39 years) and “the disease has affected everything in my life especially movement. I do not like to go out and meet people because of my condition and the tremors” (KIH/PD/male/61 years).

A few reported that they were able to adapt to the changes associated with physical disabilities: “before I used to go visit with people now it’s difficult for me to go out on a wheelchair. My friends come to visit sometime but I continue to go to the mosque” (MHM/ALS-MND/male/52 years).

Only two participants with moderate-severe decrease in intelligibility expressed physical disability as a cause of a restricted social life. They both reported that a restricted social life due to physical disability had a negative effect on their overall wellbeing and QoL; “I feel claustrophobic/upset from spending most of my time at home - I want to be able to go out, I do not like staying at home […] I cannot go out because of movement difficulties and my speech, no one can understand me” (IAJ/PD/female/55 years), and “because I cannot climb the stairs, go outside or go to stores and different places all the things in my life have diminished” (SDQ/ALS/MND/male/65 years).

The second item expressed was the impact that communication disorders had on restricting social life. The main reasons given were: not wanting people to know, it depends on the communication partner, and difficulties being understood.

Extract 1 “The whole disease upsets me and affects my QoL. Dysfluencies in my speech when they start; I do not want to speak anymore with anyone. I lock myself in my room at home and I do not want to talk to anyone.” (SHK/PD/male/50 years)

Extract 2 “After the disease I do not like to meet with a lot of people; only certain people who I am comfortable with. Because it is difficult for me to express myself and communicate.” (AMS/PD/male/61 years)

Extract 3 “People who are close to me are able to understand me, but strangers can’t and also I do not like socialise a lot due to this.” (LMS/MS/female/30 years)

Participants with moderate-severe decrease in intelligibility reported negative feelings associated with restricted social life due to communication disability: “I used to be an Imam at the mosque and I had other activities. I had to leave them when my speech started to change. My life is 95% restricted to my home” (KMW/familial ALS/MND/male/44 years).

The third factor noted was shame and embarrassment as the cause for a restricted social life. Only one participant within the moderate-severe group reported this as a cause for a restricted social life; “I am ashamed to see people and socialise with them because of my speech. But no one has ever mentioned it, it is just me” (MRA/ALS/MND/male/52 years).

For participants with mildly decreased intelligibility the reason they felt shame and embarrassment was related to people’s perception and their feelings of being different.

Extract 1	“I feel that people stare at me so I do not like to go out.” (SHK/PD/male/50 years)
Extract 2	“I used to meet with friends several times a week, friends from work. I go sometimes, but most of the time I don’t. When you feel that you are in the middle of people who are different from you in health, you feel that you are not in the right place.” (ATK/PD/male/58 years)

Participants in both groups reported being more selective about who to interact with and reported that they were more comfortable with friends and family than strangers.

Extract 1 (mild decrease in intelligibility)	“I avoid people; I only visit my parents or siblings. I do not communicate with anyone and I do not go out anymore.” (FAB/PD/female/53 years)
Extract 2 (mild decrease in intelligibility)	“Before my disease I used to have lots of relatives and friends we used to visit each other a lot. But now I like to see certain people who visit me at home.” (SHK/PD/male/50 years)
Extract 3 (Moderate-severe decrease in intelligibility	“My social life has changed; I used to go out all the time. Now it is limited to Friday prayer at the mosque and visiting my father.” (FSJ/ALS-MND/male/51 years)

Finally, they reported continuing to carry out social activities that they enjoyed despite their disabilities. These activities included visiting family and friends and travelling.

Extract 1 (mild decrease in intelligibility)	“I go on trips and visits with other retirees. Thank god I do not feel my life is empty.” (SSG/PD/male/55 years)
Extract 2 (Moderate-severe decrease in	“I enjoy listening to prayer calls. I also enjoy when my children are all with me or when my friends visit. I like to speak and joke with them.”

intelligibility)	(MMZ/PD/male/65 years)
Extract 3 (Moderate-severe decrease in intelligibility)	“Socialising with people makes me happy.” (MAM/PD/male/60 years)

6.4.6 Importance of family

In this section the participants expressed an acknowledgement of their dependence on family and the important role that family played in supporting them. They also reported their worry about the impact the disease had on their families, both emotionally and financially. Lastly, they reported that sometimes they felt like a burden on the family as indicated in Table 6.8.

Table 6-8 - Number of mentions for family

	Mild decrease in intelligibility (N=26)	Moderate-severe decrease in intelligibility (N=8)
Importance for coping and enjoying life	5	1
Concern about family	3	3
Feel like a burden	6	0

Participants reported that families’ understanding of the disease and associated disability helps them cope with their condition; “at the beginning my family did not understand the whole situation. They used to always ask me what is wrong with you, they did not know that this was related to the disease [PD], now they understand and it has become a normal situation” (ATK/PD/male/58 years). They also reported that their families were able to give them support and help them enjoy life.

Extract 1 (mild decrease in intelligibility)	“I enjoy when my children and grandchildren are around me and when I see them happy.” (AMB/PD/male/66 years)
Extract 1 (mild decrease in intelligibility)	“The best thing in my life is my family; they help me with everything and don’t leave me in need of anything.” (LMS/MS/female/30 years)
Extract 2	“My daughter’s name is R [name removed], I always talk to her

(Moderate-severe decrease in intelligibility)	and I enjoy that.” (FSJ/ALS/MND/male/51 years)

They also reported being concerned about the impact that the disease may have on their families; financial and emotional. For KMW, a participant with familial ALS/MND, his concerns were different from the others as he was mainly concerned about the hereditary aspect of the disease and the future health of his children.

Extract 1 (mild decrease in intelligibility)	“Everything is worse. I see my children hurting for my pain. They try to take me out with then but I refuse. I feel that people stare at me so I do not like to go out.” (SHK/PD/male/50 years)
Extract 2 (mild decrease in intelligibility)	“The worse thing is my financial status. I cannot work and therefore cannot provide for my family. My QoL is (0) I keep thinking about the rent and food for my children. It is exhausting.” (KIH/PD/male/61 years)
Extract 2 (Moderate-severe decrease in intelligibility)	“I am afraid that my children will know that it is hereditary and will keep thinking and worrying about it and about their future. My mother doesn’t know, until now that I have the disease, I told her that I had a stoke that affected my speech.” (KMW/ALS/male/44 years)
Extract 2 (Moderate-severe decrease in intelligibility)	“My QoL is 2. I have no activities and I do not want my children to have the same disease and I cannot tell them or my mother about the disease so they do not worry.” (KMW/familial ALS-MND/male/44 years)

Finally, feeling like a burden on the family was reported by a few of the participants with mildly decreased intelligibility, but none of those who had moderate-severely decreased intelligibility. Participants reported that they felt that their role in the family had changed over time and that they were now a burden on their families.

Extract 1	“I do not like to be a burden on anyone even if the person in front of me didn’t make me feel that I am. I am afraid that people will start avoiding me in the future.” (NSM/Juvenile PD/male/30 years)
Extract 2	“Going out used to be easy for my family, now it is difficult because of my movement and need for a wheel chair.” (ATK/PD/male/58 years)

6.4.7 Communication

Communication was mainly associated in both groups with verbal communication. They talked about changes in speech mechanism and quality, impact on interaction, emotions associated with a communication disorder, and the impact that communication disorders had. Table 6.9 presents the number of mentions within each group.

Table 6-9 - Number of mentions for communication

	Mild decrease in intelligibility (N=26)	Moderate-severe decrease in intelligibility (N=8)
Changes in speech	4	4
Interaction	7	4
Emotions and communication	5	5
Impact of communication disorders	2	7

Participants with mild decrease in intelligibility reported changes speech noting "decrease in speech volume has occurred with the disease. Speech itself is not a problem but the decrease in volume has affected my communication at work" (MJS/PD/73 years). Others reported that the changes in speech were only apparent in certain situations such as when talking on the phone; "When I answer the phone people usually say we cannot understand you easily. A lot of people ask me to raise my voice" (ATK/PD/male/58 years) or to certain people; "Some people who are close do notice it like my sister. If I speak very fast, I notice dysfluencies and some of the speech sounds are affected" (SGS/female/39 years).

Participants with moderate-severe decrease in intelligibility were more specific regarding the characteristics of speech that have been affected. They reported increased nasality; "My speech is more nasal when I speak more and I have to repeat myself often" (KMW/familial ALS-MND/male/44 years), vocal cord issues; "Speech has changed […] it's in the vocal cord" (MRS/ALS-MND/male/52 years), and decreased intensity; "This decrease in intensity of speech sometimes happens to me. You talk to a person and you think that they heard you. Later they say: what did you say?" (MAM/PD/male/60 years).

Interaction and conversation were specifically affected by the changes in communication. Participants with mild decrease in intelligibility reported difficulties with group conversations: “when you are in a group you have to participate in the conversation and when the conversation is directed towards me I feel self-conscious. I feel that my tongue is heavy and, therefore, I try to avoid questions and remain quiet most of the time” (NSM/Juvenile PD/male/30 years). The ease of conversation depends on the communication partner and situations; “my problem is when communicating with a group of strangers - not at work or with my family. A month ago I went to a funeral I got so anxious and started to sweat. I was so ashamed that I just left” (SHK/PD/male/50 years). However, participants are able to adapt to changes and carry out a conversation “my speech has changed, but it hasn’t affected my interaction. Preparing sentences before I say them has become more challenging; I try to keep it spontaneous” (ASO/PD/male/50 years).

Participants with moderate-severe decrease in intelligibility reported that they experienced more restricted interactions, spoke when absolutely necessary, and avoided conversations.

Extract 1	“I have become more restrained/restricted in my speech; I only speak when absolutely necessary.” (SDQ/ALS-MND/male/65 years)
Extract 2	“At home I avoid speaking so they do not notice that I have the disease. Because I have siblings who have the same disease I do not what it to affect them [my family].” (KMW/familial ALS-MND/male/44 years)

The emotions related to communication changes were mainly that of being upset when not understood, and shame.

Extract 1 (mild decrease in intelligibility)	“I get upset when people do not understand me or asks me to repeat. This hurts me.” (NSM/Juvenile PD/male/30 years)
Extract 2 (mild decrease in intelligibility)	“Speech has decreased because it is difficult and I find difficulties in it. It is slow and laboured and people do not accept it like they used to and I feel embarrassed. People do not understand me at times and I also cannot answer very fast.” (ATK/PD/male/58 years)
Extract 3 (moderate-severe decrease in intelligibility)	“My wife and children understand me speech but strangers [I feel] are ashamed to say they didn’t understand.” (MMZ/PD/male/65 years)
Extract 4 (moderate-severe	“You talk to a person and you think that they heard you. Later they say: what did you say? This upsets me, but then I feel I should get

decrease in intelligibility)	over it.” (MAM/PD/male/60 years)

The final item within the communication theme is the impact that this change has had on participants. Impact on social life has been discussed above. Additional impacts that were reported were the ability to communicate emotions, change in role from a communicator to more of a listener, and the impact at work.

Extract 1 (mild decrease in intelligibility)	“My problem is when communicating with a group of strangers not at work or with my family. A month ago I went to a funeral I got so anxious and started to sweat. I was so ashamed that I just left.” (SHK/PD/male/50 years)
Extract 2 (moderate-severe decrease in intelligibility)	“I used to be an Imam in the mosque, when I read [the Quran] I felt that some of the speech sounds were difficult as well as difficulties breathing this affected my production of sounds and I had to leave this responsibility.” (KMW/familial ALS-MND/male/44 years)-
Extract 3 (moderate-severe decrease in intelligibility)	“I have daily meeting time with my friends and acquaintances which has been going on for quite a long time. After the disease I have become more of a listener than a speaker in these meetings.” (SDQ/ALS-MND/male/65 years)
Extract 4 (moderate-severe decrease in intelligibility)	“My speech does not allow me to communicate my emotions and feelings.” (FSJ/ALS-MND/male/51 years)

6.4.8 Faith and spirituality

Participants in both groups placed an importance on faith and spirituality in helping them cope and accept their disease and disability. Some indicated that faith helped them to be grateful for what they still had despite their disability. Table 6.10 presents the number of mentions within each group.

Table 6-10 - Number mentions for faith and spirituality

	Mild decrease in intelligibility (N=26)	Moderate-severe decrease in intelligibility (N=8)
Help cope and accept disease and disability	5	5
Despite disability still grateful for things they can do	1	1

Five participants with mild decrease in intelligibility and five with moderate to severe decrease in intelligibility expressed that it was their belief that their disease was their fate from God and this helped them to accept the disease and its associated disabilities and helped them to cope. In addition, a participant in each group reported that despite the disability they were grateful and appreciated the things that they could still have or do.

Extract 1 (mild decrease in intelligibility)	"Initially at the beginning of the disease I was sad, then I thought about it and realised that everything is from god. The disease is from god and the cure is from him as well. I accept what he chose for me." (AMS/PD/male/61 years)
Extract 2 (mild decrease in intelligibility)	"I thank god for everything when I see the misfortune of others I feel better about what I still have and can do." (SGS/PD/female/39 years)
Extract 3 (moderate-severe decrease in intelligibility)	"First I was upset and angry because you know I couldn't even go to work. After a while I started adapting little by little and I felt it is my destiny from god [my fate]." (FSJ/ALS/MND/male/51 years)
Extract 4 (moderate-severe decrease in intelligibility)	"I am a faithful person and still able to move around. My brain is working fine." (FSJ/ALS/MND/male/51 years)

6.4.9 Perceived QoL

Seven participants with mild decrease in intelligibility and five participants with moderate-severe decrease in intelligibility rated their overall perceived QoL during the interview. They reported some factors that made their overall QoL better or worse. The factors that made QoL better were family support, faith in God, and having structure and control over life. The factors that made it worse were financial concerns, communication and a speech disorder, increased anxiety, isolation and worry.

Extract 1 (mild decrease in intelligibility)	"I give myself 7-8 in my QoL. As a Muslim I have to be patient and seek the reward from god. Plus this is something written in my destiny accepting it is better for you and if you fight or show discontent you are not going to change anything." (ATK/PD/male/58)
Extract 2 (mild decrease in intelligibility)	"The worse thing is my financial status. I cannot work and therefore cannot provide for my family. My QoL is (0) I keep thinking about the rent and food for my children. It is exhausting." (KIH/PD/male/61 years)
Extract 3 (mild decrease in intelligibility)	"Before people used to understand me, now they don't. I have to repeat myself more than once so they can understand and this has affected my QoL. It is something that is upsetting." (MHM/ALS/MND/male/52 years)
Extract 4 (mild decrease in intelligibility)	"My QoL is (6) if I said it was poor I would be have wronged my parents and if I said it was very good I would have wronged myself." (LMS/MS/female/30 years)
Extract 5 (moderate-severe decrease in intelligibility)	"I give my QoL a 5. I have become a very anxious person. If I even speak to someone I get anxious." (MAM/PD/male/60 years)
Extract 6 (moderate-severe decrease in intelligibility)	"I give my QoL 10 out of 10. This is my fate. I think that I am ok and I believe that my destiny is from god and it is what is meant for me." (MMZ/PD/male/65 years)
Extract 7 (moderate-severe decrease in intelligibility)	"My QoL is 2. I have no activities and I do not want my children to have the same disease and I cannot tell them or my mother about the disease so they do not worry." (KMW/familial ALS/MND/male/44 years)

6.4.10 Coping and acceptance

In addition to the coping and acceptance already discussed under family and faith, the participants discussed a few more items that helped them cope with their disease. Participant IAJ, who had moderate-severe decrease in intelligibility, noted that having an understanding of the disease and associated disability helped her cope and not get upset; “I do not get upset when I cannot do things. I tell myself this is from the disease” (IAJ/PD/female/55 years).

Participants with mild decrease in intelligibility discussed several other items including people who understood the disease and gave them positive feedback; “when I sit with people who know about my disease and other problems I feel comfortable. They know how to give me hope and lift my morale, I do not feel disabled (NSM/Juvenile PD/male/30 years). The ability to educate others about the disease also seemed to give one of the interviewees a positive experience; “the only positive thing in the disease is that I can give advice to others with the same condition and to the society about the disease” (OMA/MS/male/34 years). In addition, participants with PD noted the times during which the medication allowed them to function normally; “it makes me happy when I take the medication in the morning and I go back to my normal self I feel comfortable and relaxed for a little while” (SHK/PD/male/50 years).

6.4.11 Impact of the disease on life

The participants in both groups discussed the impact that the disease had on their lives at home, at work, carrying out activities and on their future goals and plans. Changes at home included a change in roles and responsibilities, feeling like a burden and being less productive, all of which have been discussed earlier within the family theme. Changes in activity included a decrease in some of the activities and the inability to carry out others. These activities included sports and exercise, driving, and leisure activities (e.g., shopping, visiting friends and gardening) all of which have been discussed under the desire to maintain identity theme.

The impact on work expressed by participants in both groups included changes in responsibilities at work, changing to part time work, or early retirement, all of which led to a lowering of satisfaction levels.

Extract 1 (mild decrease in intelligibility)	“Due to my disease I go to work on a part time basis. My energy level at work has been affected. They give me less work and less responsibilities which has had a negative effect on my satisfaction with my work.” (ATK/PD/male/58 years)
Extract 2 (mild decrease in intelligibility)	“Work has changed significantly. I do not go to work regularly. This has affected my achievements and my satisfaction with work.” (AMB/PD/male/66 years)
Extract 3 (moderate-severe decrease in	“My work responsibilities have shrunk. Meaning my motivation at work and ability at work has decreased. I am not given as

intelligibility)	many responsibilities which has affected my satisfaction.” (MAM/PD/male/60 years)
Extract 4 (moderate-severe decrease in intelligibility)	“I was told not to come to work because of my disease, they are considering giving me early retirement due to medical reasons. I miss my work.” (KMW/familial ALS-MND/male/44 years)

The final item within this theme was future goals and very few of the participants discussed this item (one participant within the moderate to severe group and three participants within the mild group). The impact on future plans included the inability to find work or continue education for a young 30-year-old man with juvenile PD, the refusal to make any future plans since they did not have any control over their future, changes in post-retirement work, and finally following the diagnosis of a terminal disease such as ALS/MND, a change in view from eating healthily and fitness to “enjoying life”.

Extract 1 (mild decrease in intelligibility)	“I am a young man and I need an income, I tried to work and sent my papers [CV] everywhere. I am a university graduate but I cannot find a job, my health and conditions do not allow it. At least if I was healthy I could go on a scholarship to continue my education then return and find a job anywhere. All my classmates from college are have jobs and are married and have kids and I am stuck in the same place.” (NSM/Juvenile PD/male/30 years)
Extract 2 (mild decrease in intelligibility)	“I do not want to make future plans that I cannot control. I want to be in control of my life. I want to have the choice whether to build it or destroy it.” (SAG/MS/male/39 years)
Extract 3 (mild decrease in intelligibility)	“Before I used to take care of what I ate for health and fitness reasons and I used to go to the gym. Now I have an open appetite. Before I was thinking of my health now that I have the worst possible disease… enjoy life.” (TSJ/ALS/MND/male/40 years)
Extract 4 (moderate-severe decrease in intelligibility)	“I wanted to do some work after I retired, I had a farm that I used to work in now I cannot do anything.” (MMZ/PD/male/65 years)

6.5 Summary

Participants with neurodegenerative disease expressed a number of domains and items that seemed to be important to their overall QoL and wellbeing (Table 6.11). There did not seem to be any difference in the domains mentioned by participants who had mild decrease in intelligibility compared to those who had moderate-severe decrease, although the frequency of mentions varied significantly within each group. However, the two groups cannot be compared legitimately because the group numbers were very different; 26 participants in the mild dysarthria group and eight in the moderate-severe group. The domain that seemed to be the most important to participants within each of the groups was the ability to maintain their independence for as long as possible following the onset of the disabilities associated with the disease. Looking over the results from the interview we note that the major factor that impacted matters affecting life quality and satisfaction was the continuous loss and changes in physical function and the consequences of this loss on other matters of life. These changes in physical function resulted in perceived loss of independence, relying on others, changes in self-image, restricted social life and leisure activities, affected ability to work, made the person feel self-conscious and others being aware of their disability. Feelings of depression, sadness, and being a burden on the family were also related to the loss of independence which was usually reported as a consequence of physical changes.

Communication was also reported as a factor that impacted life quality and satisfaction, although not as often. This may be due to the fact that the majority of the interviewees only had mildly decreased intelligibility and their communication may still not have been as prominent an issue as their physical disabilities. In addition the majority of participants with moderate to severe decrease in intelligibility had ALS/MND. Despite this, communication was also linked by some participants from both groups as a factor that affected independence, self-image, ability to work, as a source of embarrassment, and restricted leisure and social activities. When asked specifically about communication interviewees who have more severely affected communication skills reported changes in specific aspects of speech; articulation, voice intensity, and nasality. As well as being more comfortable communicating with familiar communication partners rather than strangers.

Despite the negative factors and consequences of the diseases on life satisfaction there are certain factors that were reported as contributing to better life quality and helped in coping with the disease these factors included family support and understanding, the ability to have control over life and life choices, and finally, faith.

Some participants expressed that they felt that their disease was their fate from God, and that this helped them to accept it and be grateful for what they were still able to do.

Table 6-11 - Definition of themes related to QoL and communication

Theme	Definition
Emotional and Psychological Wellbeing	A full range of positive and negative emotions including depression, sadness, fear, worry, and happiness.
Desire to Maintain Identity	The need to maintain self-image and the desire to maintain normal activities and roles. It also includes awareness of others perceptions of their disability.
Physical Function	Independence, ability to care for self, walk, need for assistive devices, and physically able to do what they want to do. These factors were related to mobility and fatigue and how they impact QoL and socialisation.
Search for Control	The need to be in control of life situations, the negative feelings associated with being dependent on others and the need for independence.
Social Life	Restriction in social life related to physical and communication disabilities, feeling of embarrassment, being more selective with who and where they socialise, and continuing with things that make them happy such as travel and visiting friends and family.
Family	Importance of family, awareness of their dependence on them and the burden that may cause, and concern about family related to financial and emotional factors
Communication	Changes in communication ability including changes in voice and articulation, change in interaction, change in role, emotional impact the change in communication ability has on their QoL and wellbeing.
Faith and Spirituality	Helping them cope and accept their condition and be grateful for what they are still able to do.
Perceived QoL	Overall rating of their current life
Factors that help in Coping and Acceptance	Factors in life that make it easier to cope with the disease and disability including family and friends, moments when health is better, being able to understand the disease, and finally learning to live with the disease.
Impact of Disease on Life	Changes in roles and responsibilities at home, at work. Inability to continue hobbies and certain activities, and finally changes and modifications in future life plans.

Chapter 7 - DISCUSSION

7.1 Introduction

In this chapter the results and findings presented in the thesis will be discussed. The chapter will begin with an evaluation of the research aims. This will be followed by a presentation of the general observations during the research, development of the communication assessment instruments, quality of life and communication, caregiver evaluation of quality of life and communication and finally clinical implications and future research.

This research aimed to identify the relationship between communication and quality of life focusing on individuals in Saudi Arabia. The absence of standardised communication assessment tools for an Arabic speaking population with neurodegenerative disease required the development of intelligibility and functional communication measures. Cultural factors were considered within this research in respect to assessment instrument development and adaptation. Since we are investigating two concepts with this thesis that are well known to be highly influenced by the cultural and linguistic background (communication and Quality of Life - QOL) (Simmons-Mackie & Damico, 2003; Threats, 2010; WHO, 1998) we made sure that assessment instruments that were used took into consideration cultural factors. We sought to develop valid and reliable measures of communication that are culturally and linguistically acceptable. In addition we reviewed the literature and selected the QoL measure that was developed following set guidelines for the development of culturally acceptable measures (Beaton, 2000; Geisinger, 1994; Guillemin *et al.*, 1993).

7.2 Evaluation of the Research Aims

The main aim of this thesis was to investigate the relationship between communication and quality of life for individuals with progressive dysarthria in Saudi Arabia in order to do so the development of both an intelligibility and a functional communication measure for an Arabic speaking population was a necessary first step in the research. The impact that the type of disease and severity of the communication disorder had on quality of life and communication in this population was to be investigated together with the difference between the participants' perceptions and their caregivers' perceptions regarding quality of life and functional communication. Finally, individual participants' perspectives of quality of life and communication were examined through qualitative research methodology.

In Chapter 1, contributions of the research were presented and these will now be examined in light of the qualitative and quantitative analysis:

- To investigate the relationship between communication and QoL in Saudi Arabian individuals suffering from different forms of neurodegenerative conditions.
- To explore and examine the role that communications plays in the quality of life of individuals with neurodegenerative conditions.
- To determine and comprehend if there is an association between the severity of the communication impairment and QoL.
- To compare the participants' judgement of health related QoL and functional communication and that of their caregivers.
- To explore participant generated themes and domains related to their QoL as it relates to their communication.

7.3 General Observations

Prior to discussing the results and outcomes of the research some general observations needed to be discussed. These areas include the selection process, participant demographics, and attitudes towards research and the interview process. In the two parts of the research the age range was very wide. This is to be expected with the different properties of the diseases; multiple sclerosis (MS) usually occurs at an earlier age than Parkinson's disease (PD), and amyotrophic lateral sclerosis/motor neuron disease (ALS/MND) has an onset in the fifth decade of life. This age difference may have had an effect on the participants' responses, particularly in qualitative interviews; it was observed that younger participants discussed different matters than older ones. For example a young participant with MS was concerned about starting a family, work, and income while participants in their middle age were considering early retirement. For those who were already retired, particularly within the PD group, they discussed different maters that impacted their social life and family life but did not mentioned work.

Although the number of participants in part two of the research (looking at the relationship between quality of life and communication) was similar to that in other research studies (Ball *et al.*, 2004; Cruice *et al.*, 2010; Worral *et al.*, 2002; Yorkston and Beukelman, 1981), there was a discrepancy between the number of participants in each group based on diagnosis and severity of communication disorder. The largest number was participants with PD (56%) followed by ALS/MND (26%) and finally MS (18%) even though this is expected with the characteristics of the diseases. PD is one of the most frequently occurring neurodegenerative conditions (Raggi et al., 2010) with 70% of patients reporting voice and speech involvement (Hartelius & Svensson, 1994). While in MS changes in speech function occurs in 51% of cases (Duffy, 2005). Finally, ALS/MND where up to 80% of cases develop dysarthria at late stages of the disease (Yorkston, et al., 2002). This factor must be taken into consideration when interpreting the results as they may be driven by the characteristics of PD since it has the highest incidence within our sample. In addition, the severity of impairment of communication varied significantly within our sample; mild (76%) and moderate to severe (24%). The majority of participants with moderate to severe deceased intelligibility belonged to the ALS/MND diagnostic group (56%). Again this wide difference between the severities of dysarthria might impact on the results particularly when comparing the groups based on the severity of the communication disorder.

Gender was also a factor. In both parts of the research there were about twice as many men as women. However, it was known that PD had an equal incidence rate in men and women (Duvoisin, 1991), MS is 2 to 3 times more common in women (Anderson *et al.*, 1992), and slightly more men are affected with ALS/MND than women with a ratio of 1.5:1 (Ferguson & Elman, 2007). Therefore, the difference in the number of men to women in this study could not be related to disease characteristics, but it might be related to cultural and social factors in Saudi Arabia. It may be that women are more restricted in their participation in clinical research since a female participant is usually accompanied by a male relative when going to an appointment, especially when travelling is required, which may lead to fewer women agreeing to take part. Therefore women may prefer to be seen at home, where transportation is not an issue.

Finally, during the interviews, in both parts of the research the participants were reserved about sharing some of the information with the researcher. They were not familiar with what research entailed and were asking how these questions were going to find a cure for the disease. They also noted that some of the questions that they were being asked were novel to them and they were apprehensive about sharing personal information with the researcher. With increased description of the aims of the research as well as the reassurance that the research information was not going to be linked to them in any way and will be labelled anonymously they seemed to be more comfortable and shared more towards the end of the session.

7.4 Development of Communication Assessment Measures

Since the cultural and linguistic background of participants heavily influences communication, there was a need to pay particular attention to guidelines set by research for the development of culturally acceptable measures for intelligibility and functional communication. We made sure that we involved individuals from the same cultural background as the participants (Carter *et al.*, 2005). This was carried out by ensuring that the judges, reviewers of the words and sentences, the researchers and participants in the pilot studies were all Arabic speakers and from Saudi Arabia. In addition we did not translate any of the test material. Instead we developed our own tests of intelligibility and of functional communication based on acceptable standards used by previous researchers in English language as described in chapter 4 of this thesis. For the intelligibility measure we used the definition of intelligibility: "… the accuracy with which an acoustic signal is conveyed by the speaker and recovered by the listener" (Yorkston and Beukelman, 1980; Yorkston et al., 1996) as basis for developing our test. We decided to use the methodologies followed in the Assessment of Intelligibility of Dysarthric Speech (AIDS) (Yorkston & Beukelman, 1981) since it is a widely acceptable measure of intelligibility (Hill, Theodoros, Russell & Ward, 2009; Sheard, Adams & Davis, 1991) and has been used in both clinical and research settings to assess intelligibility in dysarthric speakers. For the assessment of functional communication scale (FCS) we carried out semi-structured interviews in order to identify areas for communication that occur in everyday life. This was done to ensure that our assessments are acceptable valid and reliable for this specific population.

7.4.1 Assessment of intelligibility

Once the words and sentences were selected for the Arabic version of the AIDS (A-AIDS), they were reviewed by five speech language pathologists from Saudi Arabia. Agreement was reached at the end of the review process and the test was carried out and showed inter- and intra- judge reliability. However, questions regarding the validity of the measure were raised particularly in relation to the message (words and sentences). The criteria that were used and set by Yorkston and Beukelman (1981) for the selection of words was that they were similar sounding. This same standard was used by the researcher and in the instructions given to the reviewers. We ended up with 50 word groups that are similar sounding but not with specific acoustic contrasts to allow us to compare them and determine how certain acoustic features may be more sensitive to dysarthria or which ones have the most effect on intelligibility. Therefore the interpretation of the Arabic version of the AIDS should be done with caution, as we do not know if there are certain acoustic features in Arabic that are more sensitive to dysarthria, and if there are we cannot determine if the person scored less on the Word Intelligibility measure due to the presence of these features or due to the actual impairment in intelligibility. This would suggest that additional criteria be put in place during the word selection process. These include using the same number of syllables within a group, having groups of words that include only one set of minimal pairs, having certain phonemes in each group deliberately to cover all phonemes and see if some of the groups were more difficult to hear than others.

For the sentence intelligibility measure again we followed the Yorkston and Beukelman (1981) methodology in selecting the sentences. The sentence length was based on word count rather than syllables. The idea behind sentence intelligibility is to assess intelligibility of speech as it occurs with additional contextual cues. However, the sentences need to be less predictable since this may impact the results (Garcia and Cannito, 1996; Garcia and Dagenais, 1998). Sentence intelligibility scores for participants whose intelligibility is close to normal tends to be close to normal levels and therefore on such measures additional information on rate of speech needs to be included in order to differentiate normal from mildly dysarthria speech. In our sample out of 34 participants 13 scored within normal levels (96-98). To allow better differentiation between mild dysarthria/impaired intelligibility and normal speech, speaking rate analysis needs to be included, but unfortunately rate of speech measures for Arabic speakers have not yet been calculated so this would be an area for future research. Therefore we did not use sentence intelligibility scores as an indicator for severity of impairment in intelligibility.

Other factors that could impact on the intelligibility measure are the judges whom participated in the study. We decided to use five independent judges when developing the A-AIDS. These judges were speech language pathology students in their final year at university. We do not know if the fact that these judges are familiar with dysarthria and having been previously exposed to dysarthric speech may make them more sensitive in comparison with a layperson listening to dysarthric speech for the first time.

7.4.2 Assessment of Functional Communication

The functional communication measure was developed to have an acceptable instrument to assess communication as it occurs in everyday life. For the purposes of this research we decided to ask the participants to generate the themes that are to be included in the measure through semi-structured interviews. The themes that emerged were used in the development of the test that was piloted on a group of individuals with neurodegenerative disease. Scoring of the FCS (Functional Communication Scale) used the same method as the American Speech Language and Hearing Association Functional Assessment of Communication Skills (ASHA FACS) (ASHA, 1995) and indeed, it appears that the two measures have many features in common. (Appendix 16 – ASHA FACS for comparison). These similarities may have been influenced by several factors; first of all the researcher reviewed several functional communication scales including the ASHA FACS to determine the interview schedule. Second, the researcher asked speech therapists to review the measure prior to piloting it and since they were all familiar with the ASHA FACS that may have influenced their feedback. Finally, the participants were also asked to give feedback on the test but none of them had anything to change and reported that it was easy to understand and reflected their daily communication. However, participants may not have been familiar with the ideas and protocols of research and just wanted to agree with the clinician rather than critically evaluating the measure. The FCS is still considered a valid, reliable and acceptable measure to be used with this population since it was generated, reviewed and piloted on them.

7.4.3 Clinical implications

The development of the two assessment tools for intelligibility will provide Saudi clinicians with the means to look at intelligibility in a more objective manner across patients rather than the previously used subjective assessment of intelligibility through reading a passage. This can be done after conducting another review of the word list to ensure that the words within each group are more similar sounding than they currently are. In addition a review of the sentences will be necessary to ensure that some are not more predictable than others.

Also, there is much to be learned about the acoustic features of Arabic and how they are affected by dysarthria. Research looking at acoustic and phonetic contrasts to determine features of Arabic phonology that are sensitive to dysarthria and contribute to speech intelligibility is required. In addition, speech rate analysis should be included in any future research in sentence intelligibility to help differentiate the speech of very mildly dysarthric participants from normal intelligibility.

In the qualitative analysis of the FCS important information that has clinical implications was generated indicating the need for further research. The participants discussed feelings of isolation, restricted communication participation that depended on the communication partner and environment, and the avoidance of communication situations. A clinical consequence that was gained from the research is the need to increase communication opportunities for this population and a move away from traditional therapy where the aim is to improve intelligibility to include the patients' environment and communication partners to increase participation opportunities is indicated. When discussing communication, even though it was stressed that any form of communication could be discussed, it was noted that the participants mainly spoke about verbal communication and not other forms of communication such as gestures, augmentative communication including simple communication boards and/or computerised devices. This was true for all except one participant who spoke about using an alphabet board. Clinically we need to increase the exposure to other forms of communication for this population of patients, particularly due to the degenerative nature of the diseases, noting that the timing of introducing AAC is an important clinical decision making issue (Beukelman, *et al.,* 2011). This also reflects the emphasis that participants placed on verbal communication.

Further research is needed to evaluate the test-re-test reliability, construct validity and the correlation with other measures of communication function and dysarthria. Validation and reliability testing should be undertaken using a larger group size. Another approach that could be used to increase the validation of the measure is to compare the participants' scores with actual observations of communication behaviours in real life situations, similar to Communication Activities of Daily Living (Holland, *et al.,* 1999). If such an approach was to be undertaken then the judges should include participants' primary care providers or people with whom they interact frequently and, if possible, daily. This is because such caregivers observe the participants communicating in real life and over a long period of time, unlike a clinician or researcher whose interactions are more restricted. In addition, video recording of real life communication experiences is indicated to assess daily life experiences and evaluate communication breakdown in order to enhance successful communication participation (Bloch & Wilkinson, 2011).

The population on which these measures were trialled is unique and does not represent the wider population of adults with dysarthria and functional communication impairments. We made sure that the population of participants that we used did not present with any cognitive or language impairments. In addition the form of communication disorder that they have is a degenerative one, meaning that it is not stable and deteriorated over time. In general clinic situations there could be patients that present with dysarthria that occurs with aphasia or other communication or cognitive disorder post various kinds of cerebrovascular accidents. Therefore before any of the intelligibility or functional communication measures can be used in clinical situations they need to be tested with different populations to establish their validity and reliability.

7.5 Quality of Life and Communication

Prior to discussing the analysis of the relationship between communication and quality of life we need to note that this analysis is based on the measures that were discussed in the previous section. Therefore caution must be taken when interpreting the results as the results we obtain may not be sensitive to the level of intelligibility of the individuals especially those at the highest and lowest levels of the scale. This is especially important when dividing the sample based on the disease as well as on the severity of intelligibility impairment. Another factor to consider is that we used one judge in this part of the research since strong correlation was seen between the five judges in the development stage of the A-AIDS. Using one judge rather than several judges could also impact the reliability of the intelligibility scores that we obtained. In addition the demographic differences between the groups, should also be taken into consideration.

To investigate quality of life and communication in this population of participants several measurement tools were used. For QoL a generic Health Related Quality of Life (HRQoL) measure (Arabic Sickness Impact Profile – ASIP) (Almansoori, 2003), an individualised QoL measure (Scheduled Evaluation of Individual Quality of Life-Direct Weighing – SEIQoL-DW) (Browne, *et al.,* 1997), and a single item questionnaire (McGill Quality of Life-Single Item Scale – MQoL-SIS) (Cohen, *et al.,* 1995) were used. In addition we looked at the various components of the ASIP. There is a benefit in looking more closely at the three components of the ASIP separately, as it allows us to understand which of the components drive the relationship between measures of communication and the ASIP. As we realized from the results of this thesis the majority of the relationship between FCS and the ASIP was driven by the psychological and independent components of the test. We also looked at the four individual profiles of the SEIQoL-DW as well as the most frequent cues reported by the participants. This was important to carryout since the SEIQoL-DW is an interview based measure and caution must be taken when interpreting the overall index score. It is a sum of products of individual cue levels by cue weight, each of which may vary independently. Felgoise and colleagues (2009) cautioned when using SEIQoL-DW to evaluate QoL of a large group of participants and for evaluating group differences. However they highlighted that it had value in determining factors that are related to psychological wellbeing of individuals.

For the assessment of communication we used the two instruments developed in the first part of this research. Due to the fact that the Word Intelligibility may not be as sensitive at the upper and lower levels of the scale we preferred to be more cautious. Instead of using 98% WIS that was the lowest score obtained from our normal sample we decided to follow other researchers and use 95% as a cut off for our sample for mild dysarthria (Dongilli, 1994; Yorkston & Beukelman, 1981a). For the purposes of this research mild was considered 95% to 71%, moderate 71% to 50% and anything below 50% was considered severe.

When looking at the complete sample including all the disease groups, there were medium and strong correlations seen between measures of communication (FCS) and ASIP, particularly with the psychological and independent components of the measures. These components look at factors related to rest, eating, work, home management, recreation for the independent score and emotion, affect, social interactions and communication for the psychological score. We looked at the ASIP and how communication and social interaction were represented within the test. The factors related to communication included statements related mainly to speech production such as: I have a problem speaking, I use sign language, my voice can be heard only by those sitting close to me, I cannot produce certain words, I stutter, and I cannot speak clearly when I am under pressure. The statements related to social interaction were mainly on social life and included: I leave the house less, I never leave visit anyone, I care less about other people's problem, I get upset very fast, I avoid visiting anyone, I speak less with those around me, and I stay alone most of the time. It is apparent that the vast scope of the impact that communication changes has on life is not covered in these brief statements and therefore communication is not done justice within this measure, this was reported on by other researchers although not specifically looking at SIP but other measures of quality of life (Cruice, Worrall, Hickson, 2000). When developing the American Speech and Hearing Association Quality of Communication Life Scale (ASHA QCL, 2004) Paul and colleagues (2004) reviewed a number of measures that were developed specifically for communication disorders including the Voice Handicap Index (Jacobson,1997) and the Hearing Handicap Inventory for the Elderly (Weinstein & Ventry, 1983) and reported that these measures were limited to single aspects of communication and therefore are highly specific measures and cannot be used across disorders. In addition they looked at measures of health related QoL to determine if they adequately cover aspects of communication disorder. They reported that there are certain measures including the Sickness Impact profile (SIP) (Bergner et al., 1981); on which the ASIP is based, that include at most a few items related to communication. These items usually relate to the ability to communicate and none include items that are concerned with the impact that impaired communication skills have on an individuals' life. deHaan and colleagues (1993) suggested to supplement the SIP with questions of feelings of wellbeing and life satisfaction since it is mainly a behavioural measure.

By looking at the statement in ASIP on communication and social life some similarities can be seen between them and those in FCS: I can communicate my basic needs and wants, I can ask for help, I can communicate my emotions, I can have a conversation, and I can use the phone among others. From this description we can conclude that communication is measured within the ASIP in terms of the role of communication in everyday life and not in terms of the impact that it has on quality of life. This could be one of the reasons why we see FCS more frequently related to measures of QoL particularly the independent and psychological aspects of the ASIP. In addition functional communication scales were reported to relate to measures of HRQoL in patients with Aphasia (Cruice *et al*., 2003; Hilari *et al*, 2003).

When dividing the sample by disease type or by the severity of decreased intelligibility, different relationships between measures of communication and measures of QoL are observed. Most frequently we see that functional communication as measured by FCS shows correlation with ASIP total score as well as its independent and psychological components. This was observed within the group with MS, the group of participants with PD and the group of participants with a mild decrease in intelligibility. As discussed in the previous section the components related to communication within the ASIP are similar to the statements in the FCS. There were relationships that were observed between measures of intelligibility and QoL measures. Within the group of participants with ALS/MND, Sentence intelligibility score was correlated with the SEIQoL-DW total index score and within the moderate to severe decrease in intelligibility group there was a correlation between Word intelligibility score and the ASIP as well as the psychological component of the ASIP.

One important factor to observe is the fact that this relationship between QoL and measures of intelligibility was observed in cases where speech was more severely impaired i.e., it was observed in the ALS/MND group where the majority of participants had a moderate to severe decrease in intelligibility (56%) and the moderate to severe impaired intelligibility group. One could conclude that when there is an increase in impairment as reflected by measures of intelligibility there is a closer correlation between impairment and measures of QoL. However, such a conclusion should be made with great caution for several reasons. First, as discussed several times within this thesis, any conclusion that we reach based on the intelligibility measures should be treated carefully as there remain some questions related to the sensitivity of the WIS and SIS in detecting intelligibility levels at both ends so the scale (very high scores and very low scores).

In addition we noted that there was a correlation between the SEIQoL-DW (O'Boyle, et al, 1993) and the SIS within the participants with ALS/MND. As previously discussed SEIQoL-DW is an interview based instrument and therefore will reflect QoL based on the specific cues that the individual being interviewed selected at the time. It could be that with increased impairment in speech intelligibility the participants selected communication as a cue that related to their QoL and rated it as low. By looking at the results in chapter 5 we determine that the three most frequently reported cues that impact on QoL differ for participants with mild and moderate-severe decreases in intelligibility. Participants with mild decrease in intelligibility more frequently reported relatives, children, and social life as opposed to participants with moderate-severe decrease in intelligibility who reported communication, self care, and acceptance. This could be an explanation for the relationship seen between SIS and SEIQoL-DW within the ALS/MND group of participants.

One measure of QoL that didn't show any correlation with any of the measures of communication is the MQoL-SIS. This is a single item measure where the participants are asked to rate their overall QoL on a 10-point scale. The purpose of such measures is the ease of administration particularly with participants who have health conditions that may impact on communication, cognition or fatigue. Using single item measures of QoL, although it is simple and therefore desirable for ease of administration, sensitivity is typically a compromise (Fries, 1991). This appears to be the case in our research as there were no relationships found between any of the communication measures. The MQoL-SIS was used by researchers to look at the QoL of individuals with ALS/MND and they reported that there was an observed correlation between this measure and the ALS Functional Rating Scale (ALSFRS) (Lou et al., 2009).

By examining the literature in the areas of neurodegenerative disease and QoL we note that the majority of researchers did not show a correlation between the different measures of QoL i.e., HRQoL, individualised QoL, and single item scales (Felgoise et al, 2009; Goldstein, Atkins, and Leigh, 2002; Neudert, Wasner, Barasio, 2004). In research investigating the relationship between QoL and communication, the findings were not always consistent. Ross and Wertz (2010) reported that patients with aphasia did not show a correlation between measures of language impairment and impaired communication activity measure and measures of QoL. The same was reported by

Letanneux et al., (2013) in a study looking at patients with PD, no relationship was found between and Parkinson's specific measure of QoL (Parkinson's Disease Questionnaire- PDQ-39) (Peto, Jenkinson, & Fitzpatrick, 1998) and speech impairment. On the other hand Cruice, Hickson and Morison (2003) and Hilari et al. (2003) reported that language functioning and functional communication are implications of QoL. These research findings reflect the fact that QoL is a highly complex construct involving different factors that are highly individualized. This makes understanding the role that communication impairment plays within this QoL challenging. In addition QoL is measured with various tools looking at HRQoL, individual QoL, psychological wellbeing, and disease specific measures. Therefore when comparing different research findings we need to take into account the specifics of each test used, what it is really measuring and how QoL was defined.

7.5.1 Individual Perspectives

Since the interpretation of the SEIQoL-DW overall index score should be done with caution and since we saw a correlation measure of communication on only two occasions we decided to take a closer look at the cues nominated and at the profiles of four of the participants. We noted that the more severe the impairment in intelligibility the more communication is nominated as an important cue that has an impact on QoL. In the four individual profiles it can be seen that the ratings of individual QoL are highly individualized and subjective to each participant. The weight given to different factors that are important in life varied significantly and could mask the impact that certain domains have on overall QoL. Therefore, an index score may not be representative of these factors that are given very low scores on levels of importance. In addition, sometimes the most important aspects of a person's QoL are not those that are the most obvious but occur to the participants upon deeper reflection (Felgoise *et al.,* 2009). Consequently, it was important to carryout qualitative research to allow the participants to reflect further on their life and also to understand the relationships between the various aspects of their life that are important and what the each domain means to them.

The last part of the research involved carrying out a semi-structured interview with the participants. Since QoL is a highly individualized and complex construct, investigating the impact that changes in communication have on overall QoL should involve the views of the patients themselves. This is especially important since none of the QoL measures available or used in this research have been developed for this particular population of individuals with progressive dysarthria. In addition, this research aimed not only to generate themes relating to QoL but to also understand the relationships between these aspects, the factors that contribute and detract from them, how progressive dysarthria is perceived to impact QoL, and if the severity of dysarthria makes a difference in the themes and categories generated.

Semi-structured interviews were conducted with 34 participants. Qualitative analysis generated eleven themes relating to emotional and psychological wellbeing, desire to maintain identity, physical function, search for control, social life, family, communication, faith and spirituality, perceived overall QoL, factors that help in coping and acceptance, and impact of disease on life. Participants gave clear insights into daily life experiences and there was an overall sense of loss relating to changes in roles, activities and responsibilities. The importance of psychological, social, and existential domains in this study is consistent with research in the area of QoL and neurodegenerative diseases (McLoed & Clarke 2007; O'Dohety *et al.,* 2010).

The emotional impact of the changes to life related to the loss of function, change in roles. Dependence on others was also prominent theme within the interview. The most frequent emotional consequence reported was depression. In other research looking at QoL and neurodegenerative disease, depression and emotional factors have also been highlighted as being related to QoL (Mitchell, *et al.,* 2005; Ng & Khan, 2011; Reijnders, *et al.*, 2008). Other factors identified in this study related to emotional and psychological wellbeing included sadness, fear, worry and happiness.

Another prominent theme reported was the desire to maintain identity including self-image, maintaining activities, and awareness of others perception of their disability. The majority of participants reported that they were unable to maintain these roles due to physical changes, communication changes or not wanting others to know about their disability. Similar concerns have been noted specifically in patients with ALS (Foley, *et al.*, 2007).

Unlike research carried out by Foley *et al.* (2007) where participants with ALS/MND did not report physical disability as a factor related to QoL, in this research physical function was a prominent factor and related to mobility and fatigue, and how changes in physical ability restricted their independence, social life and carrying out activities. These findings do not agree with those of Nordeson *et al.* (1998) who reported that patients with neurodegenerative diseases adapt by lowering their expectations regarding physical disability and by focusing on other life areas. The participants in this research were focused on the restrictions that physical function placed on their QoL. Search for control was an important theme generated by the participants as they wanted to have control over life decisions and to be independent. They also reported that they were aware of their dependence on others, which in turn made them feel like a burden on their families.

Social life was an area of life that was highly affected, and feelings of isolation, social restriction related to their physical and communication disability, shame and embarrassment were all discussed. Participants reported that they have become selective in their social activities and social partners. Family was also important, and participants were appreciative of the role that family played in their life but expressed concerns about their families regarding emotions and economics. The importance of family has been reported in other research on QoL and neurodegenerative disease (Foley *et al.*, 2007).

Communication was mentioned by both groups of participants, those with mild dysarthria and those with moderate-severe dysarthria. Verbal communication was constantly mentioned and no other forms of communication were discussed. The impact of changes in communication was mainly related to changes in the opportunities to participate and interact with others. Participants reported the impact that the communication disorder has had on social interaction; becoming more selective in interactions, on their role at work and home as well as changes in the role they play in a conversation, which had changed from a communicator to more of a listener. In addition, emotions related to not being understood were expressed and mainly included frustration and feelings of being upset when not understood. Changes in communication, the negative impact of communication on overall life, change in roles and responsibilities at home and at work, being more selective in interactions and socializing, perceptions of others views about communication ability, emotional reaction to changes in communication were all reported by research related to communication experiences in everyday life carried out with various communication disorders including MS (Yorkston *et al.,* 2001), spasmodic dysphonia (Baylor *et al.*, 2005), Huntington's disease (Hartelius, *et al.,* 2010), aphasia (Cruice *et al.,* 2010), and neurodegenerative disease (Walshe & Miller,*,* 2011). These factors have a number of clinical implications, which will be discussed later in the chapter.

The factors that contributed to a better QoL and coping with the disease included family support and understanding, the ability to have control over life and life choices, and finally, faith. Participants expressed that they feel that this disease is their fate from God and that it helps them accept it and be grateful for what they are still able to do. The factors that hindered their QoL and wellbeing included their lack of control over life, dependence on others, restricted social life and activities, isolation, change in work responsibilities, changes in speech and communication, and finally worrying about family, both emotionally and financially.

7.5.2 Clinical implications

From the results discussed a relationship between quality of life and communication in patients with neurodegenerative disease is apparent. This relationship has been demonstrated through quantitative and qualitative analysis. When working with patients who suffer from progressive dysarthria, which is often associated with conditions that have no known cure, it is necessary to try and reduce the gap between the patients' experiences and expectations. Therefore it is important to understand what contributes to their quality of life. Quality of life measures provide an important insight into the impact a disability has on a patient's life from their own perspective, which in turn is important for decision-making.

ASHA (2004) defined evidence-based practice as 'an approach in which current high quality research evidence is integrated with practitioner expertise and client preferences and values into the process of making clinical decisions'. In this definition 'client preferences and values' are emphasised, and therefore it is important to understand these preferences and values for a Saudi Arabian population with progressive dysarthria in order to work with them during therapy. This research has uniquely explored factors that are important for this population.

From the qualitative research it is apparent that the participants face restrictions in performing everyday tasks, have a feeling of stigmatisation from their society and environment, and perceive themselves to be looked at differently. Focusing on their communication experience and how it was described by the participants, there seemed to be a lot of restriction on participation and social interactions. In addition, the emotional consequences of a failed communication experience were also reported. Clinically it is important for anyone working with this population of patients to consider their psychological wellbeing as an important factor in their health care management, particularly since emotional and psychological wellbeing was frequently mentioned. Therefore increased opportunities for participation with different communicating partners within this patient's social environment should be included in their treatment plans. A challenge would be in the development of outcome measures that assess changes in participation following therapy particularly due to individual differences (Yorkston *et. al.,* 2001). Due to the frequency of negative emotions and sense of isolation reported, support groups, increased patient and community education, and possibly group therapy should also be considered. At present, these types of interventions are not common in speech language pathology provision in Saudi Arabia.

In order to carry out research looking at therapy and the acceptance of this type of treatment procedure in the Saudi culture, gender restrictions must be borne in mind.

Similar to the point discussed within the FCS development, the majority of participants only discussed verbal communication when talking about communicating. As no other forms of communication were reported, it is important to increase exposure of this patient population to different augmentative and alternative communication (AAC) material. Further research on the development of AAC material is also recommended together with investigating patient and community acceptance and the impact it may have on quality of life and overall wellbeing (Calvo *et al., 2008)*.

7.6 Caregiver Perspectives

With increased disability and decreased independence, the family take on the role of the caregiver; or they may bring in someone external to the family to be the primary caregiver. This shift in role increases the burden that is placed on the participant and is related to factors of increased depression within this population. The presence of a communication disorder also sometimes requires the caregiver to complete questionnaires of assessments related to the quality of life of the individual (Hirsch& Holland, 2002). Caregivers can often act as informants for individuals who suffer from communication difficulties. The correlation between their perceptions and the perception of the individuals themselves on measures of QoL and communication was therefore investigated. There was a correlation between the patient judgments and the judgments of the caregivers for the FCS which was similar to findings of other researchers who looked at the reliability of measures in functional communication for participants with dysarthria and aphasia (Ball, 2004; Donovan, Rosenbek, Ketterson, & Velozo, 2006; Glueckauf et al., 2003; Ketterson et al., 2008). For ASIP the correlation seen was driven by the physical component (measures ambulation, mobility, and body care) and the psychological components of the ASIP (measures emotion, affect, social interaction, communication). This is similar to findings by Schmidt *et al.*, (2010) who also found a correlation between the patients' and the proxy's assessment of the patients' QoL. However, other researchers have reported that when using proxies they tend to underestimate the QoL of an individual (Bromberg and Forshew, 2001; Rothman, *et al.,* 1991; Schiffczyk *et al.,* 2010), or that reports on QoL completed by a proxy can be influenced by their own feelings and experiences of caring for the individual (Addington-Hall & Kalra, 2001).

Another factor that is important when dealing with individuals with neurodegenerative diseases is to keep in mind investigating the burden the caregivers have as well as the presence of other psychological conditions such as depression. Families are partners in the rehabilitation and management of these patients and caring for the patient could place them under considerable burden and stress, particularly due to the changes in roles and responsibilities as expressed in the qualitative interviews. Understanding the burden of the caregiver as well as their perspective on individual's communication and QoL is important for clinical practice. This is particularly important when counselling the family on how best to communicate and provide services at home.

7.7 Strengths and Limitations:

7.7.1 Strengths and Clinical Implications

Research carried out in communication disorders usually takes place in the US and Europe. A large amount of research is found in the English language. This research is a first time the relationship between communication and QoL has been investigated in a Saudi Arabian population. It provided us with the opportunity to develop and an objective measure of intelligibility and functional communication to use with a neurodegenerative conditions that can be used in clinical settings after a review of the reported shortcomings. Knowledge of the impact that communication impairment has on QoL provides important information that could help clinicians develop a successful rehabilitation program. Participation restriction and embarrassment from changes in communication tend to impact QoL the most. Although this practice might be more commonly used in Europe and the US it is still not the case in Saudi Arabia. In addition understanding the role that the caregiver plays and allowing them to understand the perspectives and expectations of the patient when planning therapy programs is very important. From this research wider appreciation of QoL amongst speech language pathologists in Saudi Arabia can be gained allowing them to focus on the factors in communication that impact QoL in addition to more traditional speech impairment.

7.7.2 Limitations

As discussed the development of the assessment of intelligibility is both a strength and shortcoming in this research. The word intelligibility list proved to have some word groups that are not as similar sounding as they should be to give a valid assessment tool. Questions remain to be answered regarding the acoustic characteristics of Arabic and how they are affected by dysarthria. We didn't assess the predictability of the sentences that were developed for the sentence intelligibility score. In order to be able to use the SIS with a group of participants with mild dysarthria, and provide accurate results, a measure of speech rate needs to be included. The numbers of participants within each disease group and severity of dysarthria groups were not equal, this is important to ensure rigor of statistical outcomes. And finally, the male to female ratio was not equal within the research. This is important to show the perspectives of males and females particularly in the qualitative research and in order to determine if their perspectives differ in terms of aspects of life that impact on QoL.

7.8 Future Research

At the time of the analysis we realized that the groups were not equal in number and therefore in future research it is important to have mild, moderate, and severe dysarthria equally represented and with a number that is large enough to ensure statistical power and rigor. When answering the question relating to the acoustic characteristics of Arabic and how they are affected by dysarthria it is important to be able to analyse the reasons for misperceptions in intelligibility measures. This can be carried out through the forced selection process from a list of four similar sounding words where the words are minimal pairs and they each differ from each other in a single acoustic feature. For example /saːr, suːr, sˤaːr, siːr/. Analysing the predictability of the sentences can be done by having a group of participants predict missing words within each of the sentences. If the sentences are more predictable then the listeners' that judge dysarthric speech may be using contextual cues when transcribing them. There is a need to review the word intelligibility list in order to make sure that the words within each group are more similar sounding. The criteria that will be set for the review will include: the words can be minimal pairs, minimal pairs with the same prefix and suffix, words that start and end with the same consonant, same number of syllables. There is also a need to assess the validity and reliability of the FCS with a wider population of individuals with communication disorders including aphasia and cognitive impairments. In this case we will have to revisit the statements within the test and make and possibly interview a number of participants with aphasia and/or cognitive impairment to see if they experience functional communication in daily life in a similar way as those with degenerative dysarthria or if the measure needs to be amended. It is most likely that the test will need to be amended as the communication experiences will differ and will include factors that relate to comprehension which was not part of the current FCS. For questions related to the relationship between communication and QoL, it is necessary to revisit this research using an intelligibility test that is more accurate, as discussed earlier, with a group of participants who are more equally distributed between dysarthria groups. This will give us a better understanding of the relationship between QoL and communication.

7.9 Conclusion

Studying communication and QoL in a population of Saudi Arabian individuals with neurodegenerative disease is a novel area of research. This posed a challenge during this research process. Since the two concepts (communication and QoL) are complex and highly dependent on cultural and language aspects of the individual, simple translation and back translation of the measures under development was not an option. Therefore the measures used for communication had to be developed specifically for this population. The fact that we have developed a measure of communication is a strength of this research since it provides a means for clinicians to assess intelligibility in a more objective manner. However, a significant review of the SIS and WIS needs to be carried out before this is possible.

The qualitative interviews for both functional communication and QoL gave us a perspective on individual perceptions of wellbeing, QoL, communication participation, and communication limitations as well as the aspects of life that contribute and detract from them. This information is important to carry through into clinical management of these participants and start to shift therapy from solely in the clinic to include the person's environment and natural setting as has been done in many other countries. Including the patients' perspectives when setting goals is important so we can tap into aspects of life that will have an impact on wellbeing and QoL. In addition understanding the caregivers' perspectives of the patients' QoL and communication is important in order help them understand each other better and help plan and carryout therapy goals.

The participatory approach suggested in this thesis, is possible in Saudi Arabian culture. In Saudi culture there is a strong family bond and it is rare to find sick or elderly members of the family in centres for palliative care or homes of the elderly. They tend to move in with a family member where they are taken care of either by that family member or a domestic worker who is brought in especially for this purpose. Therefore, having these individuals being part of the treatment plan, allowing them to understand the consequences that the changes in communication have on their QoL and wellbeing, facilitating the communication opportunities is important. It may also alleviate some of the burden that this caregiver is feeling if they have a better understanding of the patients' feelings. In addition since faith is an important aspect of the Saudi Arabian community, this is not to say that all Saudi Arabians are equally faithful individuals, and has been brought up several times during the SEIQoL-DW cues and the qualitative interviews it can be a factor that helps in acceptance of the consequences of the disease. When caring for patients with neurodegenerative disease it is usually done within a team approach and therefore adding a religious counsellor might be beneficial for these patients. It is also important to explain the purposes of the treatment goals to both the participants and their caregivers, which is to allow them with the ability to communicate by any means possible in the easiest and most effective way. This is important since an interesting observation during this research was that the participants expected the research to result in a cure for their conditions. Finally, the cultural aspects of Saudi Arabia make it possible to introduce more focus on participation and wellbeing while continuously taking into consideration and following the person's acceptance of these approaches.

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APPENDIX 1 – INFORMATION SHEET (ENGLISH VERSION)

Information Sheet for Participants in Research Studies

(Interviewed and Intelligibility pilot study group)

You will be given a copy of this information sheet.

Title of Project:	Investigating communication and QoL in Saudi Arabian individuals with progressive dysarthria

This study has been approved by the UCL
Research Ethics Committee 1673/001

Name, Address and Contact Details of Investigators:	**Mashael Faisal Al Saud** **UK Address:** **Department of Language and Communication** **Division of Psychology and Language Sciences** **University College London** **Chandler House, 2 Wakefiled Street** **London, WC1N 1PF** **Tel. 07717721266** **Saudi Address** **King Faisal Specialist Hospital** **Speech and Language Pathology Clinic** **Tel. 0504761646** **e-mail:** m.faisal@ucl.ac.uk

We would like to invite you to participate in this research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

Purpose of the research and what you would be doing:

The reason we are doing this research is to help us understand your perception of changes in your communicative function as it related to actual changes in speech ability. We also want to assess the validity of a new tool that allows us to assess the level of intelligibility in your speech.

If you agree to take part in this research you will be asked questions. These questions will not be testing you. They will be asking you to talk about your experience with changes in your communication. The interview will be audio-recorded and will take about 60 minutes.

We would also like you to read a number of words and sentences; again this is not a testing process. These words will be audio-recorded and should take about 30 minutes.

Do you have to take part?

It is up to you to decide whether or not you want to take part. If you do agree to take part you are still free to say you want to stop whenever you want, you do not have to tell us why. It is completely up to you and this will not affect the management you are currently receiving at King Faisal Specialist Hospital.

What are the possible disadvantages and risks of taking part?

There is nothing dangerous about what you will be asked to do during this study.

What are the possible benefits of taking part?

We hope that the information that we get from this study will help us understand more about how changes in speech production affects you in your everyday life. This will allow us to improve our knowledge in management of speech difficulties associated with progressive dysarthria.

What happens when the research study stops?

When the research is over, you will just continue with your speech therapy sessions at King Faisal Specialist Hospital.

What if I am unhappy with something to do with the research?

If you are unhappy about anything in the study, you can talk to your speech therapist and she will contact the research department at King Faisal Specialist Hospital.

Will the results of the study be kept secret?

All information collected will be kept confidential. All information that leaves the hospital will have your name removed so you cannot be recognised from it.

Your interview will be recorded on audio-tape and, once it is transcribed, the tape will be erased.

What will happen to the results of the study?

When the research is completed we will write a report on the result. We also hope to write some papers about the research for publication in journals.

What do I do now?

Think about the information in this sheet, and ask me if you are not sure of anything. If you agree to take part then sign the consent form. The consent form will not be used to identify you. It will be filed separately form all other information. If after the interview you want any more information about the study, tell your therapist and we will contact you.

Thank you,

Please note that it is up to you to decide to participate in the study. If you choose not to participate it will involve no penalties or loss of benefits. If you decide to take part in the study you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw from the study at any point without giving a reason.

All data will be collected and stored in accordance with the Data Protection Act 1998.

Information Sheet for Participants in Research Studies
(Individuals diagnosed with Progressive dysarthria)
You will be given a copy of this information sheet.

Title of Project:	Investigating communication and QoL in Saudi Arabian individuals with progressive dysarthria

This study has been approved by the
UCL Research Ethics Committee
1673/001

Name, Address and Contact Details of Investigators:

Mashael Faisal Al Saud

UK Address:
Department of Language and Communication
Division of Psychology and Language Sciences
University College London
Chandler House, 2 Wakefiled Street
London, WC1N 1PF
Tel. 07717721266

Saudi Address
King Faisal Specialist Hospital
Speech and Language Pathology Clinic
Tel. 0504761646

e-mail:
m.faisal@ucl.ac.uk

We would like to invite you to participate in this research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

Purpose of the research and what you would be doing:

The reason we are doing this research is to help us understand how changes in speech ability relate to your perception of communicative function and how that relates to your quality of life over the course of the disease.

If you agree to take part in this research you will be asked to fill in two questionnaires. One is related to your perceived health related quality of life and the other one related to how you rate your communicative function. Each of the questionnaires will take about 20 minutes to fill out and do not have to be completed during one session.

We would also like you to read a number of words and sentences in order to assess the percentage of intelligibility of your speech. This should take about 30 minutes.

Do you have to take part?

It is up to you to decide whether or not you want to take part. If you do agree to take part you are still free to say you want to stop whenever you want, you do not have to tell us why. It is completely up to you and this will not affect the management you are currently receiving at King Faisal Specialist Hospital.

What are the possible disadvantages and risks of taking part?

There is nothing dangerous about what you will be asked to do during this study.

What are the possible benefits of taking part?

We hope that the information that we get from this study will help us understand more about how changes in speech production affects you in your everyday life and how that relates to your quality of life. This will allow us to improve our knowledge in management of speech difficulties associated with progressive dysarthria.

What happens when the research study stops?

When the research is over, you will just continue with your speech therapy sessions at King Faisal Specialist Hospital.

What if I am unhappy with something to do with the research?

If you are unhappy about anything in the study, you can talk to your speech therapist and she will contact the research department at King Faisal Specialist Hospital.

Will the results of the study be kept secret?

All information collected will be kept confidential. All information that leaves the hospital will have your name removed so you cannot be recognised from it.

What will happen to the results of the study?

When the research is completed we will write a report on the result. We also hope to write some papers about the research for publication in journals.

What do I do now?

Think about the information in this sheet, and ask me if you are not sure of anything. If you agree to take part then sign the consent form. The consent form will not be used to identify you. It will be filed separately form all other information. If after the interview you want any more information about the study, tell your therapist and we will contact you.

Thank you,

Please note that it is up to you to decide to participate in the study. If you choose not to participate it will involve no penalties or loss of benefits. If you decide to take part in the study you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw from the study at any point without giving a reason.

All data will be collected and stored in accordance with the Data Protection Act 1998.

Information Sheet for Participants in Research Studies

(Primary caregivers of individuals diagnosed with Progressive dysarthria)

You will be given a copy of this information sheet.

Title of Project:	Investigating communication and QoL in Saudi Arabian individuals with progressive dysarthria

This study has been approved by the
UCL Research Ethics Committee
1673/001

Name, Address and Contact Details of Investigators:	**Mashael Faisal Al Saud**

UK Address:
Department of Language and Communication
Division of Psychology and Language Sciences
University College London
Chandler House, 2 Wakefiled Street
London, WC1N 1PF
Tel. 07717721266

Saudi Address
King Faisal Specialist Hospital
Speech and Language Pathology Clinic
Tel. 0504761646

e-mail:
m.faisal@ucl.ac.uk

We would like to invite you to participate in this research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

Purpose of the research and what you would be doing:

The reason we are doing this research is to help us understand your perception of changes in the communicative function and quality of life of your relative over the course of their disease.

If you agree to take part in this research you will be asked questions. These questions will not be testing you and will be asking you to rate your relative's experience with changes in their communicative function and quality of life. This should take about 20 minutes for each questionnaire.

Do you have to take part?

It is up to you to decide whether or not you want to take part. If you do agree to take part you are still free to say you want to stop whenever you want, you do not have to tell us why.

What are the possible disadvantages and risks of taking part?

There is nothing dangerous about what you will be asked to do during this study.

What are the possible benefits of taking part?

We hope that the information that we get from this study will help us understand more about how changes in speech production affects individuals with progressive dysarthria in everyday life and how that relates to their quality of life. This will allow us to improve our knowledge in management of speech difficulties associated with progressive dysarthria.

What happens when the research study stops?

When the research is over, your relative will continue to receive speech therapy session at King Faisal Specialist Hospital as they did before the research.

What if I am unhappy with something to do with the research?

If you are unhappy about anything in the study, you can talk to your speech therapist and she will contact the research department at King Faisal Specialist Hospital.

Will the results of the study be kept secret?

All information collected will be kept confidential. All information that leaves the hospital will have your name removed so you cannot be recognised from it.

What will happen to the results of the study?

When the research is completed we will write a report on the result. We also hope to write some papers about the research for publication in journals.

What do I do now?

Think about the information in this sheet, and ask me if you are not sure of anything. If you agree to take part then sign the consent form. The consent form will not be used to identify you. It will be filed separately form all other information. If after the interview you want any more information about the study, tell your therapist and we will contact you.

Thank you,

Please note that it is up to you to decide to participate in the study. If you choose not to participate it will involve no penalties or loss of benefits. If you decide to take part in the study you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw from the study at any point without giving a reason.

All data will be collected and stored in accordance with the Data Protection Act 1998.

APPENDIX 2- CONSENT FORM

Informed Consent Form for Participants in Research Studies

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Project:	Investigating communication and QoL in Saudi Arabian individuals with progressive dysarthria

This study has been approved by the UCL Research Ethics Committee 1673/001

- Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part.
- If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.
- I understand that if I decide at any other time during the research that I no longer wish to participate in this project, I can notify the researchers involved and be withdrawn from it immediately.
- I consent to the processing of my personal information for the purposes of this research study. I understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.

Participant's Statement

I ………………………………………….....................................

agree that the research project named above has been explained to me to my satisfaction and I agree to take part in the study. I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

Signed: Date:

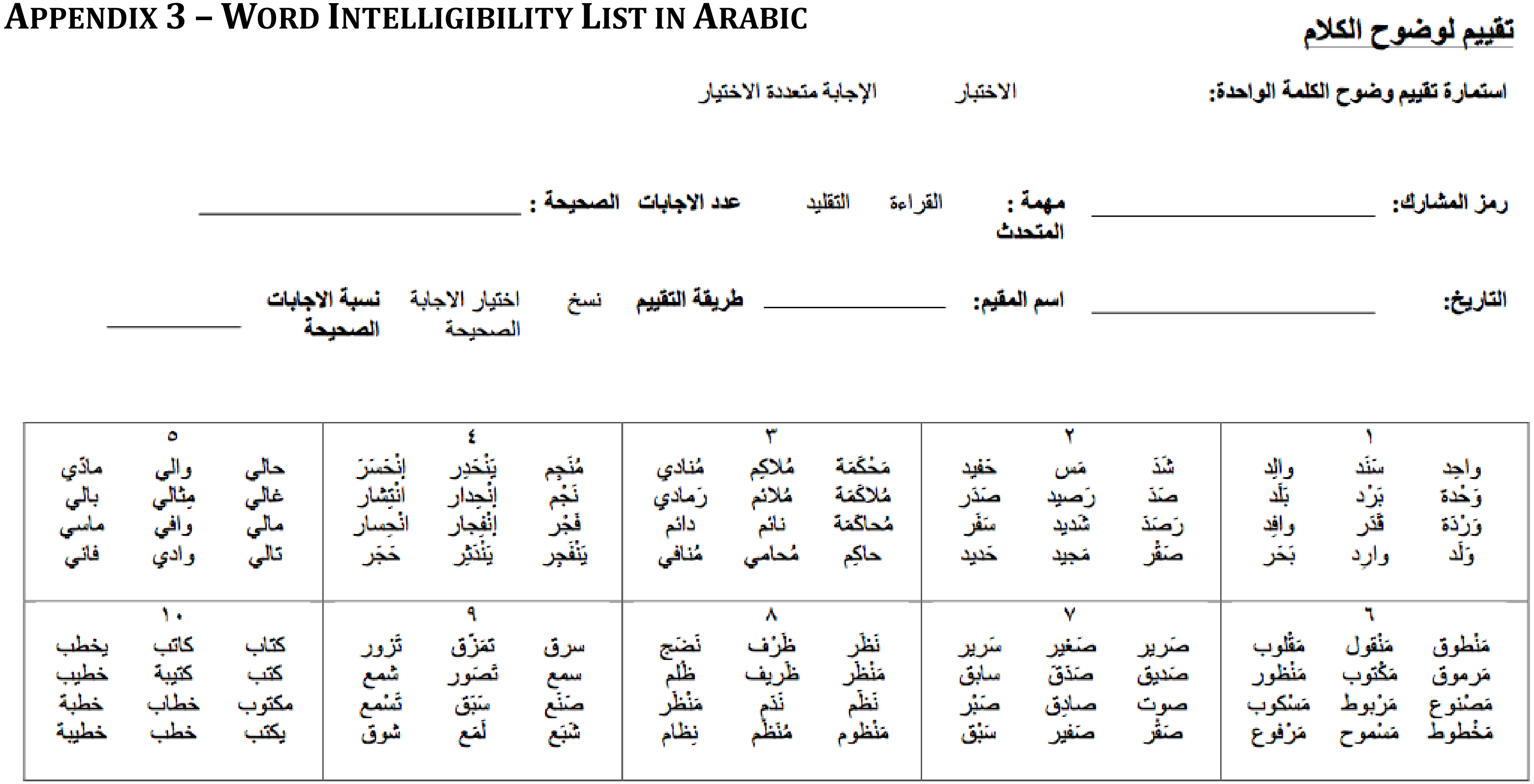
Researcher's Statement

I …………………………………………………………………..

confirm that I have carefully explained the purpose of the study to the participant and outlined any reasonably foreseeable risks or benefits (where applicable).

Signed: Date:

APPENDIX 3 – WORD INTELLIGIBILITY LIST IN ARABIC



تقييم لوضوح الكلام

استمارة تقييم وضوح الكلمة الواحدة: الاختبار الإجابة متعددة الاختيار

رمز المشارك: ____________ **مهمة : المتحدث** القراءة التقليد **عدد الاجابات الصحيحة :** ____________

التاريخ: ____________ **اسم المقيم:** ____________ **طريقة التقييم** نسخ اختيار الاجابة الصحيحة **نسبة الاجابات الصحيحة** ____________

	١			٢			٣			٤			٥	
واجِد	سَنَد	والِد	شَدّ	مَس	خَفيف	مَحْكَمَة	مُلاكِم	مُنادي	مُنَجِّم	يَنْحَدِر	إنْحَسَرَ	حالي	والي	مادّي
وَحْدَة	بَرْد	بَلَد	صَدّ	رَصيد	صَدَر	مُلائكَة	مُلائم	رَمادي	نَجْم	إنْحِدار	انْتِشار	غالي	مِثالي	بالي
وَرْدَة	قَدْر	وافِد	رَصَد	شَديد	سَفَر	مُحاكَمَة	نائم	دائم	فَجْر	إنْفِجار	انْحِسار	مالي	وافي	ماسي
وَلَد	وارِد	بَحَر	صَقْر	مَجيد	حَديد	حاكِم	مُحامي	مُنافي	يَنْفَجِر	يَنْدَثِر	حَجَر	تالي	وادي	فاني
	٦			٧			٨			٩			١٠	
مَنْطوق	مَنْقول	مَقْلوب	صَرير	صَغير	سَرير	نَظَر	ظَرْف	نَضَج	سرق	تَمَزَّق	تَزور	كتاب	كاتب	يخطب
مَرموق	مَكْتوب	مَنْظور	صَديق	صَدَق	سابِق	مَنْظَر	ظَريف	ظَلَم	سمع	تَصَوّر	شمع	كتب	كَتيبة	خطيب
مَصْنوع	مَرْبوط	مَسْكوب	صوت	صادِق	صَبْر	نَظَم	نَدَم	مَنْظَر	صَنَع	سَبَق	تَسْمَع	مكتوب	خطاب	خطبة
مَخْطوط	مَسْموح	مَرْفوع	صَقْر	صَفير	سَبَق	مَنْظوم	مُنَظَّم	نِظام	شَبَع	لَمَع	شوق	يكتب	خطب	خطيبة

١١ جَلْسَة جَرَس شَجَر مَجْلِس جَزَر زَجَر جَلَس جِسْر شَهْر جُلوس شَرِس جَهَر	١٢ مَجال قال مثال مَنال مال طال نال سال ضال مَقال حال خال	١٣ طَريق شَهيق شَقيق فَريق وَفيق رَشيق رَفيق عَميق عَريق صَديق رَقيب غَريق	١٤ اختصار انتهاز انتهاء انتصار انتظار انفطار انحدار ارتفاع ارتقاء انفجار انحصار انتقام	١٥ صورة صَوَر أذوار نورة نوح دور نور نون أسْوار أنْوار نار دار
١٦ مَطَر بط قِطَط هَطَل نَط خَط بَطَل خَطَط هَبَط خِطَة قِط فَقَط	١٧ فاقِد ناطِق حاقِد ناقِد حالِم قاصِد راكِض راقِد راكِد ساقِط رافِد رائد	١٨ غاب غَضَب غَيْث غار غد غِش غاص غَيْر غَيْم غَم غَيْب غض	١٩ جَوْهر جاز جار جِحْر جَمَل جَمَع جَهَر جَبْر فَجْر جَهْز جَرْف جوْف	٢٠ بُنْدُق مَرْموق خَنْدَق فُنْدُق مَخْنوق مَسْلوق صَنْدوق مَسْروق مَخْلوق بَرْقوق مَسْبوق مَخْفوق
٢١ أجْرَة فِكْرَة مُهْلَة نُقْطَة فُرْصَة رُكْبَة نُكْتَة حُفْرَة حُجْرَة رَكْلَة رُخْصَة شَفْرَة	٢٢ ديدان فِتيان عيدان فُرْسان عِمدان مُرْجان قُضْبان وِدْيان وِجْدان حيتّان سُفيان أشْجان	٢٣ أسْنان حَنين قُرين إنْسان حَنان أشْجان ألْوان سَمين أزْمان سنين رَنين أفْنان	٢٤ إجتياز زجاج احتاج إنزعاج دجاج احتياج إزعاج حاج احتجاج مزاج سياج امواج	٢٥ أجْر شَجَر هَدَر هَدْر نَذَر يَذَر إنْفَجر إنْحِدَر جَزَر فَجْر إنْدِثَر شَهَر
٢٦ دَفَع يَسْمَع مَنَع نَفَع سَمَع يَشْفَع يَدْفَع دَمَع يَمْنَع يَنْفَع يَدْمَع شَفَع	٢٧ مَسْموع مَصْنوع مَجْموع مَسْموح مَرْغوب مَنْزوع مَمْنوع مَقْلوب مَرْموق مَنْقول مَقْهور مَرْفوع	٢٨ لَعَب لاعِب تَعَب مَلاعِب مَتاعِب مَصاعِب مَلْعَب أتْعاب مُصْعَب ألْعاب شَعْب صِعاب	٢٩ يَسار نار مَسار سار يَنْهار شَرار حِصار مَنار مَزار نَهار فَنار خِمار	٣٠ قَصير تَفْجير صَهيل فَقير شَخير صَفير مَصير غَزير نَقير حَقير هَدير صَغير

	٣١			٣٢			٣٣			٣٤			٣٥	
انْتِصار	انْكِسار	اسْتِئصال	مات	موت	مار	تُرْكيبات	تُلْميحات	تَنْسيقات	مُناسِب	مُدافِع	مَلازِم	سفينة	سبيكة	رقيبة
اتِّصال	اخْتِصار	اسْتِفْسار	مال	ماس	من	تَجْهيزات	تُمْريرات	تُحْسينات	مُلائم	مُحارِب	مَنافِع	مدينة	نسيبة	سمينة
حِصار	اخْتِيار	اسْتِنْفار	موز	مس	مع	تُرْتيبات	تَسْجيلات	تُمْديدات	مُلاكِم	مُكافِح	مُرافِع	رهينة	رئيسة	صغيرة
انْصِهار	اسْتِنْكار	اشْتِهار	موج	مر	مل	تُرْقيات	تَرَدُّدات	تَسْهيلات	مُناقِض	مُجازِف	مُراسِل	رزينة	مريضة	سميرة
	٣٦			٣٧			٣٨			٣٩			٤٠	
رَسَم	رقص	رَبَط	سيارة	رواية	ولاية	سَريع	جَميع	وَضيع	مَنّان	قُبطان	فُرسان	أسَد	حَسَب	فَسَد
رَكَز	رَنَّد	رِباط	طيارة	هواية	رماية	رَبيع	سَميع	شَفيع	أسنان	صِبيان	رُبّان	كَسَب	رَصَد	حَسَد
رَزَق	رَد	رَكَل	مراية	زيادة	ديانة	بَديع	وَديع	مُريع	فَنّان	رِبيان	بُنْيان	جَسَد	حَصَد	مَسَد
رَكَض	رَدَم	رَتَّب	هداية	بداية	نكاية	رَفيع	رَضيع	صَريع	فِنْجان	سُلْطان	قُرْصان	نَسَب	نَصَب	قَصَد
	٤١			٤٢			٤٣			٤٤			٤٥	
دُب	قُرْب	شَرَب	أحمر	أحمد	أشجع	هَدَم	قَدَم	نَدَم	ثقيل	صغير	عزيز	سِرّي	مثالي	انتحاري
حُب	ضَرْب	نَهَب	أصفر	أسود	أمجد	أَلَم	عَ◌دَم	لَزَم	ظريف	عميل	سمير	بَرّي	بلدي	اندفاعي
رَب	رَغَب	سَلَب	أخضر	أكثر	أسعد	جَزَم	رَدَم	قَلَم	نبيل	سفير	غدير	ثري	انتقالي	ناري
ذَهَب	جَرَب	نَصَب	أنذر	أكبر	أكمل	عَلَم	دَعَم	قَزَم	خطير	غزير	جميل	ساري	انحداري	جاري
	٤٦			٤٧			٤٨			٤٩			٥٠	
أوجَد	أنكَر	أرسَل	فاكهة	رامِية	ساخِرة	إندفع	إنحدر	إنبثق	أعطى	أنقى	ألقى	لَ◌مس	لام	لَحَن
أصبَح	أصلَح	أوقَد	فاخِرة	زائدة	ماهِرة	إنعقد	إنزلق	أنفق	أصغى	أثرى	أسما	لَبَس	لانَ	لَوَّن
أصفَر	أوقَع	أوقَع	فَخامِة	ناسِية	شاكِرة	إنتصر	إنصرف	إنحصر	أملى	أجدى	أرقى	لَسَع	لَقَب	لَعَب
أنزَل	أوجَس	أوجَد	ماكِرة	فائقة	واهِبة	إنفجر	إنزعج	إنصهر	أحلى	أعلى	أغلى	لَطَم	لَفَظ	لطم

APPENDIX 4 – TRANSCRIPTION OF WORD LIST

	1			2			3	
[wa:ħid]	[sanad]	[wa:lid]	[ʃadda]	[mali:ʔ]	[ħafi:d]	[maħkama]	[mula:kim]	[munadi]
[waħdah]	[barad]	[balad]	[sˤadda]	[rasˤi:d]	[sˤadi:d]	[mulakama]	[mulaʔim]	[ramadi]
[wardah]	[qadar]	[wa:fid]	[rasˤada]	[ʃadi:d]	[safi:r]	[muħakama]	[naʔim]	[daʔim]
[walad]	[wa:rid]	[baħar]	[ħadda]	[maji:d]	[ħadi:d]	[ħakim]	[muħami]	[munafi]
	4			5			6	
[mandʒam]	[janħadir]	[ʔinħasar]	[ħali]	[wali]	[maddi]	[mantˤu:q]	[manqu:l]	[maqlu:b]
[nadʒim]	[ʔinħida:r]	[ʔintiʃa:r]	[ʁali]	[miθali]	[bali]	[masmu:ħ]	[maktu:b]	[manðˤu:r]
[fadʒar]	[ʔinfidʒa:r]	[ʔinħisa:r]	[mali]	[wafi]	[masi]	[masˤnu:ʕ]	[marbu:tˤ]	[masku:b]
[yanfadʒir]	[jandaθir]	[ħadʒar]	[tali]	[wadi]	[fani]	[maχtˤu:tˤ]	[masmu:ħ]	[marfu:ʕ]
	7			8			9	
[sˤari:r]	[sˤaʁi:r]	[sari:r]	[naðˤar]	[ðˤarf]	[tˤari:f]	[saraq]	[tamazaq]	[tazu:r]
[sˤadi:q]	[sˤadaq]	[sa:biq]	[manðˤar]	[ðˤari:f]	[ðˤulm]	[samaʕ]	[tasˤawar]	[ʃamʕ]
[sˤawt]	[sˤa:diq]	[sˤabr]	[naðˤam]	[nadam]	[manðˤar]	[sˤanaʕ]	[sabaq]	[tasmaʕ]
[sˤaqr]	[sˤafi:r]	[sabq]	[manðˤu:m]	[munaðˤim]	[niðˤa:m]	[ʃabaʕ]	[lamaʕ]	[ʃawq]
	10			11			12	
[kita:b]	[ka:tib]	[jaχtˤub]	[dʒa:lsah]	[dʒaras]	[ʃadʒar]	[madʒa:l]	[qa:l]	[miθa:l]
[katab]	[kati:bah]	[χatˤi:b]	[madʒlis]	[dʒazar]	[nahar]	[mana:l]	[ma:l]	[tˤa:l]
[maktu:b]	[χitˤa:b]	[χutˤbah]	[dʒalasa]	[dʒisir]	[ʃahar]	[na:l]	[sa:l]	[dˤa:l]
[jaktub]	[χatˤab]	[χatˤi:bah]	[dʒulu:s]	[ʃaris]	[dʒahar]	[maqa:l]	[ħa:l]	[χa:l]

13 [tˁari:q] [ʃahi:q] [ʃaqi:q] [fari:q] [wafi:q] [raʃi:q] [rafi:q] [ʕami:q] [ʕari:q] [sˁadi:q] [raqi:q] [ʁari:q]	14 [ʔiχtisˁa:r] [ʔintiha:z] [ʔinhija:r] [ʔintisˁa:r] [ʔintiðˁa:r] [ʔinfitˁar] [ʔinħida:r] [ʔirtifa:ʕ] [ʔintiqa:ʔ] [ʔinfidʒa:r] [ʔinħisˁa:r] [ʔintiqa:m]	15 [sˁu:rah] [sˁawa:r] [ʔadwa:r] [nu:rah] [nu:ħ] [du:r] [nu:r] [nu:n] [ʔaswa:r] [ʔanwa:r] [na:r] [da:r]
16 [matˁar] [batˁ] [qitˁatˁ] [hatˁal] [natˁ] [χatˁ] [batˁal] [χatˁatˁ] [habatˁ] [χitˁah] [qitˁ] [faqatˁ]	17 [fa:qid] [na:tˁiq] [ħa:qid] [na:qid] [ħa:lim] [qa:sˁid] [ra:kidˁ] [ra:qid] [ra:kid] [sa:qitˁ] [ra:fid] [ra:ʔid]	18 [ʁa:b] [ʁadˁab] [ʁajθ] [ʁa:r] [ʁad] [ʁiʃ] [ʁa:sˁ] [ʁajr] [ʁajm] [ʁam] [ʁajb] [ʁadˁ]
19 [dʒawha:r] [dʒa:z] [dʒa:r] [dʒuħur] [dʒamal] [dʒamaʕ] [dʒahar] [dʒabar] [fadʒar] [dʒahaz] [dʒaraf] [dʒawf]	20 [bunduq] [marmu:q] [χandaq] [funduq] [maχnu:q] [maslu:q] [sˁandu:q] [masru:q] [maχlu:q] [barqu:q] [masbu:q] [maχfu:q]	21 [ʔudʒrah] [fikrah] [muhalh] [nuqtˁah] [fursˁah] [rukbah] [nuktah] [ħufrah] [ħudʒrah] [raklah] [ruχsˁah] [ʃafrah]
22 [dida:n] [fitja:n] [ʕi:da:n] [fursa:n] [ʕimda:n] [murdʒa:n] [ʁadˁba:n] [widja:n] [widʒda:n] [ħita:n] [sufja:n] [ʔaʃdʒa:n]	23 [ʔasna:n] [ħani:n] [qari:n] [ʔinsa:n] [ħana:n] [ʔaʃdʒa:n] [ʔalwa:n] [sami:n] [ʔazma:n] [sini:n] [rani:n] [ʔafna:n]	24 [ħadʒi:dʒ] [zudʒa:dʒ] [ʔiħta:dʒ] [ʔinziʕa:dʒ] [dadʒa:dʒ] [ʔiħtija:dʒ] [ʔizʕa:dʒ] [ħa:dʒ] [ʔiħtidʒa:dʒ] [maza:dʒ] [sija:dʒ] [ʔamwa:dʒ]

	25			26			27	
[ʔadʒir]	[ʃadʒar]	[hadar]	[dafaʕ]	[jasmaʕ]	[manaʕ]	[masmu:ʕ]	[masˤnu:ʕ]	[madʒmu:ʕ]
[hadar]	[naðar]	[jaðar]	[nafaʕ]	[samaʕ]	[jaʃfaʕ]	[masmu:ħ]	[marʁu:b]	[manzu:ʕ]
[ʔinfadʒar]	[ʔinħadar]	[dʒazar]	[jadfaʕ]	[damaʕ]	[jamnaʕ]	[mamnu:ʕ]	[maqlu:b]	[marmu:q]
[fadʒir]	[ʔindaθar]	[ʃahar]	[janfaʕ]	[jadmaʕ]	[ʃafaʕ]	[manqu:l]	[maqhu:r]	[marfu:ʕ]
	28			29			30	
[laʕab]	[la:ʕib]	[taʕab]	[jasa:r]	[na:r]	[masa:r]	[qasˤi:r]	[tafdʒi:r]	[sˤahi:l]
[mala:ʕib]	[mataʕib]	[masˤaʕib]	[sa:r]	[janha:r]	[ʃara:r]	[faqi:r]	[ʃaχi:r]	[sˤafi:r]
[malʕab]	[ʔatʕa:b]	[musˤʕab]	[ħisˤa:r]	[mana:r]	[maza:r]	[masˤi:r]	[ʁazi:r]	[naqi:r]
[ʔalʕa:b]	[ʃaʕb]	[masˤʕad]	[naha:r]	[fana:r]	[χima:r]	[ħaqi:r]	[hadi:r]	[sˤaʁi:r]
	31			32			33	
[ʔintisˤa:r]	[ʔinkisa:r]	[ʔintiʔsˤa:l]	[ma:t]	[mu:t]	[ma:r]	[tarki:ba:t]	[talmi:ħa:t]	[tansi:qa:t]
[ʔitisˤa:l]	[ʔiχtisˤa:r]	[ʔistifsa:r]	[ma:l]	[ma:s]	[man]	[tadʒhi:za:t]	[tamri:ra:t]	[taħsi:na:t]
[ħisˤa:r]	[ʔiχtija:r]	[ʔistinfa:r]	[mu:z]	[mas]	[maʕ]	[tarti:ba:t]	[tasdʒi:la:t]	[tamdi:da:t]
[ʔinsˤiha:r]	[ʔistinka:r]	[ʔiʃtiha:r]	[mu:dʒ]	[mar]	[mal]	[tamri:na:t]	[taraduda:t]	[tashi:la:t]
	34			35			36	
[munasaba:t]	[muda:fiʕ]	[mula:zim]	[safi:nah]	[sabi:kah]	[raqi:bah]	[rasam]	[raqasˤ]	[rabatˤ]
[mulaʔim]	[muħa:rib]	[mana:fiʕ]	[madi:nah]	[nasi:bah]	[sami:nah]	[rakaz]	[radad]	[riba:tˤ]
[mula:kim]	[muka:fiħ]	[murafiʕ]	[rahi:nah]	[raʔi:sah]	[sˤaʁi:rah]	[razaq]	[rada]	[rakal]
[muna:qidˤ]	[mudʒa:zif]	[mura:sil]	[razi:nah]	[mari:dˤah]	[sami:rah]	[rakadˤ]	[radam]	[ratab]
	37			38			39	
[saja:ra]	[riwa:ja]	[wila:ja]	[sari:ʕ]	[dʒami:ʕ]	[wadˤi:ʕ]	[manna:n]	[qubtˤa:n]	[fursa:n]
[tˤaja:ra]	[hiwa:ja]	[rima:ja]	[rabi:ʕ]	[sami:ʕ]	[ʃafi:ʕ]	[murdʒa:n]	[sˤibja:n]	[ruba:n]

[mira:ja]	[zija:da]	[dija:na]	[badi:ʕ]	[wadi:ʕ]	[muri:ʕ]	[fanna:n]	[ribja:n]	[bunja:n]
[hida:ja]	[bida:ja]	[nika:ja]	[rafi:ʕ]	[radˤi:ʕ]	[sˤari:ʕ]	[findʒa:n]	[sultˤa:n]	[qursˤa:n]
	40			41			42	
[ʔasad]	[ħasab]	[fasad]	[dub]	[qurb]	[ʃarab]	[ʔaħmar]	[ʔaħmad]	[ʔaʃdʒaʕ]
[kasab]	[rasˤad]	[ħsad]	[ħub]	[dˤarb]	[nahab]	[ʔasˤfar]	[ʔaswad]	[ʔamdʒad]
[dʒasad]	[ħasˤad]	[masad]	[rab]	[raʁab]	[salab]	[ʔaχdˤar]	[ʔakθar]	[ʔasʕad]
[nasab]	[nasˤab]	[qasˤad]	[ðahab]	[dʒarrab]	[nasˤab]	[ʔanðar]	[ʔakbar]	[ʔakmal]
	43			44			45	
[hadam]	[qadam]	[nadam]	[θaqi:l]	[sˤaʁi:r]	[ʕazi:z]	[sirri:]	[miθali:]	[ʔintiħari:]
[ʔalam]	[ʕadam]	[lazam]	[ðˤari:f]	[ʕami:l]	[sami:r]	[barri:]	[baladi:]	[ʔindifaʕi:]
[dʒazam]	[radam]	[qalam]	[nabi:l]	[safi:r]	[ʁadi:r]	[θari:]	[ʔintiqali:]	[nari:]
[ʕalam]	[daʕam]	[qazam]	[χatˤi:r]	[ʁazi:r]	[dʒami:l]	[sa:ri:]	[ʔinħidari:]	[dʒari:]
	46			47			48	
[ʔawdʒad]	[ʔankar]	[ʔarsal]	[fa:kiha]	[ra:mija]	[sa:χira]	[ʔindafaʕa]	[ʔindaħara]	[ʔinbaθaqa]
[ʔasˤbaħ]	[ʔasˤlaħ]	[ʔawqad]	[fa:χira]	[za:ʔida]	[ma:hira]	[ʔinʕaqada]	[ʔinzalaqa]	[ʔanfaqa]
[ʔardʒaħ]	[ʔawqaʕ]	[ʔawqaʕ]	[faχama]	[na:sija]	[ʃa:kira]	[ʔintasˤara]	[ʔinsˤarafa]	[ʔinħasˤara]
[ʔanzal]	[ʔawdʒas]	ʔawdʒad]	[ma:kira]	[fa:ʔiqa]	[wa:hiba]	[ʔinfadʒara]	[ʔinzaʕadʒa]	[ʔinsˤahara]
	49			50			49	
[ʔaʕtˤa]	[ʔanqa]	[ʔalqa]	[lamasa]	[la:ma]	[laħna]	[ʔaʕtˤa]	[ʔanqa]	[ʔalqa]
[ʔasˤʁa]	[ʔaθra]	[ʔasma]	[labasa]	[la:na]	[lawana]	[ʔasˤʁa]	[ʔaθra]	[ʔasma]
[ʔamla]	[ʔadʒda]	[ʔarqa]	[lasaʕa]	[laqaba]	[laʕaba]	[ʔamla]	[ʔadʒda]	[ʔarqa]
[ʔaħla]	[ʔaʕla]	[ʔaʁla]	[latˤama]	[lafaðˤa]	[latˤam]	[ʔaħla]	[ʔaʕla]	[ʔaʁla]

APPENDIX 5 – SENTENCE INTELLIGIBILITY LIST IN ARABIC

٥ كلمات:

١	ظَل الفلاح يحلم طوال الأسبوع	١١	لم تكن اصابته خطيرة للغاية
٢	تخيط الأم المريلة القطنية الصفراء	١٢	سجل هدف فى آجر دقيقة
٣	درجة الرطوبة عالية جدا هنا	١٣	لا أضن أنها فكرة جيدة
٤	كانت الكتب الدراسية مكلفة جدا	١٤	اقترب القطارمن المحطة ببطء
٥	غَلَف الهدية بغلاف أحمر زاهى	١٥	طلبى الوحيد أن تظل صديقى
٦	الصندوق يحتوي على ثلاثة قمصان	١٦	لقد تحدثنا عن الموقف بالتفصيل
٧	لقد اشترينا كرسى لونه بنى	١٧	رغم ضجة الحياة أشعر بالسكون
٨	هل يمكنك أن تفتح النافذة	١٨	أريد أن استمتع بحياتى العلمية
٩	انه ليس بحاجة كبيرة للاستثمار	١٩	كانت نتائج الامتحان مخيبة للآمال
١٠	وقف على عتبة الباب المفتوح	٢٠	يعمل فى مهنة مرهقة جسديا

٦ كلمات:

١	اخترت لحظة الانسحاب المناسبة من المؤسسة	١١	لقد قمنا بهذا العمل فى الماضى
٢	هذه الوظيفة فيها الكثير من المنافع	١٢	أريد أن أعيش فى بيت مريح
٣	أتى من أعلى قمم جزيرة العرب	١٣	لم أرى صديقى هذا لعدة أعوام
٤	أريد أن تعطينى شيأ من عندك	١٤	تغيرلون البستان تحت الأشعة الحامية
٥	يمكنك الركوب فى المقاعد الخلفية للطائرة	١٥	الكثافة السكانية محدودة فى هذه الجزيرة
٦	تغيير نمط حياة الإنسان مسألة صعبة	١٦	يجب أن يسجل هدف بالدقيقة الأخيرة
٧	إنهم يحصلون على الكثير من المال	١٧	سوف يعلم ما وراء هذا الاستقبال
٨	لقد عاد ليطلب الرزق فى الصباح	١٨	القصص الشعبية سوف تضيع دون تسجيل
٩	لدينا فريق عمل ممتاز فى الشركة	١٩	لدى أولائك السائقيين خبرات واسعة بالمجتمع

١٠	يجب أن نتحاور بهدوء و عقلانية	٢٠	لقد جمعنا بعض الصَدَف على الشاطئ

٧ كلمات:

١	هناك بعض الفنادق الفاخرة قريبة من هنا	١١	هل كل الأماكن فى البلد مصرح بزيارتها
٢	أريد صرف السندات لكى أشتري قطعة أرض	١٢	ما الذى يجعلنا نتذكر مكانا دون غيره
٣	تعلمت الكثير من التجارب خلال رحلة حياتى	١٣	توقف عن التدخين قبل حوالى خمس سنوات
٤	سيصل الى الحقيقة لكن بعد فوات الأوان	١٤	لم يضع المصروفات الغير منظورة فى الحسابات
٥	أوافقك الرأي بأن المشكلة ليست فى البيئة	١٥	يلتقون بمزيج هائل من البشر بشكل يومى
٦	اننا فى العالم العربى مجرد مستهلكيين للتقنية	١٦	المأساة الحقيقية هى أنه كان عدوا لنا
٧	نظر الطالب اليه و هو فى الخارج	١٧	لقد بقيت القهوة محدودة الانتشار فى اليمن
٨	ألم تفهم ما أردت أن أقوله لك	١٨	لدينا ضغوط فى توفير المياة و الكهرباء
٩	لقد جرب هذه الوصفة و شفى تماما	١٩	يجري الآن تطوير عدد من المستشفيات الجديدة
١٠	لابد من تقليل المصروف الشهري إلى النصف	٢٠	هناك خدمات عامة مطلوبة الانتشار و التواجد

٨ كلمات:

١	مات زوجها العامل الفقير و ترك لها طفلين	١١	هو أول من أدخل القهوة إلى جزيرة العرب
٢	وجد بداخلها رجل يجلس على الأرض بين الأتربة	١٢	هى مراسلة فى الفرع النسائى لإحدى الدوائر الحكومية
٣	لقد نصحتك عشرات المرات بعدم القيام بهذا العمل	١٣	لقد مضى الاجتماع بطريقة عادية، ثم انصرف الأساتذة
٤	قمة الانتصار أن تعترف بالهزيمة فى اللحظة المناسبة	١٤	إنه رجل متميز و واعى إلى درجة التألق
٥	الفيلم الوثائقى وسيلة من وسائل التعبير عن النفس	١٥	هى احدى اللغات التى يتحدث بها الهنود الحمر
٦	أنت بحاجة إلى رفيق فى هذا الطريق الطويل	١٦	كانت الرياح قوية فحملت النار إلى أماكن أخرى
٧	الشعور بالغربة شىء عجيب يؤكد لك ارتباطك بالوطن	١٧	هذا المكان جميل و لكنه صغير بعض الشىء
٨	الدعوة إلى ترك البيع و الشراء لأداء الفريضة	١٨	أنا اقترح أن نتناول العشاء سويا هذه الليلة
٩	فى الجو غبار خانق و حر لا يحتمل	١٩	انتها من تناول العشاء مع زوجته و أولاده

١٠	الحياة قصيرة و ثمينة فلا بد من الاستمتاع بها	٢٠	لم تمض ساعة حتى كانت المدينة كلها تحترق

٩ كلمات:

١	ما كنت أحسب أنى سأفتقد أسرتى كما أشعر الآن	١١	هذا الأمر يتعلق بصرف العملة و لا يتعلق بالجودة
٢	يستطيع المزارع معرفة حالة الطقس المتوقعة باستخدام التقنية الحديثة	١٢	حتى لو كان هذا صحيح فنصيحتى لك أن تنساة
٣	سرعان ما تأزم الجو بالصمت و تبادلوا نظرات القلق	١٣	تكونت فِرَق من المتطوعين المستعدين للتضحية من أجل مدينتهم
٤	حاولت أن أنقل هذه القصص كما هى بلغة الشارع	١٤	هناك أماكن حين نعود إليها تعود بنا الذاكرة للوراء
٥	اكتشفت أن الطريق خال أمامنا لكن السيارة لا تتحرك	١٥	لم أعرف ماذا أفعل هل أنزل و أتركه نائما
٦	هناك أماكن لا نشعر بها نمر عليها مرور الكرام	١٦	لا يحصلون على الماجستير و الدكتوراة لمجرد البحث العلمى
٧	رحيلة السريع قد تسبب بضربة موجعة فى الوسط الرياضى	١٧	تذكر أن الحياة مليئة بالفرص فلا بد من الاستفادة منها
٨	الدرجات فى هذه المادة تعتمد على المشاركة خلال الدرس	١٨	المرشد يُسَخر وقته لخدمة الطلاب فيضع لهم جدول للمواعيد
٩	هناك الآلاف من العاطلين يحلمون بالحصول على هذه الوظيفة	١٩	تلقيت الكثير من المكالامات الهاتفية بين موافق و مناقش
١٠	الجانب النفسى للمريض يمثل نسبة كبيرة لتقبله للعلاج الطبى	٢٠	لا شك أن كل ذلك يأتى نتيجة للتطور العلمى الأخير

١٠ كلمات:

١	لم يشغله بريق المناصب عن ايمانه العميق برسالة أستاذ الجامعة
٢	انتشر الحوار العلمي بين الجميع في قمة التنظيم و الاحترام
٣	صاح أحد الرجال موجها صوته إلى الدور الثاني من البيت
٤	عُمْر القهوة في جزيرة العرب لا يتعدى حوالي خمس قرون
٥	المكان الذي يشكل أهمية لك قد لا يعني شيئا للآخر
٦	المرور قد ارتقى و طور أساليبه و إدارته لحركة السير
٧	نظر إلى ساعة الحائط فوجدها تجاوزت الحادية عشر و النصف
٨	على المؤسسات التعليمية و الطبية تأدية أدوارها وفقا لنص النظام
٩	مع تزايد الأعمال التلفزيونية فإنك تشاهد ما يرشحه لك الآخرين

١٠	نحن بحاجة لمثل هذه الدراسات للاستفادة منها في حياتنا اليومية
١١	سرعان ما احترق هذا البيت و من ثم البيوت المجاورة
١٢	عدم وجود الجامعات دفع الشباب إلى الهجرة إلى المدن الكبيرة
١٣	المسألة ليست صعبة لهذه الدرجة، فأنت ذكية و ستتعلمين بسرعة
١٤	كم نحتاج للمطر ليروي كل شيء و يغسل دواخلنا المتعبة
١٥	تخلص من الأفكار السلبية ثم انهض لمواصلة المسيرة مرة أخرى
١٦	كلها أيام و نتعود على الوجه الجديد الذي حل مكانه
١٧	فكرنا في تكوين فريق عمل يخدمنا جميعا و يخدم المستهلك
١٨	في الشوط الثاني تحسنت صورة الفريقين و ظهرا بمستوى أفضل
١٩	هذا السائق تجربته في مجال الهجرة بدأت منذ عشرة أعوام
٢٠	سوف أتذكر كذلك اسمه الذي سألته عنه قبل مغادرتي للسيارة

١١ كلمة:

١	لابد أن ندرك حاجة المجتمع لإيجاد أسلوب حضاري للتعامل مع الفرح
٢	لا حل أمام الجميع سوى اتخاذ قرارات صعبة للحد من الانفاق
٣	سرعان ما وجد نفسه مُطوقا من جميع الجهات بعدد من الأصدقاء
٤	لا نستطيع أن نقول أن خدمات الأمس كافية لسد إحتياجات اليوم
٥	فتح هذه الجامعات و المدارس سيوفر الكثير من المزايا في المستقبل
٦	تكاثرت في ذهنه الكثير من التفاصيل التي قرأها في صفحات الحوادث
٧	بعد خدمة سنتان وجد أن العمل في الوسط الرياضي غير مجدي
٨	أنجزت بعض المسائل في نصف ساعة بعد أن اتضحت فكرة الدرس
٩	توجه الطبيب نحو المقعد القريب ببطء و هو مرهق بعد العملية
١٠	ما أن توقف القطار حتى انفتحت أبوابه و تدافع منه الركاب

١١	تناول الأسماك ثلاث مرات في الأسبوع يوفر حاجة الفرد من الفيتامين
١٢	شرح لي أنه عاد قبل عامين مضطرا لظروف خارجة عن إرادته
١٣	في الرواية أسلوب الكتابة السلس و السريع الذي يصيب الهدف باستمرار
١٤	تقنية جديدة تساعد في نقل كمبيوتر العمل إلى المنزل دون عناء
١٥	برنامج جديد يناقش الأسرار و المعاني و العبر المتعلقة بفريضة الحج
١٦	سوف أتردد كثيرا قبل أن أراهن على فرص تغير المنظمات الحديثة
١٧	أدرك أنه لا يستطيع التأثير على قرارات مجلس إدارة الشركة بمفرده
١٨	إنه يعلم أن هناك مجموعة من الذئاب بين آلأخشاب خلف الوادي
١٩	جاء ذلك خلال افتتاح ورشة العمل الأولى لمركز التميز لأمن المعلومات
٢٠	المهم هنا هو ما يقوله فرد من المجتمع حول موضوع محدد

١٢ كلمة:

١	كان عليهم أن يصتدمو بها مرارا و تكرارا كي يدركو حواجزها الفعلية
٢	اعتدنا أن يكون لنا يوم أو يومين من كل اسبوع تعتبر عطلة
٣	مازلت أحاول منذ ثلاث أشهر أن أغير توقيت هذه الساعة دون جدوى
٤	لاشك أنه من الأفضل أن أنسى الماضي و أن أبحث عن عمل
٥	لم أتصور أن يمارس مهنة قيادة سيارات الأجرة منذ قرابة خمسين عاما
٦	تعيش القهوة الآن عصرها الذهبي حيث تنتشر بيوت القهوة في كل مكان
٧	أسباب الاستقالة تعود إلى رغبته في الابتعاد عن الوسط الرياضي بشكل دائم
٨	إن لم توصل وسائل الاعلام صوت المواطن فسيقول البعض إنها تخون رسالتها
٩	الحياة تستدعي من الفرد العمل المتواصل لتحقيق احتياجاته الضرورية و طموحاته الشخصية
١٠	إن مستوى اكتساب المعرفة هي الآلية التي يقاس بواسطتها مستوى الكفاءة الإنتاجية
١١	هناك صعوبة في إيجاد الخدمات الصحية الكافية لشمول المواطنين في جميع المناطق

١٢ كيف يكون المنتج جيد إذا لم يكن متوفرا للجميع و بسعر مناسب

١٣ حتى الزحام في أيام المطر له شكل مختلف، تجد الكل يستمتع بالجو

١٤ يمكنك أن تحصل على المركز الأول إذا وافقت أن تكون في فريقي

١٥ يوجد في هذه السفينة عدد أقل من مواصفات السلامة مقارنة بالسفن الأخرى

١٦ إن كان لديك شكوى فهل يمكنك أن تطلب من التاجر أن يساعدك

١٧ يزيد مبلغا على مجموع ما تحسبه الآلة الحاسبة مستغلا بذلك ثقة المشتري

١٨ تهنئة لكل منسوبات الجامعة، بعد سنتين أشعر أن أحد أحلامي سوف يتحقق

١٩ بحث الفريق الآخر على التعادل و قد تحقق لهم في نهاية المباراة

٢٠ إن مقياس الكتاب المفيد تكتشفه عندما يزيد معرفتك و قدرتك على الإدراك

١٣ كلمة:

١ علينا أن نضاعف قدراتنا على الإنتاج و ابتكار أساليب و طرق عيش جديدة

٢ كانت تخطط لحياة مثمره، راتب عالي، و دراسات عُلّيا، و حياة مليئة بالحركة

٣ المهم أن نتعرف جيدا على حقائق القصور و مصادرها ثم نأتي بالبدائل المؤقتة

٤ ظلو يعيشون لعشرات السنين في المدينة على ضفاف النهر يزرعون و يرعون الماشية

٥ فرحت عندما انتهيت من قراءة الرواية فقد أثبتت لي أن لدينا أديبا كبيرا

٦ في بعض المتاجر الصغيرة ثبت أكثر من مرة أن المحاسب يستغل طيبة الزبون

٧ بدأت في التشعب إلى عدة لغات ثانوية يضع كل شعب عليها مفرداته الخاصة

٨ في حال عدم تلقي العلاج قد يصاب المريض بالتهاب شديد في تجويف البطن

٩ فهو لم يعد مجرد وسيلة لدخول السيارات بل إنه أصبح أداة ضد السرقة

١٠ أخبرها المحاسب الشاب أنه عانى كثيرا في حياته فوظيفته الصغيرة لم تحقق طموحة

١١ اسأل عن الجهاز في مكان آخر و ستجد أن سعره أقل بكثير هناك

١٢ الكتب طعام الفكر، و توجد كتب لكل فكر كما توجد أطعمة لكل بنية

١٣ تم تسجيل إبنتي على قائمة الانتظار و ظللت أتابع المدرسة حتى تم قبولها
١٤ لم يكن الهدف من الاجتماع مناقشة مشاكلنا، و لكن كان لتشجيع بعضنا البعض
١٥ إن المشاريع تضل دون المستوى المطلوب من حيث جودة التنفيذ و سرعة الانجاز
١٦ سار كل شيء على ما يرام إلا أن حادثا غريبا وقع بعد لحظات
١٧ سعادتك هي أن تعيش بالطريقة التي تريدها أنت و ليس كما يريد الآخرون
١٨ إذا نظرنا إلى السماء بعد المطر فإن لها شكل مختلف حين تغطيها الغيوم
١٩ نجاح برنامج الارشاد الأكاديمي ينطلق من خطة علمية واضحة تراعي السياسة العامة للجامعة
٢٠ كان المدرس يسجل كل ما يقال في الفصل حتى يقيم كل طالب بدقة

١٤ كلمة:

١ لابد أن نتوقف عن اتخاذ أي قرارات يمكن أن ترتب علينا أوجه انفاق أخرى
٢ قد يؤثر فيلم قصير في الساحة المحلية أكثر مما يؤثر الكتاب أو المقال الصحفي
٣ الرسم فن قديم يمكن الانسان أن يعبر عن أحاسيسه و يصف الأشياء كما يتصورها
٤ يجب الا تكون الجودة أعلى مما هو مطلوب فمعنى ذلك ارتفاع التكاليف دون ضرور
٥ ماذا عن واقع مدننا بعد عشرين عاما إذا ما زادت أعداد السكان و مطالبهم
٦ في غريزتنا الثقافية اعتقاد غريب بأن صعود الآخر يعني حجب الضوء عن إنجازاتنا الشخصية
٧ أصرت أن تأخذ حقيبتها معها لأنها تعودت على استلام الكتب في أول يوم دراسي
٨ إن قلة الموارد المتاحة أمام تزايد رغبات الإنسان و طموحاته ستفرض نوعا من التغيير
٩ عليك أن تعيش أزمتك وحيدا و أن تحاول الخروج منها مهما كان ذلك صعبا
١٠ هكذا توهجت غريزة البقاء العميقة و انبعث التضامن الفطري الذي يجمع الناس لحظة الخطر
١١ قرأت هذه الكتب و أعتقد أن العلاقة بينهم متينة و إن اختلفت في الظاهر
١٢ إنها بدأت في إيجاد الأخطاء في كل ما أقول و في كل ما أفعل
١٣ كان يمشي على ضفاف البحيرة و كان البرد قارس و الجليد يغطي كل شيء

١٤	اتفق عدد من موظفي قطاع التعليم أن طريقة استقبال مدرائهم لهم تنعكس على آدائهم
١٥	الصف الجديد مؤثث و مليء بالألعاب و القصص الهادفة لتعليم الأطفال في هذا العمر
١٦	أضحك عندما أتذكر ذلك الآن، و لكني في ذلك الوقت كنت في غاية الغضب
١٧	سوف يكون بإمكانك إسترداد المبلغ الذي انفقته على التذكرة بالكامل إن لم تقوم باستخدامها
١٨	إن قوة العظام تتأسس عبر نمط صحي من الحياة يتضمن نظاما غذائيا واسع التنوع
١٩	نظرت إلى الطريق المظلم الذي تلتمع أرضه بضوء السيارة و اقترب الجبل عند المنعطف
٢٠	هناك حلول كثيرة لعلاج هذه المشكلة باستخدام وسائط التخزين الناقلة أو بعض خدمات الإنترنت

١٥ كلمة:

١	ما أجمل أن نجد إنسان هذا البلد و قد وصل بجهده العلمي الى أعلى المناصب
٢	الحصان العربي من أقدم السلالات و ينسب إلى العرب لمحافظتهم على نسله و خصائصه المميزة
٣	بدأ بعض المزارعيين في زراعة شجرة القهوة بسبب انتشار شربها بين الطبقة العليا في اليمن
٤	عدم اتقان اللغة قد يوقع الشباب في مشاكل و يعطل التواصل بينهم و بين الأجانب
٥	حتى لو إكتشف أنه على خطأ و غيره على صواب يمنعه الكبرياء من الاعتراف بذلك
٦	قد زاد من أهمية المدينة وجود البحيرة بها و تمتعها بأرض شاسعة تصلح كمرعى للحيوانات
٧	كان في بعضها عيادات خارجية لاستقبال المرضى غير المقيميين و فيها المختبرات و أقسام الأشعة
٨	لابد أن يتكون النظام الغذائي اليومي على بروتينات حيوانية و نباتية لكي يلبي احتياجات جسمك
٩	إنه بالتأكيد من حق المستهلك أن يشتكي و أن يعيد البضاعة إذا كانت غير صالحة
١٠	عندما سألت عن سبب غلاء ثمنه قيل لي أنه منتج طبيعي ليس به إضافات كيميائية
١١	ليست وصفة للقناعة و لكنها وصفة للتعامل مع ظروف الحياة التي لا نستطيع السيطرة عليها
١٢	تحول الميدان إلى ثكنة عسكرية بفضل سيارات الأمن المركزي العملاقة و عدد الكبير من الضباط
١٣	فرحت عند الإنتهاء من قراءة الرواية، لأنها أكدت لي أن لدينا أديبا كبير و موهوب
١٤	اشتهرت على مدار عقود بأنها بلدة زراعية خاصة في زراعة الزيتون و العنب و الشمام

١٥	نبل المعنى قبل كل شيء، إذ لا جدوى في الرواية إذا لم تكن نبيلة المقصد
١٦	في كل عام يزداد عدد الزوار الذين يخيمون في المناطق النائية التي يعيش بها الضباع
١٧	مما لاحظته في هذا المؤتمر هو قلة عدد الحضور و هذا يجعلني أطرح بعض التساؤلات
١٨	عندما يذوب الجليد تنبعث الحياة شيئا فشيئا في الغصون الجافة و تبدأ الزهور في التفتح
١٩	أسندت رأسها إلى الحائط، كانت فعلا بحاجة إلى الهدوء بعد تعب و إرهاق ذلك اليوم
٢٠	للعناية بالظهر قلل من الجلوس على الأرض و حافظ على إستقامته عند الوقوف أو المشي

APPENDIX 6 – TRANSLATED SENTENCE LIST

Note: the words do not match the original Arabic sentences word number

5 Word Sentences

1	The farmer dreams all week	11	His injury was not serious
2	The mother sews the yellow uniform	12	He scored a goal in the last minute
3	The degree of humidity is very high	13	I do no think it is a good idea
4	The school books were very expensive	14	The train approached slowly approached the station
5	He wrapped the present in bright red	15	I only ask that you remain my friend
6	The box contains three shirts	16	We spoke in detail about the situation
7	We bought a brown colored chair	17	Despite the hectic life I fee calm
8	Can you open the window	18	I want to enjoy my academic life
9	He is not in need to invest	19	The examination scores were disappointing
10	He stood at the open doorstep	20	He has a physically draining job

6 Word Sentences

1	Chose the best time to leave the company	11	We did this type of work in the past
2	This job has a lot of benefits	12	I want to live in a comfortable house
3	He comes from the Arabic Peninsula	13	I haven’t seen this friend for a number of years
4	I need you to give me some of what you have	14	The greenery of the garden changed from the sun
5	You can sit in the back seats of the plane	15	The population is limited in this island
6	Changing the way a person leads their lives is difficult	16	We have to score a goal in the last minute
7	They gain a lot of money	17	He will see soon what is behind this reception
8	He went back to work in the morning	18	Anecdotal stories will be lost without documentation
9	We have a very good team in the company	19	These drivers have a lot of social experiences
10	Lets be honest and discuss the mater	20	We gathered some shells from the beach

7 Word Sentences

1	There a number of luxury hotels close to here	11	Are we allowed to visit all the locations in this country
2	I want to cash the bonds in order to buy some land	12	What makes us remember certain places and not others
3	I learned a lot from my life experiences	13	He stopped smoking five years ago
4	He will arrive to the truth but after it is too late	14	He didn’t add the unforeseen expenses in the budget
5	I agree with you that the problem is not in the environment	15	They meet different people every day
6	We are only users of technology in the Arab world	16	The real tragedy is when our friend becomes our enemy
7	The student looked at him while he was out	17	Coffee remained limited in Yemen
8	Haven’t you understood what I am try to tell you	18	We are under pressure to provide sufficient supply of water and electricity
9	He tried this remedy and was completely cures	19	Development of a number of new hospitals it taking place
10	We have to decrease half our monthly expenses	20	These are general service that needs to be available

8 Word Sentences

1	Her working husband died and left her with two kids	11	He is the first to bring coffee to the Arabic peninsula
2	They found a man sitting inside in the rubble	12	She is works as a messenger in one of the government branches
3	I advised you against this kind of word a number of times	13	The meeting went normally then the teachers all left
4	The real victory is to acknowledge defeat at the right moment	14	He is a cultured and very interesting person
5	Documentary movies are a way to express personal views	15	It is one of the languages that the native Indians use
6	You need a friend for the long road ahead	16	The winds were very strong so they took the fire to other places
7	The feeling of alienated is a strange feeling that makes you miss home	17	This place is very nice but a little small
8	The call to leave selling and buying and got o prayer	18	I suggest we have dinner together this evening
9	There is an unbearable heat and dust	19	He finished having dinner with his wife and children
10	Life is short and valuable so you have to enjoy it	20	An hour didn’t go by before the entire town was on fire

9 Word Sentences
1 I didn’t think I would miss my family as much as I do
2 The farmers can use modern technology to know the weather conditions
3 There was tension in the air and they exchanged worried looks
4 I tried to convey these stories as they are in the tone of the streets
5 I noticed that the road was empty in front of us but the car was not moving
6 There are some places that just pass by and do not notice
7 His fast exit has impacted the sports world in a negative way
8 The grades in this subject depend on participation during class
9 There are thousands unemployed that dream of finding the right work
10 The psychological state of the patients impact their acceptance of the treatment
11 This mater is related to changing the currency and not the quality
12 Even if it were true I advise you to forget about it
13 Groups of volunteers gathered and were ready to sacrifice to save their town
14 There are certain places that we go back to and have distant memories
15 I didn’t know what to do, should I leave and let him sleep
16 They receive their higher education degree for academic research
17 Remember that life is full of opportunities so you have to benefit from them
18 The advisor helps the students and gives them meeting schedules
19 I received a number of phone calls from people who agreed and others who wanted to discuss maters
20 There is no question that all of this comes from recent advances in knowledge

10 Word Sentences

1 Glamour of different government positions didn’t distract him form his university position
2 Scientific discussion took place between everyone in an organised and respectful way
3 One of the mean called up with a loud voice directing his voice to the second floor of the house
4 The age of coffee in the Arabic peninsula is not more than five centuries old
5 The place that is important to you may not be as important to others
6 The traffic police have developed and improved the way they organise traffic
7 He looked at the wall clock and saw that it was passed eleven thirty
8 It is the role of academic and medical establishments to carryout their roles based on the policies and procedures
9 With the increase in television programs you rely on others recommendations to choose what to watch
10 We need these kind of studies to benefit our daily lives
11 This house burnt down very fast followed by the adjacent houses
12 The fact that there are not universities pushed the young people to move to bigger cities
13 The matter is not that difficult, you are smart and will learn very fast
14 We desperately need rain to irrigate everything and relieve out exhaustion
15 Get rid of any negative thoughts then continue your journey
16 Its only days before we get used to the new person that took his place
17 We thought of establishing a new team to serve us as well as the consumer
18 In the second half there was an improvement in both teams and they played at a better level
19 This driver’s experience with immigration stated over ten years ago
20 I will also remember his name that I asked him about before I left the car

11 Word Sentences

1	We need to be aware of the need of the community to find an acceptable way to celebrate
2	There are no choices for anyone except to take measures to decrease spending
3	He rapidly found himself surrounded by from all directions by a number of his friends
4	We cannot say that the old services are sufficient to cover today’s needs
5	Opening these universities and schools will result in a lot of future benefits
6	He had a lot of thoughts about the details he read in the accident pages
7	After working for two years he found that working in the sports industry is not beneficial
8	The idea for the lesson were very clear so she was able to do some of the mathematical problems in half an hour
9	The doctor walked towards the close seat very slowly, he was exhausted following the surgery
10	As soon as the train stopped the doors opened and the passengers got off
11	Eating fish three times a week provides the persons’ need of certain vitamins
12	He explained to me that he returned two years ago for reasons that he could not control
13	The novel in written in a smooth and fast way hitting the intended target every time
14	There is new technology that helps access work computers from home
15	There is a new program that discusses the meanings, lessons and secrets of the Hajj
16	I will be very reluctant before I wager on changes in the industry
17	He realised that he couldn’t impact the decisions of the board of directors of the company on his own
18	He knows that there are a number of wolves hiding in between the woods across the river
19	It was the opening of the first workshop of the center of excellence in information security
20	What is important here is the point of view of the individual on a certain topic

12 Word Sentences

1	They had to run into it over and over again to understand its real physical barriers
2	As soon as Allah’s name is said they all revere in prayer
3	I have been trying for the last three month to change the timing on this watch with no success
4	It is better to forget what happened in the past and look for work
5	I could not imagine that he has been working as a taxi driver for the past sixty years
6	Coffee is living its golden days as coffee houses are available everywhere
7	His reasons for resigning are related to the fact that he wants to be away from the sports industry
8	If the media does not convey the voice of the citizen then it can be said that it is betraying its responsibilities
9	Life requires constant work from the individual to achieve their basic needs and personal aspirations
10	The level of achieving knowledge is the means by which the efficiency of productivity is measured
11	There are difficulties in finding sufficient medical services to cover all the citizens in all the regions
12	For a product to be considered as good it has to be available to everyone
13	Even the traffic in rainy days has a special feel, you see everyone enjoying the weather
14	You can be in first place if you agree to join my team
15	There are less number of safety factors in this boat compared to others
16	If you have a complaint you can ask the salesman to help you
17	He adds a cost to what is calculated therefore taking advantage of the buyers trust
18	I want to congratulate all the university administration, I feel that my dream has come true after two years of work
19	The other team tried to tie the score by the end of the game
20	The measure of a good book is discovered when it increases your knowledge and ability to understand

13 Word Sentences

1	We need to increase our innovation abilities and developing new living means
2	She planned to have a productive life with a high salary, higher education and a life full of adventures
3	We have to understand the realities and sources of our shortcomings and then find alternative means
4	They continued to live for tens of years in the village on the boarders of the river farming and raising cattle
5	She was happy when she finished reading the novel as it proved that he was a successful writer
6	In a number of small stores there was evidence the that salesman takes advantage of the customer
7	After graduating from university she worked as a lecturer in the medical collage
8	In the case of the patient not receiving medical treatment he could get a severe infraction in the abdomen
9	It is not only a way for the cars to go through but it has become a mean against burglary
10	The young teller told her that he has suffered a lot throughout his life and his job doesn’t satisfy his goals
11	If you ask about the device in another store you will see that it is a lot less expensive
12	Books are food of thoughts and there are books for every thought as there are foods for every taste
13	My daughter was placed on a waiting list and followed up with the school until they accepted her
14	The purpose of the meeting was not to discuss our problems but rather to encourage each other
15	The projects continue to be less than the expected requirements in regards to speed and level of completion
16	Everything went very well except for a strange accident that took place after a few minutes
17	I helped you live in the way that you wanted and not how other wanted
18	If we look at the sky after it rains it has a different look to it
19	The success of the academic guidance program is a result of a clear plan based on the university policies
20	The teacher noted everything that was said in class in order to evaluate every student

14 Word Sentences

1	We have to stop making decisions that may result in requiring other expenses
2	A short movie could influence the social scene more than a book or a newspaper article
3	He can dive like a fish, fly like an eagle and climb the walls
4	He stopped walking when he saw the man and they shook hands covering their real feelings with a smile
5	What will happen to our cities in twenty years when the number of the population increases
6	There is something strange in our cultural belief that the rise of someone means blocking the way of someone else
7	She insisted to take her bag with her because she was used to getting her books on the first day of school
8	The decrease of the sources available to cover the human needs and aspirations will impact certain changes
9	You have to live through your problem on your own and find a way to get through it
10	This is how the deep need for survival was awakened and people joined together at the time of need
11	I read these book and I believe that the relationship between them is strong even if they appear different at first
12	She started to see mistakes in everything I say or do
13	He was walking on the side of the lack and the wind was cold and the snow covered everything
14	A number of employees in the educational sector agreed that the way their principals treat them has an impact on their work
15	The new class is full of toys and stories to teach children at that age
16	I laugh when I remember it now, but back then I was very upset
17	You can get reimbursed the entire amount for the ticket if you do not use it
18	The strength of your bones requires a good diet that has a wide range of food elements
19	I looked at the dark road shining under the car lights and saw the mountain at the curve of the road
20	There are a number of ways to resolve this problem by using different portable memory devices or certain internet services

15 Word Sentences

1 It is so nice to see the people of this country have reached highest levels due to their personal efforts
2 The Arabian horse is from the oldest breads and Arabs to this day preserve this heritage
3 Some of the farmers started growing coffee beans because people from society started consuming it
4 Not being efficient in the language might get young people in trouble and cause issues with them and the natives
5 Even if he discovers that he is wrong and the others are right his ego prevents him from acknowledging it
6 The presence of the lakes and the vast land that allows for farming animals increased the importance of the town
7 Empowering the role of experience and knowledge at work will change its opportunities and objectives
8 The eating habits have to include animal and vegetable proteins to provides the body needs
9 It is the consumers right to exchange and return supplies that are invalid for use
10 When I asked for the reason it was so expensive I was told that it was an organic product without any added chemicals
11 It is not a matter of acceptance but rather a way of dealing with life situations that we have no control over
12 The square turned into a military establishment due to the large number of military cars and officers
13 I was very happy when I finished reading the book, because it showed me that he was a talented writer
14 We rush from one another and this means that we will not have any surprises
15 The dignity in the meaning is important since there is no usefulness in the book without dignity
16 Every year there is an increase the number of visitors that camp in remote areas where hyenas live
17 From what I have observed in this conference is the small number of attendants and that makes have some questions
18 When the snow melts life returns to the trees and the flowers start to bloom
19 She put her head against the wall she needed some quite after a long and exhausting day
20 To maintain the health of your back decrease the amount of time you sit on the floor and maintain it straight when walking or standing

APPENDIX 7 – JUDGE INSTRUCTIONS FOR INTELLIGIBILLITY ASSESSMENT (SIS AND WIS)

Intelligibility Assessment Details:

- The task involves the participant reading or repeating a number of words (50) and sentences (22)
- The words read by the participant are selected from a list of 12 similar sounding words and the sentences are selected from a list of 20 sentences
- The word and sentence list will be provided the student judges prior to participation in the judgement tasks
- The student judges will listen to the sentences in the speech language pathology clinic at KFSH&RC using the headphones provided by the researcher
- They will be familiar with the word list but not the particular word spoken by the participant (They will have to read the list once prior to participation)

Single Word Intelligibility Task:

- Listen to the words spoken by the participant
- Listen to the words **Only once**
- Then they will transcribe the words spoken but the participants (Phonetic Transcription is not required – in Arabic)

Sentence Intelligibility Task:

- They may **NOT listen to the sentence more than two times**
- The first time listen to the entire sentence
- The second time list and pause when necessary to allow time to transcribe
- Transcribe what you hear into Arabic

General Research Guidelines and ethics will be followed including:

1. Confidentiality regarding the subject information
2. Not to discuss the cases with other student clinicians

APPENDIX 8 – INTERVIEW SCHEDULE FOR INTERVIEW ON FUCNTIONAL COMMUNICATION

حدثني عن تواصلك/تحدثك في اليوم العادي؟
أوصف لي كيف تتواصل؟
هل تشعر أنه تغير التواصل لديك مع مرور الوقت؟
اشرح لي كيف تطلب احتياجاتك اليومية/ الأساسية؟
اشرح لي محادثاتك و كيف تغيرة مع مرور الوقت؟

ما هي صعوبات الواصل التي تتعرض لها و كيف تحلها؟
ماذا تفعل عندما لا يفهمك الآخرين؟
ما هي المواقف التي يكون فيها التواصل أفضل؟
هل هناك مواقف أو حالات يكون فيهاالتواصل أسهل أو أصعب؟
هل قدرة الآخرين على فهمك تغيرت؟ أعطني بعض الأمثلة؟
هل هناك أي أمور أخرا لها علاقة بالتواصل التي لم أسأل عنها؟/ أو تريد أن تحدثني عنها؟

ل**مساعدة الشخص على المشاركة**
أعطني بعض الأمثلة؟
آشرح أكثر عن هذا الموضوع
أُعطي للمريض بعض الأمثلة مثل التحدث في العمل، السوق، زيارة

Appendix 9 – Interview Schedule QoL interview

كيف هي حياتك منذ الشخيص؟

أخبرني عن حياتك و كيف هي الحياة مع هذا المرض؟

ما هي الأشياء التي تغيرت في حياتك؟

ما هي الأشياء التي تقوم بها للاستمتاع باليوم؟

ما هي الأشياء المهمة بالنسبة لك؟ حدثني عنها؟

ما هي الأشياء التي تساعدك في تخطي صعوبات اليوم؟

ما هي الأشياء التي تحسن الحياة؟

ما هي الأشياء التي تجعلها أسواء؟

هل تغير دورك في المنزل؟ كيف أثر عليك ذللك؟

هل توجب عليك القيام بتعديلات في عملك للتعامل مع المرض؟ ما هي هذه التعديلات؟ كيف تشعر تجاه ذلك؟

كيف غيرت مشاكل الكلام و التواصل حياتك

اعطني بعض الأمثلة عن حياتك الاجتمتعية مع مشاكل التواصل و التغيرات الأخرى؟

كيف أثر المرض على حياتك الاجتماعية؟

هل ترغب في اضافة شيء؟

APPENDIX 10- STATISTICAL ANALYSIS FOR CHAPTER 4

Participant	J1_Wi	J2_Wi	J3_Wi	J1_Si	J2_Si	J3_Si
MSM	100	100	100	99	100	100
FAM	99	100	99	100	100	99
SMA	100	100	100	100	100	100
MMO	99	99	100	99	99	99
SAS	100	100	100	99	100	100
AMA	99	100	100	99	100	100
MAY	99	99	98	99	99	99
AAM	99	98	98	100	100	100
HMA	100	100	100	100	100	100
AFO	100	100	100	100	100	100

Percentage of words and sentences heard correctly by the three judges
J1_Wi, J2_Wi, J3_Wi: The three judges who scored the WIS
J1_Si, J2_Wi, J3_Wi: The three judges who scored the SIS

1. Normal Sample Intraclass Correlation Coefficient

a. Word Intelligibility

Cronbach's Alpha	N of Items
.839	3

Intraclass Correlation Coefficient

	Intraclass Correlation[b]	95% Confidence Interval		F Test with True Value 0			
		Lower Bound	Upper Bound	Value	df1	df2	Sig
Single Measures	.654[a]	.293	.888	6.204	9	18	.001
Average Measures	.850	.554	.960	6.204	9	18	.001

Two-way random effects model where both people effects and measures effects are random.
a. The estimator is the same, whether the interaction effect is present or not.
b. Type A intraclass correlation coefficients using an absolute agreement definition.

b. Sentence Intelligibility

Reliability Statistics

Cronbach's Alpha	N of Items
.725	3

Intraclass Correlation Coefficient

	Intraclass Correlation[b]	95% Confidence Interval		F Test with True Value 0			
		Lower Bound	Upper Bound	Value	df1	df2	Sig
Single Measures	.446[a]	.079	.790	3.636	9	18	.009
Average Measures	.707	.204	.919	3.636	9	18	.009

Two-way random effects model where both people effects and measures effects are random.

a. The estimator is the same, whether the interaction effect is present or not.

b. Type A intraclass correlation coefficients using an absolute agreement definition.

Participant	J1_wi	J2_wi	J3_wi	J4_wi	J5_wi
NSA	91	97	97	87	85
NYA	2	2	4	6	6
IBA	68	52	30	40	28
HAD	78	78	82	94	66
AMS	97	93	93	93	89
AAZ	82	88	84	80	78
MAA	80	66	74	74	72
LMS	74	56	58	84	67
MSJ	32	18	24	22	18
MJS	84	80	80	82	86
HHH	14	40	44	18	22
JMS	16	24	14	26	28
OMH	90	92	94	88	92
LAA	90	96	92	97	91
AAA	18	12	16	32	24
NAD	4	6	6	5	4

Percentage of words heard correctly by the five judges for WIS

Participant	J1_si	J2_si	J3_si	J4_si	J5_si
NSA	96	97	95	96	96
IBA	80	82	78	81	73
HAD	91	81	76	74	73
AMS	97	95	97	96	96
AAZ	94	93	94	95	92
MAA	84	76	85	81	83
LMS	96	97	96	96	95
MSJ	42	47	42	47	47
MJS	96	91	89	94	95
HHH	14	12	22	20	14
OMH	93	92	94	95	93
LAA	93	95	96	95	95

Percentage of words heard correctly by the five judges for the SIS

Participants	intrajudge_Wi1	intrajudge_Wi2	intrajudge_Si1	intrajudge_Si2
HAD	94	94	91	96
AMS	93	89	97	96
AAZ	80	82	94	96
LMS	74	80	96	95
MJS	86	90	95	97
HHH	40	54	20	26
LAA	90	96	95	96

Percentage of words and sentences heard by the judge at two different times

3. Word Intelligibly Scale

a. Intraclass Correlation Coefficient for Intra-judge reliability – WIS

Reliability Statistics

Cronbach's Alpha	N of Items
.971	2

Intraclass Correlation Coefficient

	Intraclass Correlation[b]	95% Confidence Interval		F Test with True Value 0			
		Lower Bound	Upper Bound	Value	df1	df2	Sig
Single Measures	.924[a]	.593	.987	33.994	6	6	.000
Average Measures	.960	.745	.993	33.994	6	6	.000

Two-way random effects model where both people effects and measures effects are random.
a. The estimator is the same, whether the interaction effect is present or not.
b. Type A intraclass correlation coefficients using an absolute agreement definition.

b. ANOVA for inter-judge variance analysis of variance - WIS

Test of Homogeneity of Variances

DATA

Levene Statistic	df1	df2	Sig.
3.334	4	70	.015

ANOVA

DATA

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	3503.520	4	875.880	.914	.461
Within Groups	67050.800	70	957.869		
Total	70554.320	74			

c. Intraclass Correlation Coefficient for inter-judge reliability – WIS

Reliability Statistics

Cronbach's Alpha	N of Items
.990	5

Intraclass Correlation Coefficient

	Intraclass Correlation[b]	95% Confidence Interval		F Test with True Value 0			
		Lower Bound	Upper Bound	Value	df1	df2	Sig
Single Measures	.952[a]	.905	.980	98.781	15	60	.000
Average Measures	.990	.979	.996	98.781	15	60	.000

Two-way random effects model where both people effects and measures effects are random.
a. The estimator is the same, whether the interaction effect is present or not.
b. Type A intraclass correlation coefficients using an absolute agreement definition.

4. Sentence Intelligibility Scale

a. Intraclass Correlation Coefficient for Intra-judge reliability – SIS

Reliability Statistics

Cronbach's Alpha	N of Items
.998	2

Intraclass Correlation Coefficient

	Intraclass Correlation[b]	95% Confidence Interval		F Test with True Value 0			
		Lower Bound	Upper Bound	Value	df1	df2	Sig
Single Measures	.993[a]	.950	.999	408.182	6	6	.000
Average Measures	.997	.974	.999	408.182	6	6	.000

Two-way random effects model where both people effects and measures effects are random.
a. The estimator is the same, whether the interaction effect is present or not.
b. Type A intraclass correlation coefficients using an absolute agreement definition.

b. Kruskal Wallis test for inter – judge - SIS

Test of Homogeneity of Variances

data

Levene Statistic	df1	df2	Sig.
.138	4	55	.968

ANOVA

data

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	301.900	4	75.475	.102	.981
Within Groups	40535.083	55	737.002		
Total	40836.983	59			

Test Statistics[a,b]

	data
Chi-Square	2.222
df	4
Asymp. Sig.	.695

a. Kruskal Wallis Test

b. Grouping Variable:
Judges

c. Intrarclass Correlation Coefficient inter-judge analysis - SIS

Reliability Statistics

Cronbach's Alpha	N of Items
.997	5

Intraclass Correlation Coefficient

	Intraclass Correlation[b]	95% Confidence Interval		F Test with True Value 0			
		Lower Bound	Upper Bound	Value	df1	df2	Sig
Single Measures	.984[a]	.964	.995	301.744	11	44	.000
Average Measures	.997	.993	.999	301.744	11	44	.000

Two-way random effects model where both people effects and measures effects are random.
a. The estimator is the same, whether the interaction effect is present or not.
b. Type A intraclass correlation coefficients using an absolute agreement definition.

APPENDIX 11 – WORD INTELLIGIBILITY SCALE – WORD GROUP PROFILES

Word Group	
Word Group 1	• Words within this group are a combination of one and two syllable words • The first vowel in the word is /a/ and the second in two syllable words is /a/ or /i/ • There are 3 sets of minimal pairs and that are similar sounding and the other four words are similar sounding to those minimal pair: [wa:ħid], [wa:lid], [wa:rid], [wa:fid] and [walad], [balad] and [wardah], [waħdah] as well as similar sounding words • Consonant and vowel representation: (cvcvc) and (cvccvc).
Word Group 2	• Words within this group are a combination of one and two syllable words • The first vowel in the word is a short one /a/ and the second is a long /i:/. • There are two minimal pair sets [ʃadda],[sˤadda],[ħadda] and similar sounding word based in the vowel and second phoneme /d/ [rasˤada], • The other eight words are two syllable similar sounding words that have the same first and second phoneme /a/ and /i:/: [mali:ʔ], [rasˤi:d], [ʃadi:d], [maji:d], [ħafi:d], [sˤadi:d], [safi:r], [ħadi:d] • Consonant and vowel representation: (cvcvc) and (cvccv).
Word Group 3	• Words within this group are a combination of two and three syllable words • The selection of the words was based on similar sounding root words [ħakam] and [lakam] in addition to similar sounding words [mulaʔim], [naʔim], [muħami], [munadi], [ramadi], [daʔim], [munafi].

	• Consonant and vowel representation: (cvccvcv), (cvcvcvcv), (cvcvc), (cvcvcvc), and (cvcvcv).
Word Group 4	• Words within this group are a combination of two and three syllable words • They are based on root words [fadʒara], [nadʒm] and [ħadara] as well as similar sounding words [jandaθir], [ʔinħasar], [ʔintiʃa:r], [ʔinħisa:r], [ħadʒar] • Consonant and vowel representation: (cvccvcvc) and (cvcvc).
Word Group 5	• The words within this group are a combination of two and three syllable words • They are based on a set of 10 one syllable minimal pairs and two, two syllable similar sounding words [miθali], [maddi] • Consonant and vowel representation: (cvcv), (cvcvcv), and (cvccv)
Word Group 6	• The words within this group are all two syllable words • The first vowel short /a/ and the second vowel /u:/ • The words are not minimal pairs but are similar sounding • They all start with phoneme /m/ and differ in the medial and final phoneme • Consonant and vowel representation: (cvccvc)
Word Group 7	• The words in this group are a combination of one and two syllable words • The first vowel is a short one /a/ the second one in two syllable words is /i/, /i:/, and /a/ • The words are not minimal pairs but are similar sounding • All the words start with /s/ or the pharyngeal /sˤ/ • Consonant and vowel representation: (cvcvc) and (cvcc)
Word Group 8	• The words are a combination of monosyllable and two syllable words • They are based on root words [naðˤara] and [naðˤama] in addition to other similar sounding words [ðˤarf], [nadam], [munaðˤim], [ðˤari:f], [tˤari:f], [ðˤalm]

	• Consonant and vowel representation: (cvcvc), cvccvc), cvcc) and (cvcvcvc).
Word Group 9	• The words in this group are a combination of two to three syllable words • They all have the first vowel /a/ • There are a number of minimal pairs [saraq], [sabaq] and [sˤanaʕ], [samaʕ] combined with similar sounding words • Consonant and vowel representation: (cvcv), (cvcvcvc), and (cvcvc)
Word Group 10	• The words are a combination two and three syllable words • They are based on the root words [kataba] and [χa tˤaba] • Consonant and vowel representation: (cvcvc), (cvccvc) and (cvcvcvc)
Word Group 11	• The words in this group are a combination of two and three syllable words • They are based on the root word [dʒalsa] in addition to similar sounding words [dʒazar], [dʒisir], [ʃadʒar], [ʃaris] and other similar sounding minimal pairs [dʒahar], [ʃahar], [nahar] • Consonant and vowel representation: (cvcvc), (cvccvc), (cvcvcv) and (cvcv)
Word Group 12	• The words within this group are a combination of single and two syllable words • They all include long vowel /a:/ • There are two sets of minimal pairs [na:l], [sa:l], [ma:l], [qa:l], [ħa:l,] [tˤa:l], [dˤa:l], [χa:l] and [madʒa:l], [mana:l], [miθa:l] • Consonant and vowel representation: (cvcvc) and (cvc).
Word Group 13	• All the words within this group are two syllable words • They all have the same first short vowel /a/ and the second long vowel /i:/ with different consonant • Consonant and vowel representation: (cvcvc)
Word Group 14	• The words in this group are all three syllable words • They all start with phoneme /ʔ/ followed by vowel /i/ the second vowel in the vowel is also /i/ and the third vowel is /a:/

	with various phoneme combinations • Consonant and vowel representation: (cvcvcvc)
Word Group 15	• The words a combination of one and two syllable words • They all have long vowels /a:/ or /u:/ • They are based on two root words [nu:r] and [sˤawar] in addition to other similar sounding words • Consonant and vowel representation: (cvcvc), (cvc) and (cvccvc)
Word Group 16	• The words in this group are a combination of one and two syllable words • They are based on the phoneme /tˤ/ as it occurs in initial, medial and final position. • Consonant and vowel representation: (cvcvc), and (cvc)
Word Group 17	• All the words in this group are two syllable words • They all have the long vowel /a:/ as the first vowel in the word and the short vowel /i/ as the second vowel • These vowels are presented with different consonants • Consonant and vowel representation: (cvcvc)
Word Group 18	• The words in this group are one and two syllable words • They all start with the phoneme /ʁ/ in similar sounding words • Consonant and vowel representation: (cvc), (cvcvc), and(cvcc)
Word Group 19	• The words in this group are two and three syllables • The words are similar sounding and start with the phoneme /dʒ/ except in one word where the phoneme is in the middle of the word • Consonant and vowel representation: (cvcvc) and (cvc)
Word Group 20	• The words are two syllable words

	• The words are similar sounding a have two sets of minimal pairs [bunduq], [funduq] and [masru:q] [masbu:q] [maslu:q] combined with other similar sounding words • Consonant and vowel representation: (cvccvc)
Word Group 21	• The words in this group are two syllable words • They all end with /ah/ and they all have /u/ as the first vowel in the word except for three words [raklah], [fikrah] and [ʃafrah] • Consonant and vowel representation (cvcvc)
Word Group 22	• The words in the group are all two syllable words • They all include the vowel /a:/ as the second vowel in the word. It is used with various phonemes in similar sounding words • Consonant and vowel representation: (cvcvc) and (cvccvc)
Word Group 23	• The word in this group are two syllable words • They all end with phoneme /n/ following a long vowel. • Consonant and vowel representation: (cvccvc) and (cvcv).
Word Group 24	• The words in this group are a combination of one, two and three syllable words • They include a short first vowel and a long second vowel, in addition all the words end with phoneme /dʒ/ • Consonant and vowel representation: (cvcvc), (cvccvc), and (cvccvcvc).
Word Group 25	• The words include two and three syllables • They all end with the phoneme /r/ and include only short vowels • Consonant and vowel representations: (cvcvc), (cvcvc) and (cvccvcvc)
Word Group 26	• The words within this group are all similar sounding

	• They include the vowel /a/ as a first and second vowel • They all end with the phoneme /ʕ/ • Consonant and vowel representation: (cvcvc) and (cvccvc
Word Group 27	• The words in this group are all two syllable words • They include vowel /a/ as the first vowel and /u:/ as the second vowel • All the words start with the phoneme /m/ • Consonant and vowel representation: (cvccvc)
Word Group 28	• The words in this group are two and three syllable words • They include vowel /a/ as the first vowel • They all include phoneme /ʕ/ in medial position and end with phoneme /b/ • Consonant and vowel representation: (cvcvc), (cvcvcv) and (cvccvc)
Word Group 29	• The words are one and two syllable words • They all end with phoneme /r/ following the long vowel /a:/ • Consonant and vowel representation: (cvcvc), (cvc)and (cvccvc)
Word Group 30	• The words in this group are two syllable words • They have short vowel /a/ as the first vowel and long vowel /i:/ as the second vowel • They all end with /r/ except for on word that ends with /l/; [sˤahi:l] • Consonant and vowel representation: (cvcvc) and (cvccvc)
Word Group 31	• The words in this group have two to three syllables • They all start with phoneme /ʔ/ except for one word starting with /ħ/; /ħisˤa:r/ • They all end with /r/ or /l/

	• Consonant and vowel representation: (cvccvcvc) and (cvcvcvc)
Word Group 32	• The words in this group are one syllable words • They include 3 sets of minimal pairs all starting with the phoneme /m/ and vowels /a/, /a:/ and /u:/ • Consonant and vowel representation: (cvc)
Word Group 33	• The words in this group are three syllable words • They all include the same vowel combinations; first vowel /a/, second vowel /i:/ and third vowel /a:/ • They all start and end with phoneme /t/ • Consonant and vowel representation: (cvccvcvc)
Word Group 34	• The words in the group are all three syllable words • They all start with phoneme /m/ followed by vowel /u/. The middle vowel is wither /a/ or the long version of the vowel /a:/ • Consonant and vowel representation: (cvcvcvcvc), (cvcvcvc)
Word Group 35	• The words in this group are all three syllable words • They all end with /ah/ and include short vowel /a/ as the first vowel in the word and the long vowel /i:/ as the second vowel • Consonant and vowel representation: (cvcvcvc)
Word Group 36	• The words in this group are all two syllable words • They include the vowel /a/ in its short and long versions • They all start with /r/ • Consonant and vowel representation: (cvcvc)

Word Group 37	• The words in this group are all three syllable words • They include short vowel /a/ or /i/ as the first vowel and /a:/ as the second vowel. They all end with vowel /a/ • Consonant representation: (cvcvcv)
Word Group 38	• The words in the group are all two syllable words • They all have the short vowel /a/ as and end with /i:ʕ/. • Some of the words are minimal pair [wadˤi:ʕ],[radˤi:ʕ] and [dʒami:ʕ], [sami:ʕ] • Consonant and vowel representation: (cvcvc)
Word Group 39	• The words in the group are all two syllable words • They all end with /u:n/ • Consonant and vowel representation: (cvccvc)
Word Group 40	• The words in the group are all two syllable words • They have vowel /a/ as the first and second vowel • The words all end with plosive /b/ or /d/. In addition the medial phoneme in the word is /s/ or the pharyngeal / sˤ/ • Consonant and vowel representation: (cvcvc)
Word Group 41	• The words in the group are a combination of one and two syllable words • They all end with phoneme /b/ • Consonant and vowel representation: (cvc), (cvcvc), (cvcc) and (cvccvc)
Word Group 42	• The words in the group are all two syllable words • They all start with phoneme /ʔ/ and only include short vowel /a/ • Consonant and vowel representation: (cvccvc)
Word Group 43	• The words in the group are all two syllable words

	• They only include the vowel /a/ • They all end with /m/ • There are two sets of minimal pairs [hadam], [qadam], [nadam], [ʕadam], [radam] and [ʔalam], [qalam], [ʕalam] • Consonant and vowel representation: (cvcvc)
Word Group 44	• The words in the group are all two syllable words • They include short vowel /a/ as the first vowel and /iː/ as the long vowel • Consonant and vowel representation: (cvcvc)
Word Group 45	• The words in the group are one, two, and three syllable words • They all end with long vowel /iː/ • Consonant and vowel representation: (cvccv), (cvcv), (cvcvcv), (cvccvcvcv)
Word Group 46	• The words in the group are all two syllable words • They all start with /ʔa/. • The second vowel in the word is a short vowel /a/ • Consonant and vowel representation: (cvccvc)
Word Group 47	• The words in the group are all three syllable words • They all include the long vowel /aː/ as the first vowel and they all end with the vowel /a/ • Consonant and vowel representation: (cvcvcv)
Word Group 48	• The words in the group are all four syllable words • They all start with /ʔin/ and end with the vowel /a/ • Consonant and vowel representation: (cvccvcvcv)
Word Group 49	• The words in the group are all two syllable words

	• They all start with /ʔa/ and end with the vowel /a/ • Consonant and vowel representation: (cvccv)
Word Group 50	• The words in the group are all three syllable words • They all start with /la/ and end with vowel /a/ • Consonant and vowel representation: (cvcvcv)

APPENDIX 12 – TRANSCRIPTION KEY

a) […] Indicates a pause.

b) Longer pauses are indicated by [long pause].

c) Additional information to help clarify the statement for the reader is placed between brackets [the neurologist].

d) *Italic* indicates emphatic stress.

e) CAPITAL LETTERS indicate more emphasis.

f) The sign – following a word indicates that the speaker cut off the word or the phrase. Usually used when there is a false start.

g) /?/ Indicates that something was said but not understood.

h) Non-verbal accompaniment to speech such as laughter, cough sigh are noted in between brackets (laugh)

APPENDIX 13 – CHARTING FROM THE COMMUNICATION QUALITATIVE ANALYSIS

	1. Communication Activities				
Participant	1.1. Speaking	1.2. Understanding others	1.3. Conversation	1.4. Initiate conversation	1.5. Correct communication breakdown
IBA (ALS/MND)	“I get the intention to speak […] but then I change my mind […] I think what is the point	“If there are too many people […] like in a group and they are all taking it becomes noisy. Its harder than it used to be to understand what they are saying”		“I get the intention to speak […] but then I change my mind […] I think what is the point	“I do not like it when the person in front of me doesn’t understand. That really upsets me [long pause] but when they do not understand I repeat myself”
HAD (ALS/MND)		“I have to concentrate more to understand others. But I can […] usually I can:	“When I have a long conversation and speak a lot my articulation becomes very difficult […] really difficult”	“I only like to speak when I have to […] since I got the disease and my speech got affected I do not talk a lot. Only when someone speaks to me”	“I have to repeat myself for others especially strangers to understand what I say”
LMS (MS)	“Speaking is very difficult for me […] it used to be very easy now [long pause] it is difficult and distorted. The person in front of me is not able to understand me”	“Understanding others is not a problem. But you know I spend most of my time with my family. They know me”	“I try to talk and start a conversation at home as often as I can”	“I try to talk and start a conversation at home as often as I can”	“When someone isn’t able to understand me I repeat what I said or I gesture [long pause] but when this happens it frustrates me. It frustrates me a lot”
MSG (MS)		“I can understand what others say with no	“I am a good communicator and		“I am aware when the person in front of me

		problem”	can have a productive conversation if I am comfortable and well rested. Also I need to take my time to get my thoughts in order”		doesn’t understand me […] my main problem and if I am able to solve it is that I speak too fast. If I can reduce the rate of my speech I would be fine”
AMS (ALS/MND)	“the way I speak has changed a lot, especially with some letter pronunciations. I don’t think anyone has noticed but I notice it myself” “I do not speak as often as I used to […] it has become more difficult. Before I used to start conversations and liked to discuss many things, now I am more reserved and choose what I really want to talk about and talk only when it is really necessary”	“Understanding is not a problem its speaking and having others understand me that is the problem”	“when having a long conversation it is impossible for people to understand me” “I do not speak as often as I used to […] it has become more difficult. Before I used to start conversations and liked to discuss many things, now I am more reserved and choose what I really want to talk about and talk only when it is really necessary	“I do not speak as often as I used to […] it has become more difficult. Before I used to start conversations and liked to discuss many things, now I am more reserved and choose what I really want to talk about and talk only when it is really necessary”	“the way I speak has changed a lot, especially with some letter pronunciations. I don’t think anyone has noticed but I notice it myself” “Understanding is not a problem its speaking and having others understand me that is the problem”
HHH (undiagnosed neurodegenerative disease)	“everything is my speech has changes. It is very very hard”	“my attention is affected and so sometimes I find it	“my speech is limited to short conversations	“I only speak when absolutely necessary”	“I don’t like it when I am not understood. Its so frustrating and I feel

		hard to understand as well as I used to”	when I have to […] and ask for basic things and help”		insulted when someone asks me to write down what I said because they cant understand me”
LAA (PD)	“Often I think I am going to say something and then I stop especially if I know it will be difficult […] you know depending on the timing of the medication. I feel what I was going to say is not important”	“understanding doesn’t seem to be a problem”	“when I have a productive conversation without any errors it makes me happy”		“I feel when the person in front of me is not able to understand what I am saying. I can see it in their face. Sometimes they ask me to repeat or clarify what I said. Other times I just do it myself […] I know they didn’t get it”
MAA (PD)	“speech has changes somewhat especially when the medication wears off”	“I have no problems at all with understanding others”	“I can have a conversation but not as I used to. If the timing is right, I mean for the medication then it is ok”		“if my speech is not clear and I know the person I’m talking to will not understand, when the medication wears off, I use my hand to gesture or just move my mouth”
NYA (ALS/MND)	“everything changed in my communication, I use an alphabet board now”	“I can understand most of the time”	“I only ask for help and things I need”		“I use a letter board to help people understand me”
MSJ (ALS/MND)	“I am constantly trying to speak with others. But when	“I understand when the place is quiet and one person is talking to	“I can have a conversation with someone familiar	“I am constantly trying to speak with others. But when there is a lot	

	there is a lot to say I always rely on my son especially with a large group or with strangers”	me”	[…] someone who knows me like my children”	to say I always rely on my son especially with a large group or with strangers”	
OMH (PD)	“there has not been that much change in the way I speak. At least I haven’t noticed it”	“I can understand as I used to”	“conversation is not a problem but I have never been a talkative person”		“my errors are more obvious on the phone. I now because people often ask me to clarify what I said”
NSA (PD)	“I don’t feel that my speech has changed that much. Sometimes it is more difficult”	“I can understand everything that is said”	“I avoid having long conversations because I know I cannot keep up”		
AAZ (MS)			“I avoid any topic that will require a lot of talking”	“I am not spontaneous in what I say anymore and I don’t initiate conversations”	

Participants	2.1. Request basic needs	2.2. Request help	2.4. Express agreement and disagreement
IBA (ALS/MND)	“I use speaking just to ask for things that I need, for what I need. It is rare that I talk in other things. I was never a talkative person […] this has always been my nature and it increased now”		
HAD (ALS/MND)	“I can ask for basic things around the house. Things that I need which is often since my movement has gotten worse”	“communication has become very restricted to asking for help to do things like change, go to the bathroom and saying yes and no”	“communication has become very restricted to asking for help to do things like change, go to the bathroom and saying yes and no”
LMS (MS)	“I can ask my mother to help me with things. I used to be the one to help her, but now I have to ask for help moving around the house, getting in and out of my wheel chair”	“I can ask my mother to help me with things. I used to be the one to help her, but now I have to ask for help moving around the house, getting in and out of my wheel chair”	
MSG (MS)			
AMS (ALS/MND)			
HHH (undiagnosed neurodegenerative disease)	“my speech is limited to short conversations when I have to […] and ask for basic things and help”	“my speech is limited to short conversations when I have to […] and ask for basic things and help”	
LAA (PD)			
MAA(PD)	“I can speak normally ask for everything that I need”		
NYA (ALS/MND)	“I mainly use speaking or gesturing to ask for basic things and needs. But my family know my routine so I don’t	“if I need to go to the bathroom or help with something I can get their attention”	“I use my hands and nod to agree or disagree”

	have to ask for much”		
MSJ (ALS/MND)	“my son is always there to help me with what I need I wither gesture or ask for it”	“my son is always there to help me with what I need I wither gesture or ask for it”	
OMH (PD)	“Asking for things using short words is easy”	“I am able to ask for help to go to the bathroom or help to transfer from my chair or bed”	
NSA (PD)			
AAZ (MS)	“I restrict speaking at home to what is essential only like asking for things”		“I try to express agreement or disagreement and avoid long arguments”

3. Emotions and feelings		
Participant	3.1. Anger and frustration	3.2. Emotional
IBA (ALS/MND)		
HAD (ALS/MND)		
LMS (MS)		
MSG (PD)	“when I speak it is usually understandable but when I am upset it is possible that it not as clear and people have a more difficult time understanding me”	
AMS (ALS/MND)		
HHH (undiagnosed neurodegenerative disease)		“when I am happy I am able to speak and express myself. But when I am emotional or feel down like I am a burden on everyone then I can get nothing out”
LAA (PD)	“when I am tired or I get frustrated from everything even speaking”	
MAA (PD)		
NYA (ALS/MND)		
MSJ (ALS/MND)		
OMH (PD)		
NSA (PD)	“when I am upset , frustrated or nervous people tell me that my speech becomes less clear, this has been a problem especially at university when I have to present in front of a group”	
AAZ (MS)	“When I am upset my speech errors are more obvious, or at least that is what I am told”	

4. Communication Environment					
Participant	4.1. At home	4.2. At work	4.3. On the phone	4.4. One-to-one conversation	4.5. In a group
IBA (ALS/MND)	“the easiest situations is when I am at home speaking with someone familiar like my family”		“I avoid answering the phone”	“It is so much easier to speak to one person, when you speak to a group it requires so much more effort”	“It is so much easier to speak to one person, when you speak to a group it requires so much more effort”
HAD (ALS/MND)			“it is impossible for people to understand me over the phone”		“In a group I avoid speaking, I prefer to stay quit or speak to the person closest to me […] speaking with a group of people is hard”
LMS (MS)	“At home I try to speak but when I an outside I avoid it”		“speaking over the phone used to be impossible for me. The person I am speaking to could not understand anything I am saying […] now it is a little better but still face to face is much easier”	“speaking over the phone used to be impossible for me. The person I am speaking to could not understand anything I am saying […] now it is a little better but still face to face is much easier”	
MSG (PD)					“It is very important for me to socialise with a group but it takes more effort not everyone is able to

					understand you”
AMS (ALS/MND)	“at home I am very comfortable with communication. Unlike at work and in larger groups”	“at home I am very comfortable with communication. Unlike at work and in larger groups”			“at home I am very comfortable with communication. Unlike at work and in larger groups”
HHH (undiagnosed neurodegenerative disease)	“at home I feel so comfortable communicating with my family. They are supportive and give me the time I need”				
LAA (PD)		“I am a teacher, when my speech started to get affected work has become more difficult [long pause] I am not as fluent and I keep discussions to a minimum”			
MAA (PD)		“At work it is more stressful to speak, I am more conscious of my errors”			
NYA (ALS)			“I used to love speaking on the phone. I could talk for hours especially since my family live far away. Now it is the most difficult thing for me. I can only say		

			a few words”		
MSJ (ALS/MND)			“I do not use the phone a lot but people are able to understand me”	“having a one to one conversation with someone who is familiar is the easiest and most comfortable for me”	“I am constantly trying to speak with others. But when there is a lot to say I always rely on my son especially with a large group or with strangers” “when I am in a large group it becomes more difficult for people to understand me because they can’t hear me so I avoid speaking”
OMH (PD)			“there are some things that I cannot pronounce it is more obvious over the phone” “my errors are more obvious on the phone. I now because people often ask me to clarify what I said”		
NSA (PD)		“when I am upset , frustrated or nervous people tell me that			“when I am upset , frustrated or nervous people tell me that

		my speech becomes less clear, this has been a problem especially at university when I have to present in front of a group”			my speech becomes less clear, this has been a problem especially at university when I have to present in front of a group”
AAZ (MS)	“I restrict speaking at home to the minimum”	“At work my boss always told me that my speech has changed a long time ago before anyone else has noticed. Especially my voice”	“People started noticing changes in my speech over the phone. They always ask me to repeat or what are you saying […] things like that” “I avoid answering the phone I ask my wife to answer” “I will tell you something, when I have to talk to a stranger […] I don’t like that. Like once I had to call the school regarding one of my sons I was so upset because I had to do something I do not like. Talk on the phone and with a stranger”	“since my speech has started changing I avoid speaking to my friend except in situation where I am face to face with someone I am comfortable with”	

5. Communication Partner			
Participant	5.1 Family	5.2 Familiar person	5.3 Stranger
IBA (ALS/MND)	“Communication is so much easier with my family, particularly with my daughter I rely on her a lot for communication”		
HAD (ALS/MND)	“My family are able to understand me when I talk to them face to face”	“I feel comfortable when talking with someone who I know and familiar with”	“I have to repeat myself for others to understand me especially with strangers”
LMS (MS)	“My family, I mean my parents are able to understand me [long pause] I think it is because I spend so much time with them and I rely on them. But others can’t like my aunt and cousin they need some help to be able to understand what I said”		“I don’t like speaking in front of strangers”
MSG (PD)	“with strangers I feel more reserved in what I say and how I say it than with friends and family”	“with strangers I feel more reserved in what I say and how I say it than with friends and family”	“with strangers I feel more reserved in what I say and how I say it than with friends and family”
AMS (ALS/MND)		“Strangers are not aware of my communication errors and mistakes, however with my fiends and colleagues who are used to the way I used to speak […] there is a difference between how I used to speak and now”	“Strangers are not aware of my communication errors and mistakes, however with my fiends and colleagues who are used to the way I used to speak […] there is a difference between how I used to speak and now”
HHH (undiagnosed neurodegenerative disease)	“for someone who lives with me […] they know me well and can understand what I need and what		“for someone who lives with me […] they know me well and can understand what I need and what

	I am saying. But for a stranger they need to see my mouth move and I have to keep repeating myself [long pause] sometimes I have to get someone else to explain what I am saying”		I am saying. But for a stranger they need to see my mouth move and I have to keep repeating myself [long pause] sometimes I have to get someone else to explain what I am saying”
LAA (PD)	“My husband is not able to understand me all the time and it frustrates him, it has affected our relationship”	“Conversation is so much easier with someone that I know and am familiar with”	“when I have to speak with a stranger I feel pressured and I sometimes plan what I want to tell them in advance. For example if I go to get something, go to an appointment or the bank”
MAA (PD)	“with family and friends it is easy to communicate I feel comfortable”	“with family and friends it is easy to communicate I feel comfortable”	“Since my speech started to change in the recent months I started seeing less and less people, especially strangers I don’t like talking in front of them […] I feel embarrassed”
NYA (ALS/MND)			
MSJ (ALS/MND)	“I am constantly trying to speak with others. But when there is a lot to say I always rely on my son especially with a large group or with strangers” “I can have a conversation with someone who knows me well like my children, they understand me”		“I am constantly trying to speak with others. But when there is a lot to say I always rely on my son especially with a large group or with strangers” “I don’t like to talk a lot with strangers. I try and if they do not understand me, my son is my translator”
OMH (PD)	“my family and children are able to understand me, but for others it is very difficult”		“strangers are able to understand me but I am not as fluent”

			“Doing things for myself and being independent has been so affected [long pause] especially things like going to the bank or an appointment when I have to talk with someone who doesn’t know me, the way I speak represents who I am and it this change has affected my independence”
NSA (PD)			
AAZ (MS)	“I restrict speaking at home to the minimum”	“since my speech has started changing I avoid speaking to my friend except in situation where I am face to face with someone I am comfortable with”	“I will tell you something, when I have to talk to a stranger […] I don’t like that. Like once I had to call the school regarding one of my sons I was so upset because I had to do something I do not like. Talk on the phone and with a stranger”

APPENDIX 14 - FINAL VERSION OF THE FUNCTIONAL COMMUNICATION SCALE

تشخيص التواصل الوظيفي لدى الأشخاص الذين يعانون من صعوبات في الكلام

التواصل الوظيفـي: هو القدرة على تلقي أو نقل رسالة ، بغض النظر عن الواسطة المستخدمة ،و ذلك للتواصل بشكل فعال ومستقل في البيئة الطبيعية أو اليومية.

في هذا الاستبيان نريد منكم التفكير في قدرتكم على التواصل في الوقت الحالي. يجب أن تأخذو في الاعتبار مدى احتياجكم للمساعدة و التعديلات التي تقومون بها سواءً أنتم أو الشخص الذي تتحدثون معه لنقل المعلومة بينكم

الرجاء الاجابة على كافة الأسئلة الواردة. إذا كان بعضها لا ينطبق فاختارx

الرجاء الاجابة على الأسئلة بدقة

تأكد أن الإجابات سوف تبقى سرية

الاحتياجات الأساسية	أقوم به	أحتاج لقدر بسيط من المساعدة	أحتاج لقدر بسيط إلى متوسط من المساعدة	أحتاج لقدر متوسط من الساعدة	أحتاج لقدر متوسط إلى كبير من المساعدة	أحتاج اقدر كبير من المساعدة	لا أستطيع	لا ينطبق
أعبر عن الاحتياجات الأساسية لأفراد العائلة	1	2	3	4	5	6	7	x
أعبر عن الاحتياجات (صديق، جار، عامل) الأساسية لشخص مألوف	1	2	3	4	5	6	7	x
أعبر عن الاحتياجات الأساسية لشخص غريب	1	2	3	4	5	6	7	x
أعبر عن الاحتياجات الأساسية مع مجموعة من الأشخاص	1	2	3	4	5	6	7	x
أعبر عن الموافقة أو الرفض (التعبير عن نعم/لا إما بالكلام أو الإشارة)	1	2	3	4	5	6	7	x
أعبر عن ماأريد أو لا يريد بوضوح	1	2	3	4	5	6	7	x
أطلب المساعدة عند اللزوم من أفراد العائلة	1	2	3	4	5	6	7	x
أطلب المساعدة عند اللزوم (صديق، جار، عامل) من شخص مألوف	1	2	3	4	5	6	7	x
أطلب المساعدة عند اللزوم من شخص غريب	1	2	3	4	5	6	7	x
أعبر عن المشاعر مع العائلة -مثل السعادة أو الحزن -	1	2	3	4	5	6	7	x
أعبر عن المشاعر مع شخص -مثل السعادة أو الحزن - مألوف	1	2	3	4	5	6	7	x
أعبر عن المشاعر مع شخص -مثل السعادة أو الحزن - غريب	1	2	3	4	5	6	7	x

التواصل الاجتماعي	أقوم به	أحتاج لقدر بسيط من المساعدة	أحتاج لقدر بسيط إلى متوسط من المساعدة	أحتاج لقدر متوسط من الساعدة	أحتاج لقدر متوسط إلى كبير من المساعدة	أحتاج اقدر كبير من المساعدة	لا أستطيع	لا ينطبق
أستطيع القيام بالمحادثة مع العائلة	1	2	3	4	5	6	7	x
أستطيع القيام بالمحادثة مع شخص (صديق، جار، عامل) مألوف	1	2	3	4	5	6	7	x
أستطيع القيام بالمحادثة مع شخص غريب	1	2	3	4	5	6	7	x
أستطيع القيام بالمحادثة في مجموعة	1	2	3	4	5	6	7	x
أستخدم الهاتف مع العائلة	1	2	3	4	5	6	7	x
أستخدم الهاتف مع شخص مألوف (صديق، جار، عامل)	1	2	3	4	5	6	7	x
أستخدم الهاتف مع شخص غريب	1	2	3	4	5	6	7	x
أبدأ بالمحادثة مع العائلة	1	2	3	4	5	6	7	x
أبدأ بالمحادثة مع شخص مألوف (صديق، جار، عامل)	1	2	3	4	5	6	7	x
أبدأ بالمحادثة مع شخص غريب	1	2	3	4	5	6	7	x
أبدأ بالمحادثة مع مجموعة من الأشخاص	1	2	3	4	5	6	7	x
أنتبه لأخطائي في التواصل	1	2	3	4	5	6	7	x
أفهم المحادثة مع العائلة	1	2	3	4	5	6	7	x
أفهم المحادثة مع شخص مألوف (صديق، جار، عامل)	1	2	3	4	5	6	7	x
أفهم المحادثة مع شخص غريب	1	2	3	4	5	6	7	x
أفهم المحادثة في مجموعة	1	2	3	4	5	6	7	x
أستطيع تبادل المعلومات الأساسية في العمل	1	2	3	4	5	6	7	x
أستطيع القيام بمحادثةمهنيـة/ محترفة في العمل	1	2	3	4	5	6	7	x

Appendix 15 - Final Version of the Functional Communication Scale – English translation

Functional Communication Scale:

Communicate Basic Needs

1. Expresses basic needs to family members	7	6	5	4	3	2	1	N
2. Expresses basic needs to familiar person (e.g., friend, neighbor)	7	6	5	4	3	2	1	N
3. Expresses basic needs to stranger (e.g., shopping, at the bank)	7	6	5	4	3	2	1	N
4. Expresses basic needs in a group setting	7	6	5	4	3	2	1	N
5. Express agreement and disagreement (e.g., indicating yes/no verbally or non verbally)	7	6	5	4	3	2	1	N
6. Makes strong likes and dislikes known	7	6	5	4	3	2	1	N
7. Requests help when necessary form family member	7	6	5	4	3	2	1	N
8. Request help when necessary form a familiar person (e.g., friend, neighbor)	7	6	5	4	3	2	1	N
9. Request help when necessary from a stranger	7	6	5	4	3	2	1	N
10. Expression when feeling angry, frustrated, emotional with family	7	6	5	4	3	2	1	N
11. Expression when feeling angry, frustrated, emotional with a familiar person (e.g., friend, neighbor)	7	6	5	4	3	2	1	N
12. Expression when feeling angry, frustrated, emotional with a stranger	7	6	5	4	3	2	1	N

Social Communication

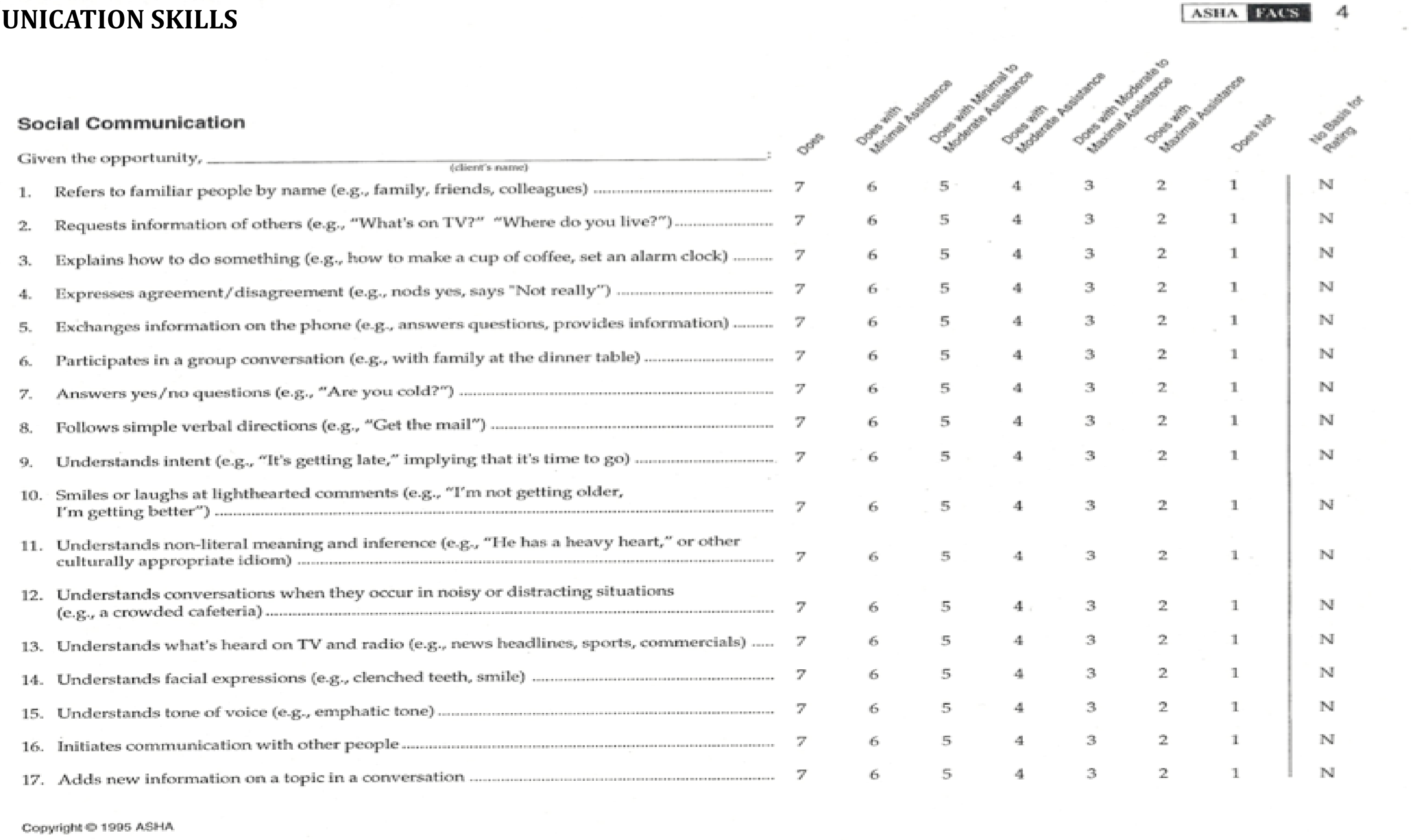
13. Has a conversation with family members	7	6	5	4	3	2	1	N
14. Has a conversation with a familiar person (e.g., friend, domestic worker, neighbored)	7	6	5	4	3	2	1	N
15. Has a conversation with a stranger	7	6	5	4	3	2	1	N
16. Has a conversation within a group setting	7	6	5	4	3	2	1	N

17. Exchange information over the phone with family	7	6	5	4	3	2	1	N
18. Exchange information over the phone with a familiar person (e.g., friend, domestic worker, neighbor)	7	6	5	4	3	2	1	N
19. Exchange information over the phone with a stranger	7	6	5	4	3	2	1	N
20. Initiates communication with family	7	6	5	4	3	2	1	N
21. Initiates communication with a familiar person (e.g., friend, domestic worker, neighbor)	7	6	5	4	3	2	1	N
22. Initiates communication with a stranger	7	6	5	4	3	2	1	N
23. Initiates communication in a group setting	7	6	5	4	3	2	1	N
24. Recognises his/her own communication errors	7	6	5	4	3	2	1	N
25. Understands conversation with family members	7	6	5	4	3	2	1	N
26. Understands conversation with a familiar person (e.g., friend, domestic worker, neighbored)	7	6	5	4	3	2	1	N
27. Understands conversation with a stranger	7	6	5	4	3	2	1	N
28. Understands conversation within a group setting	7	6	5	4	3	2	1	N
29. Understands what is on TV	7	6	5	4	3	2	1	N
30. Exchange basic information at work	7	6	5	4	3	2	1	N
31. Has professional conversation at work	7	6	5	4	3	2	1	N

Score Key:

7: Does with no assistance
6: Does with minimal assistance
5: Does with minimal to moderate assistance
4: Does with moderate assistance
3: Does with moderate to maximum assistance
2: Does with maximal assistance
1: Does not
N: Not Applicable

APPENDIX 16 – THE AMERICAN SPEECH LANGUAGE AND HEARING ASSOCIATION – FUNCTIONAL ASSESSMENT FOR COMMUNICATION SKILLS



Social Communication

Given the opportunity, ______________________ (client's name):

	Does	Does with Minimal Assistance	Does with Minimal to Moderate Assistance	Does with Moderate Assistance	Does with Moderate to Maximal Assistance	Does with Maximal Assistance	Does Not	No Basis for Rating
1. Refers to familiar people by name (e.g., family, friends, colleagues)	7	6	5	4	3	2	1	N
2. Requests information of others (e.g., "What's on TV?" "Where do you live?")	7	6	5	4	3	2	1	N
3. Explains how to do something (e.g., how to make a cup of coffee, set an alarm clock)	7	6	5	4	3	2	1	N
4. Expresses agreement/disagreement (e.g., nods yes, says "Not really")	7	6	5	4	3	2	1	N
5. Exchanges information on the phone (e.g., answers questions, provides information)	7	6	5	4	3	2	1	N
6. Participates in a group conversation (e.g., with family at the dinner table)	7	6	5	4	3	2	1	N
7. Answers yes/no questions (e.g., "Are you cold?")	7	6	5	4	3	2	1	N
8. Follows simple verbal directions (e.g., "Get the mail")	7	6	5	4	3	2	1	N
9. Understands intent (e.g., "It's getting late," implying that it's time to go)	7	6	5	4	3	2	1	N
10. Smiles or laughs at lighthearted comments (e.g., "I'm not getting older, I'm getting better")	7	6	5	4	3	2	1	N
11. Understands non-literal meaning and inference (e.g., "He has a heavy heart," or other culturally appropriate idiom)	7	6	5	4	3	2	1	N
12. Understands conversations when they occur in noisy or distracting situations (e.g., a crowded cafeteria)	7	6	5	4	3	2	1	N
13. Understands what's heard on TV and radio (e.g., news headlines, sports, commercials)	7	6	5	4	3	2	1	N
14. Understands facial expressions (e.g., clenched teeth, smile)	7	6	5	4	3	2	1	N
15. Understands tone of voice (e.g., emphatic tone)	7	6	5	4	3	2	1	N
16. Initiates communication with other people	7	6	5	4	3	2	1	N
17. Adds new information on a topic in a conversation	7	6	5	4	3	2	1	N

Social Communication (cont.)

	Does	Does with Minimal Assistance	Does with Minimal to Moderate Assistance	Does with Moderate Assistance	Does with Moderate to Maximal Assistance	Does with Maximal Assistance	Does Not	No Basis for Rating
18. Changes topics in conversation	7	6	5	4	3	2	1	N
19. Adjusts to a change in topic by conversational partner	7	6	5	4	3	2	1	N
20. Recognizes his/her own communication errors (e.g., shows awareness that he/she used the wrong word)	7	6	5	4	3	2	1	N
21. Corrects his/her own communication errors (e.g., corrects naming errors)	7	6	5	4	3	2	1	N

Qualitative Dimensions of Communication Scores				
	Adequacy	Appropriateness	Promptness	Communication Sharing
Social Communication				

Communication Independence Scores			
	Total Score	Total Items Rated (of 21)	Domain Mean Score
Social Communication			

Communication of Basic Needs

	Does	Does with Minimal Assistance	Does with Minimal to Moderate Assistance	Does with Moderate Assistance	Does with Moderate to Maximal Assistance	Does with Maximal Assistance	Does Not	No Basis for Rating
22. Recognizes familiar faces	7	6	5	4	3	2	1	N
23. Recognizes familiar voices	7	6	5	4	3	2	1	N
24. Makes strong likes or dislikes known (e.g., people, places, foods)	7	6	5	4	3	2	1	N
25. Expresses feelings (e.g., happy, sad)	7	6	5	4	3	2	1	N
26. Requests help when necessary (e.g., gestures that wheelchair is stuck)	7	6	5	4	3	2	1	N
27. Makes needs or wants known (e.g., to eat, to rest)	7	6	5	4	3	2	1	N
28. Responds in an emergency (e.g., calls 911)	7	6	5	4	3	2	1	N

Qualitative Dimensions of Communication Scores				
	Adequacy	Appropriateness	Promptness	Communication Sharing
Communication of Basic Needs				

Communication Independence Scores			
	Total Score	Total Items Rated (of 7)	Domain Mean Score
Communication of Basic Needs			

Reading, Writing, Number Concepts	Does	Does with Minimal Assistance	Does with Minimal to Moderate Assistance	Does with Moderate Assistance	Does with Moderate to Maximal Assistance	Does with Maximal Assistance	Does Not	No Basis for Rating
29. Understands simple signs (e.g., poison symbol, stop sign)	7	6	5	4	3	2	1	N
30. Uses common reference materials (e.g., telephone book, TV guide)	7	6	5	4	3	2	1	N
31. Follows written directions (e.g., prescriptions, preparing a can of soup)	7	6	5	4	3	2	1	N
32. Understands basic printed material (e.g., menus, headlines)	7	6	5	4	3	2	1	N
33. Prints/writes/types name	7	6	5	4	3	2	1	N
34. Fills out short forms (e.g., for entering a sweepstakes)	7	6	5	4	3	2	1	N
35. Writes messages (e.g., "Call your mother")	7	6	5	4	3	2	1	N
36. Understands signs with numbers (e.g., price tags, speed limit signs)	7	6	5	4	3	2	1	N
37. Makes basic money transactions (e.g., pays for items at grocery store, recognizes when given the wrong change)	7	6	5	4	3	2	1	N
38. Understands simple units of measurement (e.g., weights, distances, quantities in recipes)	7	6	5	4	3	2	1	N

Qualitative Dimensions of Communication Scores

	Adequacy	Appropriateness	Promptness	Communication Sharing
Reading, Writing, Number Concepts				▨

Communication Independence Scores

	Total Score	Total Items Rated (of 10)	Domain Mean Score
Reading, Writing, Number Concepts			

Daily Planning

	Does	Does with Minimal Assistance	Does with Minimal to Moderate Assistance	Does with Moderate Assistance	Does with Moderate to Maximal Assistance	Does with Maximal Assistance	Does Not	No Basis for Rating
39. Knows what time it is (i.e., tells time)	7	6	5	4	3	2	1	N
40. Dials telephone numbers (i.e., sequences numbers correctly)	7	6	5	4	3	2	1	N
41. Keeps scheduled appointments (e.g., arrives at doctor's office on time)	7	6	5	4	3	2	1	N
42. Uses a calendar for time-related activities (e.g., scheduling, planning)	7	6	5	4	3	2	1	N
43. Follows a map (e.g., finds a street on a road map)	7	6	5	4	3	2	1	N

Qualitative Dimensions of Communication Scores

	Adequacy	Appropriateness	Promptness	Communication Sharing
Daily Planning				▨

Communication Independence Scores

	Total Score	Total Items Rated (of 5)	Domain Mean Score
Daily Planning			

Information Sources

Information was solicited from the following individuals to complete this ASHA FACS:

☐ Family member, friend, or caregiver of client (e.g., spouse/partner, sibling, parent, child)

☐ Other professionals serving client (e.g., nurse, physical therapist, occupational therapist)

APPENDIX 17 – DESCRIPTIVE STATISTICS AND SHAPIRO-WILKS TEST OF NORMALITY

Descriptive statistics

	N	Mean	Std. Deviation	Skewness		Kurtosis	
	Statistic	Statistic	Statistic	Statistic	Std. Error	Statistic	Std. Error
Age	33	48.52	12.560	-.028	.409	-1.012	.798
Disease Duration	34	76.68	66.304	1.699	.403	3.857	.788
Word Intelligibility	34	83.88	14.167	-1.250	.403	1.557	.788
Sentence	34	89.47	20.207	-2.979	.403	8.695	.788
Functional	34	6.08	1.083	-1.145	.403	.564	.788
Significant other	34	6.23	.763	-1.006	.403	.594	.788
Significant other A-	34	19.61	13.085	.035	.403	-1.318	.788
SEIQoL-DW Index	33	56.63	16.864	-.449	.409	-.913	.798
A-SIP Health	34	26.14	16.833	.478	.403	-.543	.788
A-SIP Physical	33	29.36	21.913	.489	.409	-.930	.798
A-SIP Independent	33	24.74	14.942	.096	.409	-.874	.798
A-SIP Psychological	33	27.12	20.212	.834	.409	-.205	.798
MS Scale	6	2.58	2.538	1.960	.845	3.928	1.741
PD Scale	19	3.11	1.049	-.876	.524	-.393	1.014
ALS Scale	9	23.67	8.588	.540	.717	-1.704	1.400

(Normality testing) SPSS Shapiro-Wilk normality test results: Pre-transformation

	Shapiro-Wilk		
Study variable	*Statistic*	*df*	*Sig.*
Age (years)	.969	33	.446
Disease duration (months)	.854*	34	.000
MS Scale	.724*	6	.011
PD Scale	.799*	19	.001
ALS Scale	.847	9	.070
Word Intelligibility Score (WIS)	.889*	34	.002
Sentence Intelligibility Score (SIS)	.535*	34	.000
Functional Communication Scale (FCS)	.828*	34	.000
A-SIP Health-Related Quality of Life	.952	34	.141
A-SIP Physical Score	.921*	33	.020
A-SIP Independent Score	.972	33	.547
A-SIP Psychological Score	.911*	33	.010
SEIQoL-DW Index Quality of Life	.942	33	.078
MQoL- SIS Quality of Life	.948	33	.118
Caregiver FCS Rating of Patient	.878*	34	.001
Caregiver A-SIP Rating of Patient	.935*	34	.042

* < .05 = non-normally distributed.

SPSS Shapiro-Wilk normality test results: Post-transformation

		Shapiro-Wilk		
Study variable	*Transformation*	*Statistic*	*df*	*Sig.p-value*
Disease duration (months)	Logarithmic	.947†	34	.100
MS Scale	Logarithmic	.832†	6	.112
PD Scale	Inverse	.635*	19	.000
Word Intelligibility Score (WIS)	Inverse	.718*	34	.000
Sentence Intelligibility Score (SIS)	Inverse	.327*	34	.000
Functional Communication Scale (FCS)	Inverse	.721*	34	.000
A-SIP Physical Score	Square Root	.951†	33	.145
A-SIP Psychological Score	Square Root	.972*	33	.548
Caregiver FCS Rating of Patient	Inverse	.806*	34	.000
Caregiver A-SIP Rating of Patient	Square Root	.927*	34	.025

Note:† Indicates data has been transformed to normality.

Logarithmic and square root transformations (to improve positive skewness), Inverse Transformation (1/y) (to improve negative skewness).

* > .05 indicates the data are normally distributed.

APPENDIX 18 – STATISTICAL ANALYSIS FOR CHAPTER 5

ParticipantID	Gender	Age	Marital Status	Employment	Employment_Y_N	Duration	WIS	SIS	Dysarthria Severity	Diagnosis	FCS	ASIP	SEIQOL	MQolSIS	PHYSICALSCORE	INDEPENDENTSCORE	PSYCHOLOGICALSCORE	
ATK	1	58	1	3	1	72	90	97	1	3	6.4	28	29	6	69	40	50	
MMN	2	35	1	2	0	72	90	97	1	2	7	9	36.7	7	18	28	35	
OMA	1	34	0	4	0	108	95	97	1	2	7	5	69	9	44	12	10	
AMB	1	66	1	4	0	60	92	96	1	3	7	22	72.8	8	2	7	4	
ASO	1	50	1	4	0	132	95	96	1	3	7	28	66.6	6	24	28	37	
GBD	1	64	1	1	1	312	92	96	1	3	6.5	30	80.2	7	27	28	31	
MAJ	1	65	1	1	1	18	88	96	1	3	4.6	19	46.8	8	60	45	63	
SGS	2	39	1	4	0	60	94	96	1	3	7	8	71	9	20	19	14	
SSG	1	55	1	1	0	48	90	96	1	3	7	2	67	9	27	33	31	
MNM	2	25	0	3	0	3	80	96	1	2	7	14.7	64.2	8	20	17	10	
SAG	1	39	1	4	0	84	86	96	1	2	6.9	26.5	44.2	4	58	50	77	
MHM	1	3	1	2	1	36	7	9	1	1	6.	49	83.	5	44	33	60	

		4					4	6			7		2					
TSJ	1	40	1	4	0	12	94	96	1	1	6.9	17.6	79	6	29	7	23	
AMS	1	61	1	1	0	60	90	95	1	3	7	4	40.43	7	18	19	21	
FAB	2	53	1	2	0	216	94	95	1	3	6.1	56	31.2	4	60	45	64	
LAH	2	42	1	3	1	120	90	95	1	3	7	19	75.2	8	15	28	19	
MJS	1	73	0	3	1	96	84	95	1	3	6.4	0	60	6	18	9	17	
SHK	1	50	1	4	0	96	93	95	1	3	6.6	25.7	70.76	7	71	36	42	
AHT	2	33	1	4	0	48	94	95	1	2	5.4	28	25.2	7	0	0	2	
LMS	2	30	0	2	1	84	74	95	1	2	5.2	56.6	38.14	6	0	12	14	
AAA	1	59	0	1	0	38	92	95	1	1	6.7	52	72	4	64	19	12	
KIH	1	61	1	2	1	96	74	94	1	3	5.2	62	24.6	0	31	14	0	
NSB	2	47	1	2	0	84	95	94	1	3	4.1	45	61.04	9	0	2	12	
NSM	1	30	0	2	1	180	86	94	1	3	4.7	27	57.7	5	62	33	35	
KOM	2	42	1	2	0	60	80	91	1	3	5.7	19	53.2	9	9	43	19	
MRH	2	3	1	2	0	6	7	9	1	1	4	43	60.	44	44	38	52	

		7					2	1					3					
IAJ	2	55	1	2	0	168	68	89	2	3	5.7	16	69.12	5	11	24	46	
MMS	1	65	1	1	0	108	68	87	2	3	7	31.6	53.4	10	2	0	12	
MAM	1	60	1	1	0	24	64	66	2	3	7	14.7	62.7	5	29	36	14	
MRS	1	52	1	2	0	12	58	65	2	1	4.9	25	65.81	7	44	55	10	
FSJ	1	51	1	3	1	12	70	64	2	1	6	20	59.6	5	7	5	10	
MRA	1	52	1	2	1	16	62	63	2	1	5.3	5	43.9	5	15	26	35	
SDQ	1	65	1	1	0	48	65	20	2	1	6.8	35.2	34.7	2	2	2	2	
KMW	1	44	1	3	1	18	42	15	2	1	3	45	52.5	2	24	21	10	

Raw Data for demographic information of the 34 participants and scores in the QoL (ASIP, SEIQoL-DW, MQoL-SIS and ASIP components physical, psychological, independent) and communication (WIS, SIS, FCS) measures

ParticipantID	FCS	SigOtherFCS	ASIP	PHYSICALSCORE	INDEPENDENTSCORE	PSYCHOLOGICALSCORE	SigOther ASIP	Caregiverphysicalscore	Caregiverindependentscore	Caregiverpsychologicalscore		
AAA	6.7	7	52	69	40	50	32.5	56	19	29		
AHT	5.4	6.9	28	18	28	35	15	9	17	19		
AMB	7	6.5	22	44	12	10	27	56	17	10		
AMS	7	7	4	2	7	4	6	9	7	4		
ASO	7	7	28	24	28	37	29	28	28	37		
ATK	6.4	5.3	28	27	28	31	31	36	28	31		
FAB	6.1	5.6	56	60	45	63	41	44	42	38		
FSJ	6	6.3	20	20	19	14	0	0	0	0		
GBD	6.5	7	30	27	33	31	32	29	40	27		
IAJ	5.7	6.5	16	20	17	10	18	20	24	12		
KIH	5.2	6.3	62	58	50	77	39	47	35	35		
KMW	3	4.1	45	44	33	60	32	23	26	46		
KOM	5.7	4.5	19	29	7	23	42.9	56	43	31		
LAH	7	7	19	18	19	21	20	18	20	21		
LMS	5.2	5.3	56.6	60	45	64	33	29	31	40		
MAJ	4.	5.8	19	15	28	19	23.5	22	33	19		

	6											
MAM	7	6.6	14.7	18	9	17	18	22	14	17		
MHM	6.7	5.8	49	71	36	42	34	64	23	35		
MJS	6.4	6.8	0	0	0	2	3	7	2	0		
MMN	7	7	9	0	12	14	7	0	14	8		
MMS	7	7	31.6	64	19	12	7.3	18	3	0		
MNM	7	6.6	14.7	31	14	0	8	14	12	0		
MRA	5.3	5.5	5	0	2	12	4	0	4	8		
MRH	4	5.4	43	62	33	35	23.5	60	31	19		
MRS	4.9	6.4	25	9	43	19	30	15	47	23		
NSB	4.1	5.6	45	44	38	52	0	0	0	0		
NSM	4.7	5.4	27	11	24	46	20	11	19	29		
OMA	7	7	5	2	0	12	9	11	7	8		
SAG	6.9	6.5	26.5	29	36	14	10.3	16	7	8		
SDQ	6.8	5.9	35.2	44	55	10	9.6	22	7	2		
SGS	7	6.3	8	7	5	10	32	33	32	31		

SHK	6.6	6.4	25.7	15	26	35	24	16	26	31		
SSG	7	7	2	2	2	2	3	4	2	2		
TSJ	6.9	6.5	17.6	24	21	10	2	4	0	2		

Caregiver and participant scores on FCS, ASIP, ASIP_physical, ASIP_independent, ASIP_psychological

1. Spearman Correlation – Overall Sample

			Word Intelligibility Score	Sentence Intelligibility Score	Functional Communication Scale
Spearman's rho	Word Intelligibility Score	Correlation Coefficient	1.000	.843**	.419*
		Sig. (2-tailed)	.	.000	.014
		N	34	34	34
	Sentence Intelligibility Score	Correlation Coefficient	.843**	1.000	.330
		Sig. (2-tailed)	.000	.	.056
		N	34	34	34
	Functional	Correlation	.419*	.330	1.000

	Communication Scale	Coefficient			
		Sig. (2-tailed)	.014	.056	.
		N	34	34	34
	SEIQoL-DW Index Score	Correlation Coefficient	.288	.127	.341
		Sig. (2-tailed)	.104	.480	.052
		N	33	33	33
	ASIP	Correlation Coefficient	-.183	-.041	-.458**
		Sig. (2-tailed)	.300	.819	.006
		N	34	34	34
	MQoL- SIS	Correlation Coefficient	.308	.325	.338
		Sig. (2-tailed)	.081	.065	.055
		N	33	33	33

Correlations

			SEIQoL-DW Index Score	ASIP	MQoL- SIS
Spearman's rho	Word Intelligibility Score	Correlation Coefficient	.288	-.183	.308
		Sig. (2-tailed)	.104	.300	.081
		N	33	34	33
	Sentence Intelligibility	Correlation Coefficient	.127	-.041	.325

	Score	Sig. (2-tailed)	.480	.819	.065
		N	33	34	33
	Functional Communication Scale	Correlation Coefficient	.341	-.458**	.338
		Sig. (2-tailed)	.052	.006	.055
		N	33	34	33
	SEIQoL-DW Index Score	Correlation Coefficient	1.000	-.182	.272
		Sig. (2-tailed)	.	.310	.132
		N	33	33	32
	ASIP	Correlation Coefficient	-.182	1.000	-.424*
		Sig. (2-tailed)	.310	.	.014
		N	33	34	33
	MQoL- SIS	Correlation Coefficient	.272	-.424*	1.000
		Sig. (2-tailed)	.132	.014	.
		N	32	33	33

2. Spearman Correlation by Disease

Diagnosis = ALS

			Word Intelligibility Score	Sentence Intelligibility Score	Functional Communication Scale
Spearman's rho	Word Intelligibility Score	Correlation Coefficient	1.000	.714[*]	.718[*]
		Sig. (2-tailed)	.	.031	.029
		N	9	9	9
	Sentence Intelligibility Score	Correlation Coefficient	.714[*]	1.000	.475
		Sig. (2-tailed)	.031	.	.197
		N	9	9	9
	Functional Communication Scale	Correlation Coefficient	.718[*]	.475	1.000
		Sig. (2-tailed)	.029	.197	.
		N	9	9	9
	SEIQoL-DW Index Score	Correlation Coefficient	.323	.802[*]	.240
		Sig. (2-tailed)	.435	.017	.568

		N	8	8	8
	ASIP	Correlation Coefficient	-.159	.126	-.109
		Sig. (2-tailed)	.683	.748	.781
		N	9	9	9
	MQoL- SIS	Correlation Coefficient	.198	.482	.025
		Sig. (2-tailed)	.639	.227	.954
		N	8	8	8

Correlations[a]

			SEIQoL-DW Index Score	ASIP	MQoL- SIS
Spearman's rho	Word Intelligibility Score	Correlation Coefficient	.323	-.159	.198
		Sig. (2-tailed)	.435	.683	.639
		N	8	9	8
	Sentence Intelligibility Score	Correlation Coefficient	.802[*]	.126	.482
		Sig. (2-tailed)	.017	.748	.227
		N	8	9	8
	Functional Communication Scale	Correlation Coefficient	.240	-.109	.025
		Sig. (2-tailed)	.568	.781	.954
		N	8	9	8
	SEIQoL-DW Index Score	Correlation Coefficient	1.000	.381	.408

		Sig. (2-tailed)	.	.352	.364
		N	8	8	7
	ASIP	Correlation Coefficient	.381	1.000	-.503
		Sig. (2-tailed)	.352	.	.204
		N	8	9	8
	MQoL- SIS	Correlation Coefficient	.408	-.503	1.000
		Sig. (2-tailed)	.364	.204	.
		N	7	8	8

*. Correlation is significant at the 0.05 level (2-tailed).

a. Diagnosis = ALS

Diagnosis = MS

Correlations[a]

			Word Intelligibility Score	Sentence Intelligibility Score	Functional Communication Scale
Spearman's rho	Word Intelligibility Score	Correlation Coefficient	1.000	.828*	.395
		Sig. (2-tailed)	.	.042	.439
		N	6	6	6
	Sentence Intelligibility Score	Correlation Coefficient	.828*	1.000	.000
		Sig. (2-tailed)	.042	.	1.000
		N	6	6	6
	Functional Communication Scale	Correlation Coefficient	.395	.000	1.000
		Sig. (2-tailed)	.439	1.000	.
		N	6	6	6
	SEIQoL-DW Index Score	Correlation Coefficient	.029	.000	.516
		Sig. (2-tailed)	.957	1.000	.295
		N	6	6	6
	ASIP	Correlation	-.600	-.207	-.941**

		Coefficient			
		Sig. (2-tailed)	.208	.694	.005
		N	6	6	6
	MQoL- SIS	Correlation Coefficient	.522	.525	.678
		Sig. (2-tailed)	.288	.285	.139
		N	6	6	6

Correlations[a]

			SEIQoL-DW Index Score	ASIP	MQoL- SIS
Spearman's rho	Word Intelligibility Score	Correlation Coefficient	.029	-.600	.522
		Sig. (2-tailed)	.957	.208	.288
		N	6	6	6
	Sentence Intelligibility Score	Correlation Coefficient	.000	-.207	.525
		Sig. (2-tailed)	1.000	.694	.285
		N	6	6	6
	Functional Communication Scale	Correlation Coefficient	.516	-.941**	.678
		Sig. (2-tailed)	.295	.005	.139
		N	6	6	6
	SEIQoL-DW Index Score	Correlation Coefficient	1.000	-.543	.464
		Sig. (2-tailed)	.	.266	.354

		N	6	6	6
	ASIP	Correlation Coefficient	-.543	1.000	-.696
		Sig. (2-tailed)	.266	.	.125
		N	6	6	6
	MQoL- SIS	Correlation Coefficient	.464	-.696	1.000
		Sig. (2-tailed)	.354	.125	.
		N	6	6	6

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

a. Diagnosis = MS

Diagnosis = PD

Correlations[a]

			Word Intelligibility Score	Sentence Intelligibility Score	Functional Communication Scale
Spearman's rho	Word Intelligibility Score	Correlation Coefficient	1.000	.841**	.289
		Sig. (2-tailed)	.	.000	.231
		N	19	19	19
	Sentence Intelligibility Score	Correlation Coefficient	.841**	1.000	.110
		Sig. (2-tailed)	.000	.	.654
		N	19	19	19
	Functional Communication Scale	Correlation Coefficient	.289	.110	1.000
		Sig. (2-tailed)	.231	.654	.
		N	19	19	19
	SEIQoL-DW Index Score	Correlation Coefficient	.418	.094	.450
		Sig. (2-tailed)	.075	.703	.053
		N	19	19	19
	ASIP	Correlation	.076	.105	-.374

		Coefficient			
		Sig. (2-tailed)	.757	.670	.115
		N	19	19	19
	MQoL- SIS	Correlation Coefficient	.158	.082	.275
		Sig. (2-tailed)	.519	.740	.255
		N	19	19	19

Correlations[a]

			SEIQoL-DW Index Score	ASIP	MQoL- SIS
Spearman's rho	Word Intelligibility Score	Correlation Coefficient	.418	.076	.158
		Sig. (2-tailed)	.075	.757	.519
		N	19	19	19
	Sentence Intelligibility Score	Correlation Coefficient	.094	.105	.082
		Sig. (2-tailed)	.703	.670	.740
		N	19	19	19
	Functional Communication Scale	Correlation Coefficient	.450	-.374	.275
		Sig. (2-tailed)	.053	.115	.255
		N	19	19	19
	SEIQoL-DW Index Score	Correlation Coefficient	1.000	-.278	.311
		Sig. (2-tailed)	.	.250	.194
		N	19	19	19

	ASIP	Correlation Coefficient	-.278	1.000	-.202
		Sig. (2-tailed)	.250	.	.407
		N	19	19	19
	MQoL- SIS	Correlation Coefficient	.311	-.202	1.000
		Sig. (2-tailed)	.194	.407	.
		N	19	19	19

3. Spearman Correlation by severity of decrease in intelligibility

Mild decrease in intelligibility

Correlations[a]

			Word Intelligibility Score	Sentence Intelligibility Score	Functional Communication Scale
Spearman's rho	Word Intelligibility Score	Correlation Coefficient	1.000	.779**	.409*
		Sig. (2-tailed)	.	.000	.038
		N	26	26	26
	Sentence Intelligibility Score	Correlation Coefficient	.779**	1.000	.326
		Sig. (2-tailed)	.000	.	.104
		N	26	26	26
	Functional Communication Scale	Correlation Coefficient	.409*	.326	1.000
		Sig. (2-tailed)	.038	.104	.
		N	26	26	26

	SEIQoL-DW Index Score	Correlation Coefficient	.307	.043	.421*
		Sig. (2-tailed)	.128	.836	.032
		N	26	26	26
	ASIP	Correlation Coefficient	-.110	-.077	-.586**
		Sig. (2-tailed)	.593	.708	.002
		N	26	26	26
	MQoL- SIS	Correlation Coefficient	.231	.125	.281
		Sig. (2-tailed)	.266	.550	.174
		N	25	25	25

Correlations[a]

			SEIQoL-DW Index Score	ASIP	MQoL- SIS
Spearman's rho	Word Intelligibility Score	Correlation Coefficient	.307	-.110	.231
		Sig. (2-tailed)	.128	.593	.266
		N	26	26	25
	Sentence Intelligibility Score	Correlation Coefficient	.043	-.077	.125
		Sig. (2-tailed)	.836	.708	.550
		N	26	26	25
	Functional	Correlation Coefficient	.421*	-.586**	.281

	Communication Scale	Sig. (2-tailed)	.032	.002	.174
		N	26	26	25
	SEIQoL-DW Index Score	Correlation Coefficient	1.000	-.172	.258
		Sig. (2-tailed)	.	.400	.212
		N	26	26	25
	ASIP	Correlation Coefficient	-.172	1.000	-.583**
		Sig. (2-tailed)	.400	.	.002
		N	26	26	25
	MQoL- SIS	Correlation Coefficient	.258	-.583**	1.000
		Sig. (2-tailed)	.212	.002	.
		N	25	25	25

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

a. Dysarthria Severity = mild

Moderate to severe decrease in intelligibility

Correlations[a]

			Word Intelligibility Score	Sentence Intelligibility Score	Functional Communication Scale
Spearman's rho	Word Intelligibility Score	Correlation Coefficient	1.000	.524	.467
		Sig. (2-tailed)	.	.183	.243
		N	8	8	8
	Sentence Intelligibility Score	Correlation Coefficient	.524	1.000	.443
		Sig. (2-tailed)	.183	.	.272
		N	8	8	8
	Functional Communication Scale	Correlation Coefficient	.467	.443	1.000
		Sig. (2-tailed)	.243	.272	.
		N	8	8	8
	SEIQoL-DW Index Score	Correlation Coefficient	.036	.536	-.288
		Sig. (2-tailed)	.939	.215	.531
		N	7	7	7

	ASIP	Correlation Coefficient	-.881**	-.595	-.168
		Sig. (2-tailed)	.004	.120	.691
		N	8	8	8
	MQoL- SIS	Correlation Coefficient	.013	.651	.263
		Sig. (2-tailed)	.976	.080	.529
		N	8	8	8

Correlations[a]

			SEIQoL-DW Index Score	ASIP	MQoL- SIS
Spearman's rho	Word Intelligibility Score	Correlation Coefficient	.036	-.881**	.013
		Sig. (2-tailed)	.939	.004	.976
		N	7	8	8
	Sentence Intelligibility Score	Correlation Coefficient	.536	-.595	.651
		Sig. (2-tailed)	.215	.120	.080
		N	7	8	8
	Functional Communication Scale	Correlation Coefficient	-.288	-.168	.263
		Sig. (2-tailed)	.531	.691	.529
		N	7	8	8
	SEIQoL-DW Index Score	Correlation Coefficient	1.000	-.286	.355
		Sig. (2-tailed)	.	.535	.435

	N	7	7	7
ASIP	Correlation Coefficient	-.286	1.000	-.294
	Sig. (2-tailed)	.535	.	.480
	N	7	8	8
MQoL- SIS	Correlation Coefficient	.355	-.294	1.000
	Sig. (2-tailed)	.435	.480	.
	N	7	8	8

**. Correlation is significant at the 0.01 level (2-tailed).

Caregiver and patient Intraclass Correaltion Coefficient scores

1. FCS

Reliability Statistics

Cronbach's Alpha	N of Items
.797	2

Intraclass Correlation Coefficient

	Intraclass Correlation[b]	95% Confidence Interval		F Test with True Value 0			
		Lower Bound	Upper Bound	Value	df1	df2	Sig
Single Measures	.661[a]	.423	.814	4.927	33	33	.000
Average Measures	.796[c]	.595	.898	4.927	33	33	.000

Two-way mixed effects model where people effects are random and measures effects are fixed.

a. The estimator is the same, whether the interaction effect is present or not.

b. Type A intraclass correlation coefficients using an absolute agreement definition.

c. This estimate is computed assuming the interaction effect is absent, because it is not estimable otherwise.

2. Overall ASIP

Reliability Statistics

Cronbach's Alpha	N of Items
.710	2

Intraclass Correlation Coefficient

	Intraclass Correlation[b]	95% Confidence Interval		F Test with True Value 0			
		Lower Bound	Upper Bound	Value	df1	df2	Sig
Single Measures	.510[a]	.206	.722	3.451	33	33	.000
Average Measures	.675[c]	.341	.839	3.451	33	33	.000

Two-way mixed effects model where people effects are random and measures effects are fixed.

a. The estimator is the same, whether the interaction effect is present or not.

b. Type A intraclass correlation coefficients using an absolute agreement definition.

c. This estimate is computed assuming the interaction effect is absent, because it is not estimable otherwise.

3. Physical ASIP

Reliability Statistics

Cronbach's Alpha	N of Items
.809	2

Intraclass Correlation Coefficient

	Intraclass Correlation[b]	95% Confidence Interval		F Test with True Value 0			
		Lower Bound	Upper Bound	Value	df1	df2	Sig
Single Measures	.666[a]	.430	.818	5.242	33	33	.000
Average Measures	.800[c]	.602	.900	5.242	33	33	.000

4. Psychological ASIP

Reliability Statistics

Cronbach's Alpha	N of Items
.824	2

Intraclass Correlation Coefficient

	Intraclass Correlation[b]	95% Confidence Interval		F Test with True Value 0			
		Lower Bound	Upper Bound	Value	df1	df2	Sig
Single Measures	.640[a]	.312	.817	5.670	33	33	.000
Average Measures	.781[c]	.476	.900	5.670	33	33	.000

5. Independent ASIP

6.

Reliability Statistics

Cronbach's Alpha	N of Items
.571	2

Intraclass Correlation Coefficient

	Intraclass Correlation[b]	95% Confidence Interval		F Test with True Value 0			
		Lower Bound	Upper Bound	Value	df1	df2	Sig
Single Measures	.387[a]	.075	.635	2.329	33	33	.009
Average Measures	.559[c]	.139	.777	2.329	33	33	.009

APPENDIX 19 – CHARTING OF PART TWO - EXAMPLE

Mild decrease in intelligibility

2. Desire to maintain identity		
2.1. Self image	**2.2. Others perception**	**2.3. Need to maintain activity (work, home, hobbies, travel, sports)**
"I feel that I used to be an achieving person now I am a burden on my husband, family, and daughter. I try to find anyway to be independent. I am emotionally tired and exhausted I cannot be normal I feel that I am living just as a picture I am sitting and watching my life go by" (FAB/PD/female/53years) - change in the way thy view themselves from a productive person to a burden and having no control on life	"my relationship with people has decreased. Actually it hasn't decreased I started feeling that I am a burden on society and I am the kind of person who doesn't want to be a burden on anyone. I try to avoid embarrassment in anyway possible" (NSM/Juvenile PD/male/30years) - Feeling like a burden on others in society	"I go on trips and visits with other retirees. Thank god I do not feel my life is empty" (SSG/PD/male/55 years) - Need to maintain activities (going on trips and visiting friends)
"I used to fix my hair on my own, put my makeup on my own now I have to wait for someone to come comb my hair. My hands are tied dependent on others. I used to enjoy cooking, now I cannot even go into the kitchen" (KOM/PD/female/42years) - Self-image was an important part of who she was before the disabilities now she is dependent on others	"people have become kinder, but this is not a good thing. For example you do not want your parents to worry about all the time and treat you differently from the other members of your family. My family do not live here they live in Madina [different city], whenever they come to visit they always say let her sleep, let her rest this may affect other members of the family" (SGS/PD/female/39years) - When the family treats her different from other members of the family it makes her feel different-somewhat like a burden	"Surfing the web, readings are things that I can still enjoy doing. I also go to the market and stores with my children" (SSG/PD/male/55years) - Continue with activities surf the web and go out with family

“The fatigue and muscle spasticity in my face is restricting. Not like before the disease. My face and general image were normal” (MNM/MS/female 25years) - Changes in appearance due to the disease.	“People’s kindness and help has increased significantly but this hurts me a lot, it reminds me that I am different”. (FAB/PD/female/53years) - People’s kindness has increased but it is painful	“Work has changed significantly. I do not go to work regularly. This has affected my achievements and my satisfaction with work” (AMB/PD/male/66years) - Not achieving at work decreases level of satisfaction
“weakness in one leg has affected my movement and climbing the stairs. I go out less often. I do not want to walk with a cane, I do not want people to see that I need help” (SAG/MS/male 39) - do not want people to see me walking with a cane	“the disease has affected my job a lot any my relationship with my students. I feel that they think that I am afraid or nervous [due to tremor in hands]” (SGS/PD/female/39years) -As a teacher it affects the way job is carried out and relationship with students	“Due to my disease I go to work on a part time basis. My energy level at work has been affected. They give me less work and less responsibilities which has had a negative effect on my satisfaction with my work” (ATK/PD/male/58years) - changed to a part time job decreased responsibility and therefore decreased satisfaction
“I feel that I move like a machine. Even patients with cancer can move easily they do not look like they are sick. But for me I feel disabled I feel tied up and do not have any independence... then worst thing in my life is movement. When you are able to move you feel like a human being not tied up like a corps” (FAB/PD/female/53) - Feel that she has no control over life and due to the disease feels like a machine	“I do not like to be a burden on anyone even if the person in front of me didn’t make me feel that I am. I am afraid that people will start avoiding me in the future” (NSM/Juvenile PD/male/30years) - Do not like feeling like a burden, afraid of the consequences people might start avoiding him	“Now I accept the situation I am in. if I think about fatigue I would never go out. I travel everywhere and live with my disease” (AMB/PD/male/66years) - Accept the disease and continue to lead as much of a normal life as possible – continue to travel and socialise (big part of life before the disease)
“I do not want people to see me like this until I’m back to my usual appearance” (MNM/MS/female/25years) [patient with facial palsy after MS attack] - Remitting and relapsing MS does not want people to see her with facial palsy	“Everything is worse. I see my children hurting for my pain. They try to take me out with then but I refuse. I feel that people stare at me so I do not like to go out” (SHK/PD/male/50years) - Feels that people around her feel sorry for her and hurt for her pain	“I participate in conversations and joking when meeting with friends and family in large groups. But when I need to drink, eat, or leave I get a moment of sadness, I remember the past but thank god I do not spend all my day depressed and sad” (AAA/ALS-MND/male/59years) -Sad when reminded about life before the disease especially when they can’t be independent

	“Finances are not a problem but the way the people look at you, I feel that they feel sorry for me” (AAA/ALS-MND/male/59years) - The perception that others feel sorry for him	“cleaning the house and work around the house has decreased significantly. I used to clean all the house once a week now I do it once a month. I feel that my daughters and husband notice this but say nothing. I used to enjoy cooking now I do not have the energy. This has affected me emotionally I feel that I neglect my responsibilities” (NSB/PD/female/47) - the need to maintain role at home and carryout household chores
	“I used to meet with friends several times a week, friends from work. I go sometimes but most of the time I don’t. When you feel that you are in the middle of people who are different from you in health you feel that you are not in the right place. (ATK/PD/male/58years) - Feeling different from other people restricts socialising and carryout usual activities	“if I have the energy to go into the kitchen and cook I feel that I have accomplished something. I like to embroidery it was one of my hobbies that I sometime still do” (NSB/PD/female/47) - Happy when able to carryout usual activities such as cooking

7. Communication			
7.1. Changes in speech (articulation, voice)	**7.2. Interaction**	**7.3. Emotions and communication**	**7.4. Impact of communication disorder**
	“the whole disease upsets me and affects my quality of life. Dysfluencies in my speech when they start I do not want to speak anymore with anyone. I lock myself in my room at home and I do not want to talk to anyone” (SHK/PD/male/50years) - When speech becomes dysfluent interaction is affected. He doesn’t want to interact with anyone.	“I get upset when people do not understand me or asks me to repeat. This hurts me” (NSM/Juvenile PD/male/30years) - Upset when asked to repeat	
		“I get upset because my speech is not normal” (LMS/MS/female/30years) - Feeling upset in relation to speech changes	
“I feel I have a problem in my speech which is mainly in slow speech and my voice is low. When I answer the phone people usually say we cannot understand you easily. A lot of people ask me to raise my voice”(ATK/PD/male/58years) - changes in speech and decreased comprehension especially when answering the phone	“when you are in a group you have to participate in the conversation and when the conversation is directed towards me I feel self-conscious. I feel that my tongue is heavy and therefore I try to avoid questions and remain quiet most of the time” (NSM/Juvenile PD/male/30years) - Self conscious when interacting and having a conversation with a group of people	“before people used to understand me now they don’t. I have to repeat myself more than once so they can understand and this has affected my quality of life. It is something that is upsetting” (MHM/ALS-MND/male/52years) - Upset when not understood	“my problem is when communicating with a group of strangers not at work or with my family. A month ago I went to a funeral I got so anxious and started to sweat. I was so ashamed that I just left” (SHK/PD/male/50years)

“I feel that I have a problem in communication and speech but people do not notice it. Some people who are close do notice it like my sister. If I speak very fast I notice dysfluencies and some of the speech sounds are affected. This doesn’t upset me because it is not clear to people, it is most obvious when I speak while upset” (SGS/female/39years) - Some changes in speech output in certain situations. It is still not obvious to everyone except the person and people who are close to him	“if a person is used to my speech its is easier for me. There are certain words that are difficult for me to pronounce my communication partner is familiar with them and knows what I will say” (NSM/Juvenile PD/male/30years) - the ease of having a conversation depends in the communication partner	“speech has been significantly affected, when I speak the person in front of me does not understand. They tell me to raise my voice so I try to raise my voice and repeat what I said this upsets me. Speech is difficult” (KIH/PD/male/61years) - upset when not understood and asked to repeat	
“decrease in speech volume has occurred with the disease. Speech itself is not a problem but the decrease in volume has affected my communication at work” (MJS/PD/73years) - changes in speech have affected communication in particular situations	“my problem is when communicating with a group of strangers not at work or with my family. A month ago I went to a funeral I got so anxious and started to sweat. I was so ashamed that I just left” (SHK/PD/male/50years) - interaction and having a conversation depends on partner and environment		
	“people who are close to me are able to understand me but strangers can’t and also I do not like socialise a lot due to this” (LMS/MS/female/30years) - ease of having a conversation depends on communication partner		

Moderate-Severe decrease in intelligibility

5. Social Life				
5.1. Restricted due to physical disabilities	**5.2. Restricted due to communication disabilities**	**5.3. Restricted due to feelings of embarrassment**	**5.4. More selective/ limited**	**5.5. Enjoy doing**
"I feel claustrophobic/upset from spending most of my time at home I want to be able to go out, I do not like staying at home… I cannot go out because of movement difficulties and my speech, no one can understand me" (IAJ/PD/female/55years) - Do not go out due to movement difficulties lead to the feeling of being claustrophobic	"I feel claustrophobic/upset from spending most of my time at home I want to be able to go out, I do not like staying at home… I cannot go out because of movement difficulties and my speech, no one can understand me" (IAJ/PD/female/55years) - Do not go out or interact due to communication difficulties leads to the feeling of being claustrophobic	"I am ashamed to see people and socialise with them because of my speech. But no one has ever mentioned it, it is just me" (MRA/ALS-MND/male/52years) - Does not like to socialise due to speech problems, feels shame.	"My social life has changed, I used to go out all the time. Now it is limited to Friday prayer at the mosque and visiting my father" (FSJ/ALS-MND/male/51years) - social life is more selective and limited	"I enjoy visiting my friends or my friends visiting me. I also like going shopping" (IAJ/PD/female/55years) - things they enjoy doing (visiting friends and shopping)
"because I cannot climb the stairs, go outside or go to stores and different places all the things in my life have diminished" (SDQ/ALS-MND/male/65years) - Everything in life has decreased due restrictions related to movement	"I used to be an Imam at the mosque and I had other activities. I had to leave them when my speech started to change. My life is 95% restricted to my home" (KMW/familial ALS-MND/male/44years) - Changes in speech affected going to public places and restricted life to the home		"before people used to visit me a lot and have coffee with me. Now no one comes anymore" (MRA/ALS-MND/male/52years) - restricted social life, no more visiting. Isolation	"I enjoy listening to prayer calls. I also enjoy when my children are all with me or when my friends visit. I like to speak and joke with them" (MMZ/PD/male/65years) - Enjoy friends and family speaking with them and joking

				“before I used to go out a lot on trips, visits, to my farm but now my life is more restricted at home with my wife and children. I am content” (SDQ/ALS-MND/male/65years) - travel and trips have decreased and life is restricted to the home but I am content
				“Socializing with people makes me happy” (MAM/PD/male/60years) - enjoy socializing
				“I am a social person. My social life has not changed, I used to visit my friends now they visit me” (MMZ/PD/male/65years) -ability to adapt to change and enjoy socializing