
**Speech intelligibility and marital communication
in Motor Neuron Disease**

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“In all change there is loss. For anyone undergoing catastrophic change, it is the loss of the expected future that is grieved so deeply...”

(Luterman, 1996, p. 48-49)

***Dedicated to Taedes, Riemer and Leroux –
The men in my life!***

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ABSTRACT

The onset of a progressive, fatal illness such as Motor Neuron Disease (MND) inevitably results in physical and communication disabilities that impinge on the individuals' ability to remain functionally independent. The loss of speech as a result of dysarthria, a motor speech disorder, is one of the most profound changes that the person with MND will experience. The decline in the individuals' speech intelligibility, that negatively influences communication effectiveness, implies that in 80% of cases alternative and augmentative communication (AAC) strategies are required to support the daily communication needs of individuals with MND.

The dyadic nature of chronic illness implies that multiple aspects of one of the most important adult relationships, marriage, will be affected. Roles and responsibilities performed by each member of the couple will continually change as the disease progresses. The emotional trauma of adjusting to the unavoidable alteration in their relationship elicits strong emotions such as guilt, anger and frustration. Communication is one of the most constructive ways of dealing with these emotions. The ability of spouses to convey their innermost thoughts, feelings and intimacy through communicative interaction is vitally important in marital communication.

The aim of this study was to compare how persons with MND and their spouses perceive changes in their marital communication in relation to the deteriorating speech of persons with MND. Fourteen couples divided into two participant groups, persons with MND and spouses, participated in this non-experimental correlational research study. Data was collected during three visits at six-monthly intervals over a 12 month period. At each of these visits both participant groups completed a variety of objective and subjective measures, of which twenty percent were interratered by independent raters.

Results confirmed the inevitable decline in speech intelligibility of persons with MND across the disease progression. The persons with MND did not report a change in their perception of marital communication although their spouses indicated a statistically

significant decrease between the first and last visits. Interestingly, there was no statistically significant relationship between the deteriorating speech of persons with MND and the couples' perception of marital communication, confirming that marital communication was not influenced by decreased speech intelligibility.

Key words: Amyotrophic Lateral Sclerosis (ALS), Augmentative and Alternative Communication (AAC), Closeness, Communication, Communication effectiveness, Dysarthria, Marital communication, Motor Neuron Disease (MND), Progressive neurodegenerative disease, Speech intelligibility, Spouses.

OPSOMMING

Die diagnose van Motor Neuron Siekte (MNS), 'n progressiewe, noodlottige siekte het die onvermydelike impak op individue se vermoë om funksioneel onafhanklik te wees as gevolg van fisiese- en kommunikasie gestremdhede. Die verlies van spraak as gevolg van disartrie, 'n motoriese spraakafwyking, word beskou as een van die mees diepgaande veranderinge wat hierdie individue sal ervaar. Die afname in spraakverstaanbaarheid beïnvloed ook kommunikasie effektiwiteit, en daar is bevind dat in 80% van gevalle aanvullende en alternatiewe kommunikasie (AAK) strategieë ingespan moet word om aan die kommunikasie behoeftes van individue met MNS te voldoen.

Die tweeledige natuur van kroniese siektes impliseer dat veelvoudige aspekte van die huwelik affekteer sal word. Die rolle en verantwoordelikhede van albei eggenote sal deurentyd verander met die verloop van die siekte. Die emosionele trauma wat deur die egpaar ervaar word as gevolg van die veranderinge in hulle verhouding, ontlok emosies soos frustrasie, skuldgevoelens en gebelgdheid. Daar is gevind dat kommunikasie een van die mees konstruktiewe wyses is om hierdie emosies aan te spreek. Die vermoë van egpare om deur kommunikasie hulle diepste gevoelens, gedagtes en intimiteit aan mekaar te ontbloot, is essensieël vir suksesvolle huwelikskommunikasie.

Die doel van die studie was om die verband tussen die spraak agteruitgang van persone met MNS en die egpare se persepsie van huwelikskommunikasie te bepaal. Veertien egpare, verdeel in twee groepe (die persone met MNS en eggenote) het deelgeneem in hierdie nie-eksperimentele korrelasie studie. Data is ingesamel oor 'n periode van twaalf maande tydens drie besoeke met ses-maandelike tussenposes. Tydens hierdie besoeke het die deelnemers verskeie objektiewe en subjektiewe meetinstrumente voltooi, waarvan twintig persent deur 'n onafhanklike evalueerder geëvalueer is.

Resultate het die onafwendbare afname in spraakverstaanbaarheid van die persone met MNS bevestig. Die persone met MNS het aangedui dat hulle persepsie van huwelikskommunikasie nie beduidend verander het nie. Die eggenote het wel aangedui

dat daar 'n statisties betekenisvolle verskil was in hulle persepsie van huwelikskommunikasie tussen die eerste en laaste besoeke. Die interessantste bevinding was dat daar nie 'n statisties betekenisvolle verband tussen die spraak agteruitgang van persone met MNS en die persepsie van huwelikskommunikasie van die egpare was nie. Hierdie bevinding bevestig dat huwelikskommunikasie nie deur die afname in spraakverstaanbaarheid beïnvloed word nie.

Sleutel woorde: Aanvullende en Alternatiewe Kommunikasie (AAK), Disartrie, Eggenote, Huwelikskommunikasie, Kommunikasie, Kommunikasie effektiwiteit, Motor Neuron Siekte (MNS), Nabyheid, Progressiewe neurodegeneratiewe siekte, Spraakverstaanbaarheid.

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CHAPTER 1

ORIENTATION

1.1 INTRODUCTION

This chapter provides an orientation to the research. It encompasses background information, the purpose of the research, definitions of terms used within the context of the research, an explanation of the abbreviations used and, finally, an outline of the each of the chapters in the study.

1.2 BACKGROUND

The diagnosis of an acquired illness such as Motor Neuron Disease (MND) during adulthood has a dramatic effect on the physical and psychosocial well-being of the individual. Progressive muscular weakness experienced by the person with MND impacts on his/her ability to walk, perform activities of daily living, speak, to swallow and eventually to breathe independently. The performance of social roles and responsibilities therefore has to be greatly modified or abandoned by the individual, as these roles and duties formerly fulfilled with ease can no longer be performed. Relinquishing important life roles (such as breadwinner, homemaker, active family member, and spouse) inevitably create an imbalance among these roles. The resultant excessive commitment to one role may be detrimental to the feelings of psychosocial well-being of the individual. Depression, low self-esteem, anxiety and hopelessness are frequently reported in the literature as impacting on the psychological well-being of persons with MND. In addition, anecdotal reports by persons with MND highlight decreased satisfaction in social interaction as a result of declining communication abilities.

The aftermath of MND not only radically alters the lives of individuals with MND but also those of their family members. This holds particularly true for spouses of persons with MND. The spouses must often make significant changes in their own lives, when assuming the constant burden of primary care responsibilities in order to meet their spouse's new

needs and changing lifestyle. Role changes, increased responsibilities such as managing finances and providing medical care, depression, anxiety, stress, and social isolation are reported in the literature.

These changes, experienced by both the persons with MND and their spouses, will inevitably present challenges to the marital relationship. Spousal responsibilities will increase as a result of the person with MND's declining physical abilities. The time shared by the couple will often be consumed by fulfilling care-giving needs such as washing, dressing, and eating. Experiencing the loss of 'little things' such as holding hands, attending social events together, working side by side and a spontaneous hug, contribute to couples' personal reports describing their fear of love fragmenting, and being eroded by the demands of caring.

Research on the psychosocial impact of acquired, sudden-onset disorders such as traumatic brain injury during adulthood suggests that the communicative loss significantly impacts on the roles that people assume within the marital relationship (Doyle, Kennedy, Jausalaitis, & Phillips, 2000; Blais & Boisvert, 2007). In comparison to these disorders, the progressive nature of MND involves many continuous losses that require a constant process of adapting to one loss as another presents itself. The final loss, as described by Mathy, Yorkston and Gutmann (2000) is the loss of speech. Especially for persons with bulbar onset MND this implies that as the disease progresses, they might move from communicating through speech to communicating through the use of augmentative and alternative communication (AAC) or eventually another person (Murphy, 2004). Reduced speech intelligibility in MND as a result of dysarthria therefore critically impacts on social participation, and for many persons with MND this signifies a loss of access to intimate talking.

It is confirmed by various studies that the main purpose of communication for all persons with communication disorders and their spouses is to nurture their personal relationships and maintain social closeness (Locke, 1998; Lyon, 1998; Murphy, 2004). It is widely recognized that clear and accurate communication between spouses is considered essential in maintaining relationships and is an expected element in marital roles. Frustration as a

result of communication breakdowns and limited verbal communication, especially in the later stages of disease progression, are reported to influence the level of intimacy experienced by couples. Bob Williams' (2000) quotation: 'The silence of speechlessness is never golden' (p. 255) aptly describes reported perceptions of widening gaps in relationship and decreased closeness as a result of impaired speech intelligibility.

The impact of physical and psychosocial problems on marital relationships where one spouse has MND has been investigated. Although it has been established that "communication plays a central role in marriage" (Burlison & Denton, 1997; p. 884), little research is available on the association between deteriorating speech in MND and marital communication.

The aim of this study is therefore to compare how persons with MND and their spouses perceive changes in their marital communication in relation to the deteriorating speech of persons with MND.

1.3 DEFINITION OF TERMS

The following frequently used terms need some clarification within the context of the study:

Augmentative and alternative communication

This term refers to an area of clinical practice that attempts to compensate for the impairment and disability patterns of individuals with little or no functional speech (Beukelman & Mirenda, 2005; Lloyd, Fuller, & Arvidson, 1997). Augmentative and alternative communication (AAC) strategies employed by individuals with MND to enhance and facilitate communication varies and ranges from unaided strategies (e.g. gestures, facial expression), aided low technology strategies (e.g. topic and alphabet cues, alphabet boards) to high technology strategies such as sophisticated computer systems with digitized speech (Fried-Oken, et al., 2006; Beukelman, Ball, & Fager, 2008).

Closeness

Closeness is a multidimensional construct consisting of the frequency of time spent together by individuals, the diversity of interactions engaged in together and the degree of influence the other has over one's plans, decisions and activities (Aron, Aron, & Smollan, 1992).

Communication

Communication is a dynamic and complex process and is defined by the National Joint Committee for the Communication Needs of Persons with Severe Disabilities (1992) as:

Any act by which one person gives to or receives from another person, information about that person's needs, desires, perceptions, knowledge, or affective states. Communication may be intentional or unintentional, may involve conventional or unconventional signals, may take linguistic or non-linguistic forms, and may occur through spoken or other modes (p.2).

Communication Effectiveness

Communication effectiveness is the ability of an individual to produce a message that has the intended result (Burlison & Denton, 1997; Hustad, 1999). Individuals with MND are particularly vulnerable to decreased communication effectiveness as a result of declining speech intelligibility and consequently a reduction in their ability to participate in communication interactions (Ball, Beukelman, & Pattee, 2004).

Dysarthria

Dysarthria is the collective name for a group of speech disorders that results from disturbances in muscular control (e.g. weakness, slowness, or incoordination) of the speech mechanism due to damage to the central or peripheral nervous system. This term includes coexisting neurogenic disorders in all the basic processes of speech: respiration, phonation, resonance, articulation, and prosody (Darley, Aronson & Brown, 1969). The speech

characteristics of individuals with MND can be classified as mixed dysarthria, as symptoms related to both spastic and flaccid dysarthria may be present throughout the course of the disease (Duffy, 1995; Freed, 2000).

Marital communication

The positive relationship between communication and a good marital relationship has been established as marital communication involves the critical ability of both members of the couple to listen to and understand each other, and ultimately express themselves clearly and accurately (Beach & Arias, 1989; Kahn, 1970; Navran, 1967).

Motor Neuron Disease

Motor Neuron Disease (MND) is an adult onset, progressive, degenerative neurological disease of unknown etiology that affects the motor neurons of the brain and spinal cord. (Kotchoubey, Lang, Winter, & Birbaumer, 2003). The types of MND are categorized as either bulbar (brainstem and upper motor neurons), spinal (lower motor neurons) or mixed (bulbar and spinal cord involvement).

Individuals with ***bulbar onset MND*** usually experience dysarthria early in the disease process. The deterioration of these individuals' speech and swallowing function may be rapid. As motor impairments in their trunks and limbs are generally less extensive until much later in the disease process, they are usually able to control direct selection AAC techniques using their hands and fingers (Beukelman & Mirenda, 2005).

Individuals with ***spinal onset MND*** usually present with predominant involvement of the spine and they may retain normal to mildly dysarthric speech for an extensive period despite extensive motor impairments in their trunks and limbs. These individuals may require an augmented writing system before a conversational system is necessary (Beukelman & Mirenda, 2005).

Speech intelligibility

Speech intelligibility is defined as the accuracy with which a spoken utterance is conveyed by the speaker and understood by the listener (Yorkston, Beukelman, Strand, & Bell, 1999)

and is seen as a significant factor in determining whether an individual is an effective communicator within a conversation (Yunusova, Weismer, Kent, & Rusche, 2005). Speech intelligibility is one of the critical aspects in the assessment and monitoring of speech in persons with MND and encompasses a variety of factors, including compensatory strategies employed by the speaker to facilitate listener understanding and the cumulative effects of the impairment (Yorkston, et al., 1999).

1.4 ABBREVIATIONS

| | | |
|--------|---|--|
| AAC | – | Augmentative and Alternative Communication |
| ALS | – | Amyotrophic Lateral Sclerosis |
| ALSSS | – | Amyotrophic Lateral Sclerosis Severity Scale |
| CETI-M | – | Modified Communication Effectiveness Index |
| IOS | – | Inclusion of Others in the Self |
| MND | – | Motor Neuron Disease |
| PCI | – | Primary Communication Inventory |
| PMND | – | Person with MND |
| SIT | – | Sentence Intelligibility Test |
| TBI | – | Traumatic Brain Injury |

1.5 CHAPTER OUTLINES

The research will be presented in five chapters. **Chapter 1** provides a basic orientation and motivation for the study; the definitions of terms used within the framework of the research, the abbreviations used and lastly an outline of the chapters in the study.

In **Chapter 2** the conceptual framework for the study is provided. It commences with a description of MND and its impact on the lives of the individuals living with MND, with specific reference to the decline in physical and communication abilities. This discussion continues with the losses experienced by the individual as a result of MND. This is followed by a discussion on how the lives of the spouses are affected. The importance of

communication in moderating the effects of a chronic disability is described and the chapter concludes with a discussion on the effects of communication disabilities on the marital relationship.

The methodology is set out in **Chapter 3** and includes a description of the aims, sub-aims and research design. This followed by a presentation and evaluation of the pilot study, and thereafter the main study. Finally, a description of the participants, equipment, measuring instruments, and data collection procedures is provided, as well as of the data analysis and statistical procedures.

Chapter 4 provides an overview of the results obtained and includes a critical discussion of the results. This chapter commences with a presentation of the interrater reliability results. The chapter next focuses on reporting the findings in relation to the aims of the study. Data is organized, analyzed and interpreted so that conclusions can be drawn regarding the association between the deteriorating speech of persons with MND and the couples' perception of marital communication across the disease progression. The discussion of results is integrated throughout this chapter. Factors contributing towards the outcomes of the research are suggested.

In **Chapter 5** the conclusions and critical evaluation of the study are presented, followed by the implications and recommendations for future research.

The **appendices** supply important information for the understanding of the data collection and analysis procedures, and thus the replication of the study.

1.6 SUMMARY

This chapter provided the rationale for the study by describing the background information that led to its development, as well as a description of the purpose of the study. It included a definition of terms used within the context of the research, together with an explanation of the abbreviations used. The chapter concluded with an outline for the different chapters by which the aims of the study are described and realized.

CHAPTER 2

LITERATURE REVIEW AND PROBLEM STATEMENT

2.1 INTRODUCTION

The life of adults with acquired disorders and those of their spouses are irreversibly altered as a consequence of the onset of a progressive, degenerative illness such as MND. The purpose of this chapter is to provide an overview of the literature that will serve as the conceptual framework for this study. The chapter commences with a description of MND and how it impedes an individual's physical and communication abilities, with more specific reference to speech intelligibility and communication effectiveness. A description of the losses experienced by the person with MND and the psychosocial impact it has, is then followed by a discussion of the impact of all these aspects on the marital relationship. The importance of communication in moderating the effects of a chronic disability will also be presented.

2.2 DESCRIPTION OF MND

MND is a progressive neurological disease which usually results in severe physical disability involving all four limbs, speech, swallowing and ultimately breathing (Kotchoubey et al., 2003; Miglioretti, Mazzini, Oggioni, Testa, & Monaco, 2008; Young & McNicoll, 1998). The disease was first described by Jean-Martin Charcot in 1874, who named it amyotrophic lateral sclerosis (ALS) (McLeod & Clarke, 2007). The term, ALS, now classifies the most common form of the illness and is often used synonymously with MND (McLeod & Clarke, 2007).

The cause of MND is unknown and has an incidence of between 1.5 and 2.5 per 100,000 of the population worldwide (Freed, 2000; Logroscino et al., 2008; Worms, 2001) with the average age of onset at 65 years and a greater incidence in males (Freed, 2000; Logroscino et al., 2008). Life expectancy ranges between two and five years after onset of the first symptoms (Doyle & Phillips, 2001) with some studies reporting a small number of persons

with MND having lived for ten years or more (Young & McNicoll, 1998). People with MND usually do not show any changes in cognitive abilities (Young & McNicoll, 1998) although evidence of a variety of cognitive and language difficulties (e.g., insight, concentration and ability to change topics) has been described (Abrahams et al., 1997; Abrahams, Leigh, & Goldstein, 2005; Goldstein, Atkins, & Leigh, 2002; Mathy et al., 2000; Neary, Snowden, & Mann, 2000; Strong et al., 1999).

MND is characterized by deficits in either the lower motor neurons (e.g. weakness, wasting and fasciculation) or the upper motor neurons (e.g. spasticity, pseudo-bulbar features), but usually results from a combination of both (Freed, 2000; Leigh et al., 2003; Mathy et al., 2000; McLeod & Clarke, 2007). The rate of progression is highly variable and this progression across the functional modalities of speech, mobility and ability to use upper limbs for activities of daily living has been documented by Riviere, Meininger, Zeisser and Munsat (1998) (See Appendix A). In the early stage (State 1), there is a mild deficit in only one of three regions (speech, arms, legs) and the individual remains functionally independent in speech, upper extremities for daily living and ambulation. As the disease progresses, the individuals' abilities to function independently is compromised until when, at the final stage (State 4), the person with MND has no functional use of at least two regions and moderate or no functional use of a third region. Persons with bulbar onset MND typically experience the most rapid deterioration associated with the disease while those with spinal onset are reported to experience the slowest deterioration (Ball, Beukelman, Ullman, Maassen, & Pattee, 2005).

2.3 THE IMPACT OF MND ON THE INDIVIDUAL

The Family Systems Illness model, a framework for the assessment of and intervention with families facing chronic life-threatening conditions such as MND, allows for the categorization of these conditions according to psychosocial types (Rolland, 1999). This psychosocial typology is based on broad distinctions in the pattern of onset, course, outcome, type and degree of disability and level of uncertainty, all of which will ultimately impact on the individual with MND, the spouse and the couple's relationship (Katz, 2002; Rolland, 1999).

Individuals facing a gradual onset, progressive disease such as MND, where the decline in physical and communication abilities will result in severe disability and ultimately death, require constant, protracted periods of adjustment as they are confronted with continuous losses (Lasker & Bedrosian, 2000; Mathy et al., 2000; Rolland, 1999; Sapey, 2002). Various stages of adjustment to illness are described by Charmaz (1995). The first two stages, experiencing and defining impairment and making bodily assessments and lowering expectations to reach realistic goals, are particularly pertinent to persons with MND who experience increasing physical and communication impairment.

2.3.1 Physical abilities

As the disease progresses, persons with MND will continually experience increasing *physical* impairment as a result of relentless progressive muscular weakness. Performing many activities of daily living such as walking, driving, writing, dressing, eating, swallowing and breathing will become progressively more difficult until ultimately dependence in most of these areas are inevitable (Lasker & Bedrosian, 2000). This will require a constant process of adapting to one loss of physical function before another presents itself (Mathy et al., 2000; McLeod & Clarke, 2007).

2.3.2 Communication abilities

One of the most profound changes that a person with MND will experience is the loss of speech (Fox & Sohlberg, 2000; Lasker & Bedrosian, 2000; Light, Arnold, & Clark, 2003). Speech, one of the pre-dominant forms of communication is used in every facet of our lives. The rapid decline of speech function as a result of dysarthria is common as 75% of persons with MND will reach a point where intelligible verbal communication is no longer possible (Ball et al., 2004; Freed, 2000). Dysarthria, a motor speech disorder that results from damage to the peripheral or central nervous system, is characterized by the imprecision of the movement of speech musculature (Darley et al., 1969). The type of dysarthria that individuals with MND present with depends on which motor neurons are affected: In the early, mild stages, individuals with lower motor neuron involvement will present with flaccid dysarthria, whereas those with upper motor involvement present with spastic

dysarthria. However, as the disease progresses to involve both the upper and lower motor neurons, individuals will present mixed spastic-flaccid dysarthria that will predominate throughout most of the disorder (Duffy, 1995; Freed, 2000). It has been reported that for 30% of individuals with bulbar onset MND mixed spastic-flaccid dysarthria is an early symptom (Ball et al., 2005).

The typical progression of dysarthria in individuals with MND was documented by Yorkston, Miller and Strand (1995): In the early stage (Stage 1), no obvious deficits are noticeable in an individuals' speech, but as the disease progresses, speech intelligibility becomes more compromised until when at the 5th and final stage, individuals lose all speech function. This progression of dysarthria was used by Hillel et al. (1989) as the basis to develop the speech sub-scale of the Amyotrophic Lateral Sclerosis Severity Scale (ALSSS). The ALSSS (Speech Scale) allows for accurate assessment of the functional impairment that a person with MND presents with in the area of speech (ranging from normal speech to the loss of useful speech), with speech intelligibility specifically used as the indicator of functional impairment across the disease progression (See Appendix B).

2.3.2.1 Speech intelligibility

Speech intelligibility is defined as the accuracy with which a spoken utterance is conveyed by the speaker and understood by the listener (Yorkston et al., 1999; Yunusova et al., 2005). Sentence intelligibility measures, such as the Sentence Intelligibility Test (SIT), are often used for clinical purposes in quantifying the severity of dysarthria (See Appendix C) (Ball, Willis, Beukelman, & Pattee, 2001; Hustad, 2008; Hustad & Cahill, 2003). The orthographic transcriptions of standardized speech samples are compared to 'normal' parameters. The speaking rate (in words per minute) of normal adults has been determined as 190 words per minute, and combined with the percentage of intelligible speech productions provide clinicians with an indication of individuals' communication efficiency ratio and severity of dysarthria (Yorkston, Beukelman, & Tice, 1996).

Various studies have been conducted on speech intelligibility in MND (Ball et al., 2001; Ball et al., 2004; Klasner & Yorkston, 2005; Nishio & Niimi, 2000; Strong et al., 1999; Yorkston,

Strand, Miller, Hillel, & Smith, 1993; Yorkston et al., 1996; Yorkston et al., 1999). In studies examining the speech intelligibility, speaking rate and diadochokinetic rate, no significant speech production differences were found between patients with bulbar and spinal onset MND and a control group (with dysarthria) over time. It was, however, found that diadochokinetic rate significantly declined in the MND group at 90% intelligibility (Strong et al., 1999) and supported in a similar study conducted by Nishio and Niimi (2000). This is further confirmed by other studies that revealed that regardless of the onset type (bulbar, spinal or mixed), decreased speaking rate will be evident before a decline in speech intelligibility is observed (Ball et al., 2001; Ball et al., 2004; Ball et al., 2005; Nishio & Niimi, 2000; Yorkston et al., 1993). Interestingly, it was established that individuals with spinal onset MND may experience a gradual reduction in speaking rate for an extended period, while for those with bulbar onset this period may be relatively brief (Ball et al., 2001; Yorkston et al., 1993). In both groups, a precipitous deterioration of intelligibility frequently occurred when speaking rate ranges between 100 and 125 words per minute (Ball et al., 2001; Yorkston et al., 1993). Speaking rate is, for that reason, the most effective measure to predict the loss of functional speech of persons with MND despite the traditional focus on the speech intelligibility for this purpose (Beukelman et al., 2008). Reduced speech intelligibility and speaking rate are thus significant factors in determining whether individuals are effective communicators (Ball et al., 2004; DePaul & Kent, 2000).

2.3.2.2 Communication effectiveness

Communication effectiveness, the ability of an individual to produce a message that has the intended result (Burlison & Denton, 1997; Hustad, 1999) implies that an individual has an adequate level of communication to meet important communication goals or communicative competence (Light, 1989). Communication, by nature, is interactive and does not occur in universal situations but rather in specific contexts characterized by personal communication purposes and circumstances (Burlison & Denton, 1997; Tönsing, Alant, & Lloyd, 2005). It is therefore essential to document the effectiveness of communicative interactions across a range of social communication situations. The Modified Communication Effectiveness Index (CETI-M) (Yorkston et al., 1999), a

standardized measure adapted specifically to the MND population, is often used to provide an indication of communication effectiveness (See Appendix D) (Ball et al., 2004; Ball et al., 2001). This measure is completed by both the person with MND and frequent communication partners and provides personalized evidence of individuals' communication performance in a variety of social situations. A number of studies conducted revealed that both the persons with MND and their familiar communication partners consistently agreed on the communication situations which were most difficult for the speakers with MND: They were rated to be more effective in quiet environments, whereas adverse communication situations such as noisy environments, speaking for a long time and speaking before a group were found to be the least effective (Ball et al., 2001; Ball et al., 2004)

2.3.2.3 Speech intelligibility and communication effectiveness

These studies also investigated the relationship between speech intelligibility, speaking rate and communication effectiveness in MND (Ball et al., 2001; Ball et al., 2004; Yorkston et al., 1993). A positive relationship between the decline in speech intelligibility, speaking rate and communication effectiveness as rated by speakers and familiar communication partners were confirmed. As with speaking rate, the decline in communication effectiveness preceded a decrease in speech intelligibility. This inevitable decline in the communication function of persons with MND implies that in 80% of cases alternative communication strategies are required to support the daily communication needs of persons with MND and their family (Ball et al., 2004; Murphy, 2004).

AAC strategies can preserve communication even in the face of profound motor deterioration (Mathy et al. 2000). AAC is acknowledged as best practice as supported by the Speech Scale of the Amyotrophic Lateral Sclerosis Severity Scale (ALSSS) developed by Hillel et al. (1989). AAC intervention is widely accepted among persons with MND and their families (Beukelman et al., 2008; Fried-Oken et al., 2006; Murphy, 2004). A variety of strategies are successfully used by persons with MND to facilitate communication; Unaided strategies (e.g. facial expressions, eye gaze, gestures and sign language), low technology strategies (e.g. topic and alphabet cues, alphabet boards) and high technology strategies

such as dedicated AAC devices such speech generating devices, absolute head-tracking and eye-tracking technology) (Beukelman et al., 2008; Fried-Oken et al., 2006; Murphy, 2004; Mathy et al., 2000).

Given its pre-eminence over physical abilities and function, communication is essential for the human experience (Light , 1997) and may be the single most important aspect for personal well-being. For many people communication is the key to their psychological independence even when physical dependence increases. The ability to communicate empowers them to participate in their own care, preserve some degree of control and independence while still maintaining social networks (Lubinsky, 1997). The human longing for meaningful relationships and the powerful role that communication plays in fulfilling this longing is poignantly illustrated in the words of Diamanti (2000):

I am alone in my thoughts. I am alone among other people. My identity is locked inside my mind...The inability to communicate one's own words fluently, is the greatest disability a person can have in the social circle of life (p. 98).

2.3.3 Social roles

As permanent physical and communication disability become part of everyday life, losses are reinforced on a daily basis (Katz, 2002). These diverse losses experienced by a person with MND have many consequences. In the initial stages of the disease, activities and duties previously performed with ease might require modification and might eventually as the disease progresses have to be abandoned. These changes will predictably shatter the long-established roles that an individual performs on a daily basis and consequentially impose dramatic lifestyle changes (Fox & Sohlberg, 2000; Rolland, 1994).

Research has indicated that the social roles adults perform in their daily life are placed in the five broad categories of worker, student, citizen and leisurite, roles performed during recreation and leisure activities, and family member (Fox & Sohlberg, 2000). Disability increases the amount of effort required to participate in these roles (Stuart, Lasker, & Beukelman, 2000) and one of the first roles that a person with MND has to relinquish is that of 'worker'. Decreased muscle strength and increased fatigue combined with

progressive communication difficulties impede on their ability to successfully perform their daily work which in turn lead to loss of income and position in society (Mathy et al., 2000). The opportunities to fulfil the roles of citizen, student and leisurite are also curtailed as they struggle to main independence in activities of daily living. Although important, these roles were found to be less important than fulfilling the role of family member (Brintnell, Madill, Montgomerie, & Stewin, 1992; Madill, Brintnell, Macnab, Stewin, & Fitzsimmons, 1989).

As symptoms increase and work and physical activities decrease, more importance is placed on interpersonal relationships (Young & McNicoll, 1998). It is this role of 'family member' that is reportedly most affected by an acquired disability as functional aspects of the illness impinges on participation patterns within the family (Fox & Sohlberg, 2000; Rolland, 1999). New roles and responsibilities must be established within existing family relationships: the responsibility of financially supporting the family might shift to the spouse, the direct caregiving role of the mother with small children affected and children have to take over responsibilities previously fulfilled by the affected parent. Adults with acquired communication disabilities anecdotally relate that their inability to fulfill communicative roles (e.g. within their roles of parent, friend and even patient) as the loss of access to life. Social activities become increasingly limited as friends and family find it difficult to tolerate their reduced communication ability and subsequently decrease the time spent with them (Mathy et al., 2000). This exacerbates the social isolation they already experience as a result of decreased physical abilities (McLeod & Clarke, 2007). The shift in responsibilities and excessive commitment to one role may be detrimental to the feelings of psychological well-being of the individual with MND (Fox & Sohlberg, 2000; McLeod & Clarke, 2007; Rolland, 1994, 1999; Ross & Deverell, 2004).

2.3.4 Psychosocial impact

In an extensive review of literature on the psychosocial aspects of MND, McLeod and Clarke (2007) demonstrated that a great psychological burden accompanies the experience of MND. The prevalence of depression in large sample size studies indicates a rate of between 11% and 15% (Ganzini, Johnston, & Hoffman, 1999). No evidence of direct association has,

however, been found between the loss of physical ability in general and depression (Hillemacher et al., 2004). Anxiety and levels of self-esteem were associated with the degree of physical disability and impact of illness on everyday functioning (Goldstein et al., 1998). It has been reported that persons with a chronic disabling condition, despite family members' willingness and ability to provide support and help, may feel that they are a burden (Cutrona, 2004). These feelings of inadequacy, embarrassment, frustration and helplessness are exacerbated by the presence of increasing communication difficulties (Dickson, Barbour, Brady, Clark, & Paton, 2008; Lasker & Bedrosian, 2000; Mathy et al., 2000).

Although the psychosocial effects of progressively declining abilities in mobility, activities of daily living and communication on the person with MND cannot be underestimated, it also greatly alters the life of the family (Cheung & Hocking, 2004; McLeod & Clarke, 2007; Michallet, Tètreault, & Le Dorze, 2003; O'Connor, McCabe, & Firth, 2008; Murray, Manela, Shuttleworth, & Livingston, 1997; Savundranayagam, Hummert, & Montgomery, 2005).

2.4 IMPACT OF MND ON THE MARITAL RELATIONSHIP

Chronic illness is a dyadic affair. One of the most important adult relationships, marriage, will predictably be affected by the onset of an illness such as MND. Although partners make the marriage vow 'to love and to cherish, in sickness and health', no one really expects to deal with severe disability in a spouse (Cutrona, 2004; Ross & Devereil, 2004). Multiple aspects of the couple's life will be affected and their relationship will never be the same (Rolland, 1994).

2.4.1 Experiences of the spouses

Spouses could experience intolerable strain as they most often become the primary source of emotional support and direct physical care for the person with MND (Cutrona, 2004). The demands that the spousal caregivers face can be divided into three general categories: (a) the financial expense; (b) physical demands of direct care; and (c) emotional demands (Kinsella, Cooper, Picton, & Murtagh, 1998).

The first category of demand, financial expense, is expected, as the family's income decreases when the individual with MND has to relinquish their employment. The costs of assistive technology needed for numerous life functions (e.g. wheelchairs for mobility, adaptive vehicles for transportation and respirators for mechanical ventilation) moreover decrease their already dwindling funds. This is supported by the findings of a study conducted with families of persons that suffered traumatic brain injuries reporting a decrease in income (Wells, Dywan, & Dumas, 2005).

As the disease progresses the physical care demands on the spouse will intensify (Cutrona, 2004; Rolland, 1994). The well-spouse, whose vision of the future in all probability never included caring for a severely disabled spouse, may be weighed down with the demands of taking over the ill-partner's household duties and responsibilities (Ross & Deverell, 2004). Day to day routines are disrupted as new direct caregiving tasks may evolve as the disease progresses (Rolland, 1994): Providing increasing assistance with activities of daily living, driving the ill-partner to treatments, and preparation of special meals as dysphagia becomes more pronounced, will lead to exhaustion as there are often few periods of relief from the demands of the illness (Rolland, 1999). These physical care demands may over time impose dramatic lifestyle changes on the spouse who has to live with continual role changes and adjustment as the disease progresses (Cutrona, 2004; Fox & Sohlberg, 2000; Rolland, 1994; 1999; Kowal, Johnson, & Lee, 2003).

In addition, the spouse is faced with the emotional demands of dealing with the concerns of not only their ill partner, but their own distress (Kinsella et al., 1998). The emotional demands experienced by spousal carers of persons with multiple sclerosis, a progressive neurological disease, described by Cheung and Hocking (2004), include anxiety, depression, and reduced feelings of self-esteem. This is supported by Hunt (2003) and Kinsella et al. (1998) who in addition found that caregivers of the terminally ill reported more somatic health problems and fatigue. Feelings of social isolation increase as opportunities and time for leisure activities are restricted (Murray et al., 1997). Social support for caregivers is often lacking as family, friends and healthcare providers mostly focus on the person with chronic illness, negating the spouse's need for support (Kowal et al., 2003; Murray et al., 1997).

It is evident that on an individual level both members of the couple will have to continually adjust to the illness that affects many aspects of their lives. They will experience similar psychosocial effects as they deal with their own distress and that of their partner. Facing the emotional trauma of losing their relationship elicits strong emotions from both members. Guilt, anger, resentment, frustration are often reported and couples facing the stress of chronic illness must find ways to manage these emotions (Baikie, 2002; Ross & Deverell, 2004). One of the most constructive ways of dealing with these emotions is communication (Cutrona, 2004; Rolland, 1994).

2.4.2 Moderating effect of communication in marriage

Sensitive, open and direct communication not only plays a central role in marriage (Burlinson & Denton, 1997) but is essential for couples to cope with chronic illness (Cutrona, 1996; Rolland, 1994, 1999; Ross & Deverell, 2004). One of the four purposes of communication 'social closeness', specifically relevant to this study, is vital for maintaining and nurturing this intimate relationship (Light, 1988). The transfer of personal thoughts, feelings, connectedness, and intimacy through communicative interaction is of primary importance in communicative acts of social closeness (Light, 1989; Locke, 1998).

The ability of spouses to listen, to understand each other, and to express themselves clearly and accurately is critically important in marital communication (Beach & Arias, 1989; Kahn, 1970; Navran, 1967). This is achieved by the key characteristics of marital communication, namely verbal (i.e., speech) and non-verbal communication (i.e., gestures, facial expressions and body language). Repetitive conversations are characterized by one spouse disclosing emotionally charged experiences to the other partner, who in turn reacts by listening carefully (Lewis, 1998). These conversations assist in the exploration of these experiences by understanding the spouse's subjective reality (Lewis, 1998). Non-verbal cues qualify and colour our verbal communication but can also occur independently of it all. Spouses, through their history of multiple shared interactions, are expected to become sensitive to each other's facial expressions, idiosyncratic gestures, vocalizations and feelings (Kahn, 1970). Self-exploration, self-understanding and feelings of intense closeness are therefore facilitated by communication.

The importance of the positive relationship between communication and marital satisfaction is emphasized in the literature (Beach & Arias, 1989; Blais & Boisvert, 2007; Burleson & Denton, 1997; Gordon, Baucom, Epstein, Burnett, & Rankin, 1999; Kahn, 1970; Navran, 1967; Rhoades & Stocker, 2006). A study conducted by Navran (1967) investigated the relationship between the verbal and non-verbal items on the Primary Communication Inventory and the Marital Inventory Scale (n = 48). Verbal communication was found to be a much stronger factor associated with marital satisfaction than non-verbal communication. Kahn (1970), however, postulated that without accurate non-verbal communication of intentions, attitudes and wishes, marriage could also be particularly vulnerable to marital disagreement. This was confirmed by a study conducted (n = 48 couples) by Gottman and Porterfield (1981) who established that non-verbal components of messages were more effective than verbal components in discerning distressed and non-distressed married couples. Further research confirms that couples that reported good marital satisfaction made superior use of both verbal and non-verbal communication (Beach & Arias, 1989).

Couples who report good marital satisfaction are those with communication skills that allow for daily interactions and decision-making to run smoothly, as well as the expression of emotions, thoughts and feelings. Even under the best circumstances couples often fail to achieve successful communication. Research has indicated that it is reasonable to expect that damage to couples' ability to communicate effectively would negatively impact on their relationship with each other, as communication skills are a major determinant of marital satisfaction (Blais & Boisvert, 2007; Burleson & Denton, 1997; Cutrona, 2004; Gordon et al., 1999; Lewis, 1998; Navran, 1967; Segrin & Flora, 2001).

2.4.3 Impact of negative life events on marital communication

Negative life events disrupt the couples' balance of connection, and influence the opportunity for them to communicate in the most influential way: the spoken word (Cutrona, 2004; Navran, 1967; Segrin & Flora, 2001). Being apart from each other (such as separation as a result of one spouse being incarcerated or drafted for military duty), the amount of communication is reduced and gestures, facial expressions and body language

are invisible. This reduction in both verbal and non-verbal communication may therefore very well decrease intimacy and promote misunderstanding that could result in frustration and anger as implicit expectations and desires are not fulfilled (Cutrona, 2004; Navran, 1967).

Couples' communicative competence or their ability of couples to be functionally adequate in daily communication (Light, 1989) are also disrupted by other non-normative life events such as the onset of acquired communication disorders as a result of traumatic brain injury (TBI) (Baikie, 2002; Beukelman & Garrett, 1988; Blais & Boisvert, 2007; Cutrona, 1996; Linebaugh, Kryzer, Oden, & Myers, 2008). After an initial period of recovery, clear-cut communication deficits associated with TBI will remain and may include cognitive-communication disorders, specific language impairment and motor speech disorders (Doyle et al., 2000). These disorders, will, depending on the impairment, directly affect the use of language; as verbal output may be disorganized and tangential, or word retrieval and fluency may be disrupted. Verbal expression could be further compromised if motor speech disorders such as dysarthria and apraxia are present. Individuals with TBI are consequently more passive in conversation and show less interest in their communication (Blais & Boisvert, 2000). These difficulties will inevitably reduce the ability of individuals with TBI to participate successfully in marital communication interactions and spouses often have to assume more responsibility during these interactions to facilitate meaning. The share of the responsibility of each participant in the conversation, or communicative burden (Linebaugh et al., 2008) ensures that meaning can be constructed with the least overall collaborative effort.

In contrast to constant course communication disorders in TBI, communicative competence in MND is affected in a gradual way (Rolland, 2005). Both members of the couple need to move toward integrating AAC techniques into a new lifestyle and learning to become effective communicators in interactions that involve various AAC approaches (Beukelman & Yorkston, 1998). In the early stages of the communication disorder, persons with MND rely on residual speech to facilitate social closeness with their spouse, but as their impairment become more severe, multiple communication approaches are used for this purpose (Beukelman & Yorkston, 1998; Fried-Oken, et al., 2006; Murphy,

2004). Although limited information is available on the use of AAC to maintain social closeness (Fried-Oken, et al., 2006; Murphy, 2004), it was reported that persons with MND preferred low technology strategies to facilitate intimate talking (Murphy, 2004). High technology devices requiring concentration and effort to operate were reported to act as barriers between persons with MND and their spouses as non-verbal communication is decreased. This is fittingly described by the following person with MND: “A lot of communication is non-verbal... it could be important not to let these non-verbal communications stop... to become oblivious to it” (Murphy, 2004, p. 264). This is supported by the findings of the study conducted by Goldstein et al. (2002) which concluded that the spouses of persons with MND experienced psychological distress that correlated with their perceived loss of intimacy predicted by communication changes.

Although much is known about the way in which persons with MND and their spouses are affected by MND, the changes that may occur in their relationship in the context of marriage have received minimal attention (O’Connor et al., 2008) with marital - and sex life satisfaction (O’Connor et al., 2008), perceived intimacy (Goldstein et al., 1998) and psychosocial problems (Trail, Nelson, Van, Apple & Lai, 2004) the focus. Due to the dearth of information on the changes that occur in the marital relationship as a result of the declining speech intelligibility in persons with MND, the current study was conducted. It was postulated that the couples’ perception of marital communication will decrease as the persons with MND’s speech intelligibility decline over the disease progression. Therefore, the primary aim of this study was to compare how persons with MND and their spouses perceive changes in their marital communication in relation to the deteriorating speech of persons with MND.

2.5 SUMMARY

This chapter provided an overview of MND and its impact on the lives of persons living with MND in the areas of physical abilities, communication abilities, performance of social roles and psychosocial dimensions. This was followed by a discussion on how the marital relationship is impacted with specific reference to the communication disabilities experienced and the importance of communication in moderating the effects of chronic

disability highlighted. The chapter concluded with highlighting the dearth of available information on the impact of these communication abilities on marital communication in couples where one person has MND.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION

In this chapter the research methodology used in the study is discussed. Firstly, the aims and objectives of the research are identified, followed by a discussion of research design. The pilot study is then presented in terms of the results and recommendations. Finally, a description of the participants, measuring instruments, data collection procedures and data analysis used in the main study follows.

3.2 METHODOLOGY

3.2.1 Main research aim

The aim of the study was to compare the changes in marital communication as perceived by persons with MND and their spouses in relation to the deteriorating speech of persons with MND at six-monthly intervals over a 12 month period.

3.2.2 Sub-aims

Three objectives delineate the means by which the aim of the study was realized, namely:

- To describe the communication abilities and speech intelligibility patterns of persons with MND across the disease progression.
- To describe the perception of marital communication as indicated by the couple across the disease progression.
- To compare and describe the similarities and differences between the constructs measured in sub-aims 1 and 2.

3.3 RESEARCH DESIGN

3.3.1 Research design

A non-experimental correlational design was implemented for this study to examine the extent to which differences in one variable are related to changes in one or more other variables at intervals over time (Maxwell & Satake, 2006). The relationship between the deteriorating speech of persons with MND and the couples' perception of marital communication was examined during three visits at six-monthly intervals over a 12 month period.

3.3.2 Research phases

The research comprised two major phases. Phase I, the development phase was divided into three sub-phases. Phase II consisted of the main study. The phases are outlined in Table 3.1 below.

Table 3.1 Research phases

| RESEARCH PHASES | | |
|---|--|---|
| Phase I: Developmental Phases | | |
| Identification and selection of measuring instruments | Pilot study | Participant identification |
| <p>This phase aimed at identifying and selecting appropriate measuring instruments to be used in the study.</p> <p>Factor analysis was conducted on the Primary Communication Inventory (PCI) to determine its reliability for the purpose of this study.</p> | <p>The pilot study aimed at finalizing the data collection measurements, procedures and equipment needs.</p> | <p>Identification and selection of participants.</p> |
| Phase II: Main Study | | |
| Visit 1 | Visit 2 | Visit 3 |
| <p>Application of all measuring instruments at visit 1.</p> | <p>Application of all measuring instruments at visit 2.</p> | <p>Application of all measuring instruments at visit 3.</p> |

3.4 DEVELOPMENTAL PHASE

The objectives of the development phase were to identify and select the measuring instruments, conduct a pilot study and identify and select participants for inclusion in the main study (as outlined in Table 3.1).

3.4.1 Factor analysis: Primary Communication Inventory

The PCI was designed to assess marital communication (Navran, 1967). Initially, two subscales, verbal and non-verbal communication, determined by face validity were used to describe marital communication (Navran, 1967). Beach and Arias (1983) however indicated that this instrument consisted of two subscales that measured the individual's perception of his or her own communication ability, and the partner's perception of their spouses' communication abilities (Beach & Arias, 1983). A factor analysis of the PCI was consequently conducted to determine the reliability of this instrument for the purpose of this study as a discrepancy has been reported by researchers on the use of sub-scales in this instrument.

The PCI was administered to 51 couples ($n = 102$) whose demographics were representative of those of the members of the MND Association of South Africa to be included in the main study (See Table 3.2).

Table 3.2 Description of participants factor analysis of PCI ($n=102$)

| Variable | <i>N</i> | Mean | Median | SD | Minimum | Maximum |
|---------------|----------|-------|--------|------|---------|---------|
| Age | 102 | 44.4 | 43.6 | 11.8 | 21.70 | 69 |
| Years married | 102 | 18.05 | 15 | 11.8 | 0.30 | 43 |

One factor, namely communication, was identified. The eigenvalue was 7.56 for all but three items (VV 10 = 0.179; VV 12 = 0.188 & VV 28 = 0.059). These questions were: "Do you and your spouse avoid certain subjects in conversation?"; "When you start to ask a question, does your spouse know what it is before you ask him?"; "If you and your spouse are visiting friends or relatives and one of you starts to say something, does the other take over the conversation without the feeling of interrupting?". Despite low factor loadings on

these three items they were still included for the purposes of the study. These factor loadings on these three items can be a result of them being context-bound or related to the emotional aspects in the relationship.

Reliability was measured with Cronbach's alpha, as it is generally the most appropriate type of reliability for questionnaires in which there is a range of answers for each item (Maxwell, & Satake, 2006). The alpha for the entire sample was .89, indicating high reliability. The PCI was therefore found to be appropriate for use in this study as it provided valuable information on the individual's perception of marital communication.

3.4.2 Pilot Study

3.4.2.1 Objectives

The objectives of the pilot study were to (a) finalize the selection of measuring instruments and data collection procedures; (b) assess the feasibility of the research; and (c) determine the equipment to be used in the main study. The results of the pilot study were used to refine the methodology and to reduce threats to internal and external validity. The objectives are discussed in detail in Table 3.3.

3.4.2.2 Context and participants

All participants were members of the MND Association of South Africa and met the selection criteria as outlined for the main study (Section 3.6.1.2). The pilot study was conducted at the participants' homes at times most convenient for both the persons with MND and their spouses. One couple resided in the North West Province and two in the Western Cape Province.

The first participant group included the three persons with MND: All were male aged 42, 51 and 58.3 years respectively with spinal onset MND. One participant's MND Classification was 'moderate' while the other two participants were classified as 'severe' (Riviere et al., 1998). The primary mode of communication for all the participants was speech, with only one participant using an AAC device to augment his communication. On the ALSSS: Speech Scale their rating was 4, 4 and 5 respectively; with a '4' indicating frequent repeating

required and a '5' that speech plus augmentative communication was required (Hillel et al., 1989). The second participant group included the spouses of the persons with MND: All were female aged 39.4, 47.6 and 59 years respectively. None reported any communication, vision or hearing difficulties that impacted on their activities of daily living. They had been married for 14, 30 and 32 years respectively.

3.4.2.3 Procedures

The same steps as outlined for the main study were followed and all measuring instruments were completed and coded. Once written consent was obtained from the MND Association of South Africa the care workers of the association were requested to identify potential participants and to distribute informed consent forms. Three couples that met the selection criteria completed and returned the forms. Appointments were made in collaboration with care workers to visit the participants at their homes.

3.4.2.4 Results and recommendations

The objectives, materials and equipment, procedures, results and recommendations made after the completion of the pilot study are outlined in Table 3.3.

Table 3.3 Objectives, materials, procedures, results and recommendations from pilot study

| | Objectives | Materials & equipment | Procedures | Results | Recommendations |
|---|---|--|---|--|--|
| 1 | To determine the feasibility of the selection procedure and participant selection criteria. | Selection criteria | The same participant selection procedure and criteria for the main study was used. | The participant selection process through the MND Association was appropriate. | No changes to the participant selection process needed. |
| | | | | The El Escorial criteria for diagnosing (Brooks, Miller, Swash, & Munsat, 2003) are not widely used in South Africa. | A neurologist confirmed diagnosis of MND will be used to identify possible participants. |
| 2 | To evaluate the familiarity with, understanding of and the cultural appropriateness of terminology used in the measuring instruments. | ALSSS, SIT, CETI-M & PCI | The MND Association care worker was consulted on the terminology used. Participants were questioned on the familiarity and understanding of terminology after completion of measuring instruments. | Both the care worker and participants indicated that the terminology used was appropriate. | No changes were required on measuring instruments as all the selected instruments are standardized and internationally accepted. |
| 3 | To test the clarity of the instructions used in the measuring instruments | ALSSS, SIT, CETI-M & PCI | The MND Association care worker and participants were questioned on the clarity of instructions used in the measuring instruments. | Both the MND Association care worker and participants indicated that the instructions were easily understood. | No changes to the instructions were recommended as all the selected instruments are standardized and internationally accepted. |
| 4 | To determine whether required information will be obtained with the measuring instruments selected. | ALSSS, MND Classification, SIT, CETI-M & PCI | All data was encoded and analyzed using basic descriptive statistical procedures. | Information regarding the perception of the marital relationship needs to be expanded by selecting an additional instrument. | The IOS was selected to highlight the couples' perception of their marital relationship. The IOS was thus administered to the last couple and was found to be appropriate for inclusion in the main study. |

Table 3.3 (continued) Objectives, materials, procedures, results and recommendations from pilot study

| | Objectives | Materials & equipment | Procedures | Results | Recommendations |
|---|---|--|--|---|--|
| 5 | To determine the length of time required to complete the data collection process. | Timer | The timer was set when the data collection process commenced. | The time to complete the data collection process ranged between 50 and 80 minutes per couple. | Participants need to be informed that the appointment will be scheduled for approximately 65 minutes. |
| 6 | To determine the suitability of the equipment used in the data collection. | Notebook computer with rear band headset (Dell Latitude D 520) Stereo digital voice recorder (SANYO ICR-B180NX) | Audio recordings were made of all the sessions - initially using the Notebook computer for the first two sessions. The digital voice recorder was used for the last session for audio recording the sessions. | The computer and headset was initially used (with two participants) to audio record the sessions. It was found to be cumbersome with poor sound quality making accurate transcription difficult. A digital voice recorder was successfully used at the visit to the remaining participant. | A digital voice recorder should be used for the audio recording of all sessions to increase the accuracy of speech intelligibility transcriptions. |
| 7 | To test the ease and accuracy of coding the measuring instruments. | ALSSS, MND Classification, SIT, CETI-M & PCI | A statistician was consulted on the accuracy of the coding on measuring instruments. | The coding format for the date of birth and date of data collection as DD/MM/YYYY was indicated as difficult for data analysis. | Changes to coding formats for the date of birth and date of data collection were changed to YYYY/MM/DD. |
| | | | In addition, the researcher coded all the measuring instruments before and after data collection to ensure ease of coding. | Coding of responses on all measuring instruments was done with ease. | No changes recommended. |

3.4.2.5 Summary

After completion of the pilot study minor modifications to the instruments and procedures were required. The initial participant selection criteria of the El Escorial criteria for diagnosing MND were discarded as this criterion is not widely used in South Africa. It was replaced with 'neurologist confirmed diagnosis of MND'. The participants and MND care worker reported that the clarity of instructions and terminology were adequate, and that there were no ambiguous or misleading questions in the measuring instruments. Results regarding the adequacy of selected instruments to fulfil the aims of the study indicated that an additional instrument should be added for determining the couple's perception of their marital relationship. The Inclusion of Other in the Self (IOS) developed by Aron, Aron and Smollan (1992) was thus included in the main study (See Appendix F). The use of a digital voice recorder was indicated above the use of a laptop for audio recording the sessions and especially the SIT to ensure good sound quality for transcription purposes. Minor changes were made to the coding format of the measuring instruments as suggested by the statistician to ensure the accuracy and ease of coding.

3.4.3 Participant selection and description

The selection criteria for participants as well as their description are provided in this section.

3.4.3.1 Participant selection

Purposive sampling was used to identify participants representative of the MND population in South Africa. The care worker of the MND Association contacted possible participants and supplied names of the participants who consented to take part in the study. All the participants who met the selection criteria were contacted by the researcher. As the nature of MND progression posed a threat to participant attrition the researcher aimed to identify and include as many suitable participants as possible to ensure that the collected data yield valuable results.

The researcher selected participants based on the knowledge of their characteristics. This type of sampling is used in infrequent phenomena (such as degenerative disorders) where characteristics existing in individuals are judged to be representative of the problem (Maxwell & Satake, 2006). Although purposive sampling has many advantages, the generality may suffer if they fail to adequately represent the population as intended.

3.4.3.2 Selection criteria

Participants comprised two groups: Participant group 1 included the persons with MND and participant group 2, their spouses. The participant selection criteria are described in Table 3.4.

Table 3.4 Participant selection criteria

| Participant group 1: Persons with MND | | | |
|--|---|--|--|
| | <i>Criteria</i> | <i>Justification</i> | <i>Method</i> |
| 1 | Neurologist confirmed diagnosis of MND regardless of onset. | Diagnosis of MND is required for participant to be included in the study as set out by the topic of the study. The limited number of persons with MND that were married required that participants were included in the study regardless of the type of onset (bulbar, spinal and mixed). | The MND care worker accessed neurology reports confirming the diagnosis of MND. This was confirmed by the researcher during the initial visit through clinical observation and interviews with participants. |
| 2 | Presence of communication difficulties that impact on speech intelligibility. | The presence of communication difficulties that impacts on speech intelligibility is required for inclusion in the study as set out by the topic of the study. | The researcher, a speech therapist with 20-years clinical experience, confirmed the presence of communication difficulties through clinical observation and administering of the ALSSS. A rating of 4,5,6,7 or 8 on the ALSSS Speech Scale was required for inclusion. |
| 3 | In an established relationship with the spouse for a period of at least 12 months prior to the onset of MND | Cutrona (1996) states that in the context of ongoing relationships support can prepare a person to deal with future stressors and help a person to deal with crises after they occur. | Relationship status was identified by the care worker prior to the initial visit and confirmed by the researcher at the initial visit. |
| 4 | No reported communication or visual impairment prior to onset of MND | Visual impairment and pre-existing communication impairment will impact on the communication effectiveness of speakers with dysarthria (Hustad, 1999). | The researcher confirmed this at the initial visit. None of the participants reported any pre-existing communication or visual impairments. |
| 5 | Proficient in English | English is the language used in all measuring instruments. | Proficiency in English was used by the care worker to identify possible participants. The researcher confirmed language proficiency at the initial visit by requesting participants to read sample SIT sentences. |
| Participant group 2: Spouses | | | |
| 1 | No reported communication or visual impairment that impact on their activities of daily living. | Listeners with communication and visual impairment could be a potential environmental barrier when communication with speakers with dysarthria (Hustad, 1999). | At the initial visit this was confirmed by the researcher. No participants reported communication or visual impairments that impacted on their activities of daily living. |
| 2 | Proficient in English | English is the language used in all measuring instruments. | Proficiency in English was used by the care worker to identify possible participants and confirmed by the researcher during the initial visit. |

3.4.3.3 Descriptive information on participants

Nineteen couples initially consented to participate in the study, but four persons with MND passed away shortly *after* the first data collection visit. One person with MND preferred not to complete the sentence intelligibility task at either of the visits. The data collected from these five couples were consequently not included for the purposes in this study. The descriptive information of the participants excluded from the study is reflected in Table 3.5.

Table 3.5 Descriptive information of participants excluded from the study ($n = 5$)

| Gender | Age | Years married | Years since onset of symptoms | Years since diagnosis | Type of MND | MND Classification | ALSSS Speech Scale |
|--------|------|---------------|-------------------------------|-----------------------|-------------|--------------------|--------------------|
| M | 67.3 | 41.0 | 3.1 | 2.6 | Bulbar | Moderate | 5 |
| M | 45.8 | 20.6 | 2.3 | 1.9 | Bulbar | Severe | 4 |
| M | 67.3 | 50.2 | 4.2 | 2.1 | Spinal | Moderate | 8 |
| M | 70.4 | 28.0 | 2.9 | 2.3 | Spinal | Severe | 8 |
| M | 71.6 | 49.5 | 3.8 | 3.0 | Spinal | Severe | 6 |

A total of 14 couples ($n = 28$) participated in this study; 14 persons with MND and 14 spouses. Nine couples resided in the Gauteng Province, three in the Western Cape Province, and one each in the North West and Eastern Cape Province, respectively. Each of the couples lived together in the same home. A detailed description of participants is included in Table 3.6 and Table 3.7.

Although this study had a relatively small sample size ($n_1 = 14$; $n_2 = 14$), it is important to place the sample size in a broader context by considering the probable size of the MND population in South Africa. As information on the incidence of MND in South Africa is not available, it is assumed to be consistent with the internationally reported population incidence of 2 per 100 000 per year (Logroscino et al., 2008). This suggests that 98 new cases of MND will be diagnosed in South Africa each year. The prevalence of MND is approximately 5 - 7 per 100 000 (Fong et al., 2005; Logroscino et al., 2008) which would relate to 245 people in South Africa currently living with MND. At the onset of the study, a total of 119 persons were registered members of the MND Association of South Africa. Of

these only 81 (68%) were married and only 35 (43%) of these members presented with communication difficulties that impacted on speech intelligibility.

Participant group 1: Persons with MND

The sample of persons with MND comprised 14 participants: three females and eleven males (See Table 3.6). This sample is representative of the broader population of individuals with MND as men are typically more affected than women, with a ratio of 1.5 to 2.1 reported until the age of 70 years when the rate becomes equal (Freed, 2000; Mitsumoto, 1997; Nalini, Thennarasu, Gourie-Devi, Shenoy, & Kulshreshtha, 2008). The participants' ages ranged from 44.1 to 70.4 years with a mean age of 64.8 years (SD = 8.67 years). As MND peaks in the fifth and sixth decade of life (Chiò et al., 2004), the average age of the present sample was therefore consistent with the literature.

Table 3.6 Descriptive information for participant group 1: Persons with MND (n = 14)

| No | Gender | Age | Years since onset of symptoms | Years since diagnosis | Type of MND | MND Classification | ALSSS** Speech Scale | Sentence Intelligibility Test | |
|-------------|--------|-------------|-------------------------------|-----------------------|---|--------------------|------------------------------------|-------------------------------|-----------|
| | | | | | | | | % Intelligibility | CE* ratio |
| P 1 | M | 69.0 | 1.9 | 0.7 | Bulbar | Moderate | Use of augmentative communication | 44 | 0.12 |
| P 2 | F | 68.0 | 2.1 | 0.5 | Bulbar | Moderate | Detectable speech disturbance | 98 | 0.52 |
| P 3 | M | 44.3 | 1.6 | 1.0 | Spinal | Severe | Detectable speech disturbance | 99 | 0.64 |
| P 4 | M | 70.4 | 5.0 | 2.0 | Spinal | Severe | Detectable speech disturbance | 97 | 0.74 |
| P 5 | M | 41.10 | 5.1 | 4.3 | Spinal | Severe | Use of augmentative communication | 59 | 0.28 |
| P 6 | M | 58.2 | 5.9 | 5.6 | Spinal | Severe | Behavioural modifications required | 95 | 0.86 |
| P 7 | M | 51.9 | 5.7 | 4.1 | Spinal | Severe | Behavioural modifications required | 43 | 0.15 |
| P 8 | F | 56.1 | 3.0 | 1.0 | Bulbar | Moderate | Detectable speech disturbance | 77 | 0.59 |
| P 9 | M | 64.1 | 8.6 | 7.0 | Spinal | Severe | Detectable speech disturbance | 100 | 1.17 |
| P 10 | F | 59.5 | 2.8 | 1.8 | Bulbar | Moderate | Detectable speech disturbance | 89 | 0.7 |
| P 11 | M | 66.6 | 3.5 | 2.6 | Bulbar | Moderate | Behavioural modifications required | 35 | 0.11 |
| P 12 | M | 59.6 | 1.6 | 1.0 | Bulbar | Moderate | Behavioural modifications required | 80 | 0.44 |
| P 13 | M | 68.4 | 5.0 | 1.1 | Mixed | Mild | Detectable speech disturbance | 63 | 0.44 |
| P 14 | M | 52.2 | 0.8 | 0.5 | Mixed | Moderate | Behavioural modifications required | 79 | 0.47 |
| Mean | | 57.1 | 3.76 | 2.37 | Note: * CE ratio: Communication efficiency ratio = % intelligible words per minute ** Description of ALSSS Speech Scale categories in Appendix B | | | | |
| SD | | 8.64 | 2.19 | 2.08 | | | | | |

The average time since onset of symptoms to the month of data collection was determined as 3.76 years (SD = 2.19 years) with a range of 3 months to 8.6 years. The average time from the month of confirmation of the disease by the neurologist to the month of data collection was 2.37 years (SD = 2.08 years) with a range of 5 months to 7 years. Thus, from the onset of symptoms until the diagnosis of MND an average of 15 months (SD = 12 months) had lapsed. It is stated that worldwide the average time since onset of symptoms to confirmation of diagnosis is approximately 16 to 18 months (Gelinas, 1999). Six participants presented with bulbar onset MND, six with spinal onset MND and two with mixed onset MND. At the onset of the study, one participant's MND Classification (Riviere et al., 1998) was mild (State 1), seven participants were classified as moderate (State 2) and six participants as severe (State 3).

The participants' functional impairment in the area of communication at the onset of the study was also established with the ALSSS Speech Scale. Seven participants reported 'detectable speech disturbances' where speech changes were noticeable to others or their speech were obviously dysarthric. Five participants indicated that 'behavioural modification' was required and that they had to occasionally or frequently repeat messages to facilitate understanding. Two participants were included in the 'use of augmentative communication' category as although they still use speech in response to questions, they had to resolve intelligibility problems by using alternative means of communication such as writing. Speech intelligibility scores for participants ranged between 43% and 100% at the onset of the study and their communication efficiency ratio between 0.7 and 1.17.

Participant group 2: Spouse

The sample of spouses also comprised 14 participants: eleven females and three males. A detailed description of participants is included in Table 3.7. The spouses' ages ranged from 47.6 to 70.3 years, with an average age of 57.8 years (SD = 8.64). All were proficient in English and none reported communication, vision or hearing difficulties that impacted on the activities of daily living.

The couples were married for an average of 29.10 years (SD = 13.81 years) with a range of 3 years to 45.6 years.

Table 3.7 Descriptive information for participant group 2: Spouses ($n = 14$)

| No | Gender | Age | Years married |
|-------------|--------|--------------|---------------|
| S 1 | F | 61.4 | 37.10 |
| S 2 | M | 67.1 | 45.60 |
| S 3 | F | 47.6 | 12.80 |
| S 4 | F | 55.7 | 12.00 |
| S 5 | F | 39.8 | 14.00 |
| S 6 | F | 59.3 | 32.00 |
| S 7 | F | 47.6 | 30.00 |
| S 8 | M | 54.4 | 3.00 |
| S 9 | F | 70.3 | 40.00 |
| S 10 | M | 64.5 | 40.10 |
| S 11 | F | 61.1 | 39.80 |
| S 12 | F | 57.1 | 39.00 |
| S 13 | F | 64.1 | 44.05 |
| S 14 | F | 49.1 | 30.01 |
| Mean | | 64.83 | 29.96 |
| SD | | 8.67 | 13.81 |

3.5 MAIN STUDY

3.5.1 Equipment and Measuring instruments

The equipment and measuring instruments used in the research are discussed in this section.

3.5.1.1 Equipment

The equipment used for data collection and analysis included:

- Stereo digital voice recorder (SANYO ICR-B180NX)
- Notebook computer (Dell Latitude D 520) using a Windows XP Professional (Version 2002) operating system, with Microsoft multimedia tools including an MS Sound Recorder and driver.

3.5.1.2 Measuring Instruments

In order to meet the requirements posed by the research aims, six measuring instruments were used. The measuring instruments will be discussed in relation to the aims of the study, namely disease progression, communication abilities and speech intelligibility patterns and lastly the marital relationship.

i. Disease progression

a. Classification on MND

This classification system developed by Riviere et al. (1998) defines the health state of persons with MND according to the severity and progression across the functional modalities of speech, mobility and ability to use upper limbs for activities of daily living. It has been used extensively in clinical drug trials in which the object of treatment was to maintain persons with MND in the early states of health (Mathy et al., 2000; Riviere et al., 1998). The classification ranges between four states: State 1 (mild), State 2 (moderate), State 3 (severe) and State 4 (terminal) (See Appendix A). Despite the fact that reliability and validity data have not been

reported for this classification system, it is widely used in practice and for research purposes to describe the severity and progression of MND (Mathy et al., 2000; Murphy, 2004). At each visit the researcher identified the current MND classification through clinical observation and participant interviews which was confirmed by a second rater for 20% of the participants.

ii. Communication abilities and speech intelligibility

a. Amyotrophic Lateral Sclerosis Severity Scale: Speech Scale

The ALSSS, an ordinal rating system developed by Hillel et al. (1989), provides a means to quickly and accurately assess the functional impairment of a person with MND. Information is obtained regarding the level of severity in four areas namely speech, swallowing, lower extremity (LE) and upper extremity (UE) abilities. Information obtained on speech, LE and UE abilities are all of critical importance for the selection of an appropriate AAC system. A choice of ten scores based on the progressive decline in function is provided (See Appendix B) and the rating is accomplished within ten minutes through clinical observation and interviews with the person with MND and/or spouse (Hillel et al., 1989; Yorkston, Strand, Miller, Hillel, & Smith, 1993). An average estimated reliability coefficient of 0.95 between examiners has been shown for the ALSSS. In addition, the rates of progression of the total score in a small sample of participants ($n = 14$) ranged from -3.4 to -24.0 points per year with a mean of -11.3 points per year. Ratings on the speech scale were correlated greater than 0.80 for objective speech measures that included speech intelligibility, words per minute and oral diadochokinetic rates (Hillel et al., 1989). This was confirmed by a study conducted by Ball et al. (2001) where the clinic visits for 49 persons with MND were documented in a database for analysis. The ALSSS Speech Scale was plotted against speaking rate and an overall correlation of $R^2 = 0.845$ was found, significant at the $p = 0.000$ level.

For this study, the ALSSS: Speech scale was used to obtain information regarding the functional impairment experienced by the persons with MND in the area of

speech. A rating was derived at each visit by the researcher on the basis of clinical observation and an interview with the person with MND and/or the spouse. This rating was confirmed by a second rater who accompanied the researcher on 20% of the visits.

b. Sentence Intelligibility Test

Transcription intelligibility strategies are widely used to objectively measure the intelligibility of speech (Ball et al., 2001; Ball et al., 2004; Yorkston et al., 1999). In this study the standardized clinical transcription test, the SIT (short test) was used to determine speech intelligibility. It consists of a series of 11 unrelated randomly generated sentences with sentences varying in length from 5 to 15 words (See Appendix C). This measure was specifically chosen as sentences more closely approximate the demands of ordinary speaking situations than single words (Yorkston et al., 1996). Normative data associated with this assessment indicates no influence of fatigue on productions of typical speakers. Interjudge reliability coefficients for the SIT ranges between 0.93–0.99 for percentage intelligibility and 0.99 for rate of intelligible speech (or communication efficiency ratio). The intersample correlation coefficients range from 0.92 to 0.99 for intelligibility measures (Yorkston et al., 1996).

Standard administration and measurement procedures were employed for this study. The Windows version for SIT was loaded on a Notebook computer. Sentence stimuli were printed for each participant and presented in New Times Roman (12 font). Speech samples were digitally recorded using a stereo digital voice recorder and the sound files saved on the Notebook computer for later analysis (Klasner & Yorkston, 2005; Mathy, 2005). Production of the entire test required approximately three minutes per participant, although the duration varied according to individual participants' communication abilities.

Recorded responses were transcribed by the researcher using broad orthographic transcription techniques. The transcription and analysis was done by the

researcher, a speech language pathologist with 20-years clinical experience. Transcription analysis resulted in the percentage of intelligible productions in sentences. Following transcription, speech samples were timed to obtain a measure of speaking rate in words per minute (wpm) and the rate of intelligible speech (communication efficiency ratio) calculated. Twenty percent of these speech samples were transcribed by a second rater to determine percentage speech intelligibility.

c. Modified Communication Effectiveness Index

The Communication Effectiveness Index initially developed as a measure of functional communication for adults with aphasia was adapted by Yorkston et al. (1999) for use in the MND population. The Modified Communication Effectiveness Index (CETI-M) uses a visual analogue and 7-point Likert scale (ranging from '1' – not at all effective to '7' – very effective) for 10 contextual communication situations (See Appendix D). The communication effectiveness of persons with MND across these situations is rated by both the individual with MND and the spouse. These ratings give an indication of personalized evidence on communication performance of the person with MND (Ball et al., 2001; Ball et al., 2004; Yorkston, et al., 1999). In a study that examined the relationship between speech intelligibility and communication effectiveness of persons with MND ($n = 54$) the CETI-M demonstrated high internal test reliability ($r = 0.97$) and significant correlational values for individual item analysis for all items (Ball et al., 2004).

For this study, the researcher provided verbal directions for completion of the CETI-M in addition to the directions printed at the top of each questionnaire. The persons with MND and their spouses completed the CETI-M separately. The researcher assisted the participants with MND to complete the CETI-M by marking the response form in accordance with their verbal or gestured responses as all participants were unable to hold and manage a pen due either to fatigue, muscle weakness or paralysis. The self-rating of participants with MND and their spouses' listener perceived ratings provided a measure of the perceived social limitation of

the communication of persons with MND (Ball et al., 2004). The CETI-M ratings of the persons with MND were confirmed by a second rater who accompanied the researcher on 20% of the visits.

iii. Marital relationship

a. Primary Communication Inventory

The Primary Communication Inventory (PCI), a 25-item instrument, was designed to assess marital communication (Navran, 1967) (See Appendix E). Both members of the couple complete the PCI as it includes items dealing with both the individuals' communication and that of their partners. The overall score appears to be a reliable indicator of the soundness of communication between two members of a couple (Beach & Arias, 1989; Navran, 1967). The validity of the PCI has been well established. The PCI has excellent concurrent validity, correlating strongly ($r = .82$) with the Lock-Wallace Marriage Relationship Inventory, a marital satisfaction questionnaire. A factor analysis of the Primary Communication Inventory (PCI) was conducted to determine the reliability for the purposes of this study. The alpha for the entire sample was .89, indicating very high reliability (Refer to Section 3.4.1).

For this study, the researcher provided verbal directions for the completion of the PCI in addition to the directions printed at the top of the response form. The persons with MND and their spouses completed the PCI separately. The researcher assisted participants with MND to indicate their choice by marking the response form in accordance with their verbal or gestured responses as they were unable to hold and manage a pen. The PCI ratings of the persons with MND were confirmed by a second rater who accompanied the researcher on 20% of the visits.

b. Inclusion of Others in the Self Scale

The IOS scale, a single item, non-verbal self-report measure was developed by Aron et al. (1992) to determine people's perceived closeness to another (See Appendix F). The IOS demonstrated high alternate-form (.95), test-retest reliability (0.85) for

romantic relationships and concurrent validity with other social closeness measures such as the Relationship Closeness Index (.90) and the Sternberg Intimacy Scale (Aron et al., 1992). Participants are required to select one of seven Venn-like diagrams of overlapping circles most descriptive of their relationship. The circles were designed so that the degree of overlap progresses linearly, creating a seven-step, interval-level scale measuring two overarching factors 'behaving close' and 'feeling close' (Aron et al., 1992; Aron et al., 1991).

Although closeness cannot be discreetly categorized (Aron & Fraley, 1999), numerical values (1 – 7) were assigned to each diagram to facilitate encoding and description of the results of this study. A '1' indicated that the individual did not perceive any feelings of closeness to their spouse, while a '7' represented a perception of complete overlap or closeness between the self and the spouse.

The researcher provided verbal directions for the completion of the IOS scale in addition to the directions printed at the top of response form. Persons with MND and their spouses completed the IOS separately. The researcher assisted participants with MND to indicate their choice by marking the response form in accordance with their verbal or gestured responses as they were unable to hold and manage a pen. The IOS ratings of the participants with MND were confirmed by a second rater who accompanied the researcher on 20% of the visits. The self-rating of participants' sense of interconnectedness with their spouses provided a measure of their perceived social closeness (Aron et al., 1992; Aron, Aron, Tudor, & Nelson, 1991).

3.5.2 Data collection procedures

Ethical, specific and procedural considerations had to be taken into account with data collection to ensure reliability.

3.5.2.1 Ethical considerations

The researcher adhered to strict ethical guidelines and ethical considerations were implemented throughout the research study. The researcher obtained ethical clearance from the University of Pretoria's Research Ethics Committee before this research study was conducted (See Appendix G). Written permission was obtained from the MND Association of South Africa (See Appendix H) and all participants, using established and approved methods. All participants in the study were fully informed of the nature of the study and were assured of confidentiality (See Appendix I). Each participant was required to sign a consent form, providing proof of his/her willingness to partake in the study and had the right to withdraw from the study at any time, without any negative consequences. Verbal consent was obtained from the persons with MND who were unable to write and this was confirmed by their spouse who signed the consent forms on their behalf.

3.5.2.2 Specific considerations

In order to assure reliability, specific considerations were implemented throughout data collection:

- In an attempt to minimize the Hawthorne effect, the researcher made it clear to participants that there were no correct or incorrect answers to the questions (Maxwell & Satake, 2006; McMillan & Schumacher, 2001). Interviews and completion of measuring instruments were conducted separately with the two participant groups. Spouses completed the measuring instruments in another room, while the researcher assisted persons with MND who were unable to write by completing these instruments on their behalf based on their verbal or gestured response. The researcher checked the spouses' completed instruments to ensure that there were no missing data.

- Interrater reliability of all measurements was determined. Two different independent raters were used to determine the interrater reliability for all the measures used in the study. The first independent rater was the MND care worker, a registered nurse with 30-year clinical experience. Her selection was based on her expertise in the field on MND that stems from her 10-years of employment by the MND Association of South Africa. This rater was trained by the researcher on the application of the various measuring instruments used in the study. She accompanied the researcher on 20% of the visits (House, House, & Campbell, 1981) and independently completed all measuring instruments based on her observations of the interviews conducted by the researcher with the persons with MND. Her presence at the actual sessions was essential for accurate scoring of measuring instruments as decreased speech intelligibility and use of AAC by persons with MND compromised the use of audio recordings for this purpose. A second rater, a speech therapist with five years clinical experience transcribed 20% of the recorded SIT responses to determine the percentage of intelligible productions. She was unfamiliar with the speakers and stimuli sentences and was instructed by the researcher to orthographically transcribe the stimuli sentences.
- All the sessions were audio-recorded. The audio-recording of the SIT facilitated the transcription of the sample sentences. In addition, the researcher used the audio-recordings of the first visit to verify that all measuring instruments were completed correctly. The use of audio-recordings during the second and third visits were however ineffective as the use of AAC during communication interaction was not successfully captured.

3.5.2.3 Procedures

The procedure used during both phases of the research (developmental phase and main study) are described below:

- a) Consent for the research was obtained from the MND Association of South Africa. Telephonic contact was made with the National Chairperson during which the aim and procedures of the research were discussed. This was followed up by e-mail. Written permission to conduct the research was subsequently obtained.
- b) The *developmental phase* followed and comprised the development and selection of data collection tools, the pilot study and participant selection.
 - Data collection tools to be used in the study were selected. A factor analysis was done on the PCI to determine its reliability for the purpose of this study as various subscales for this measure have been reported by different researchers. Once the PCI was confirmed as an appropriate instrument for this study, the pilot study was conducted.
 - The pilot study was conducted to finalize the measuring instruments and data collection procedures, to assess the feasibility of the research and lastly, to determine the equipment to be used in the main study.
 - Participants in the pilot study were identified in consultation with an MND care worker.
 - Once participants were identified, appointments were made by the researcher to visit them at their homes. Appointments were made at times indicated as most convenient for both the person with MND and the spouse.
 - The aim of the research was explained, informed consent obtained and measuring instruments applied.
 - Participants were then requested to comment on their understanding of terminology used and the clarity of instructions.

- The researcher noted the time it took to complete the interview process and the suitability of the equipment to be used in the study. The accuracy and ease of coding of the measuring instruments were also determined.
 - All the relevant changes based on recommendations were made prior to the main study.
 - Participant selection for the main study was done in consultation with the MND Association of South Africa according to the predetermined participant selection criteria.
- c) The *main study phase* commenced with the researcher confirming appointments with the identified participants. Participants were visited at home at times indicated as most convenient for both members of the couple.
- During the first visit, the aims of the research were explained and consent obtained. Demographic information was obtained from the couple, the ALSSS (Speech Scale) and MND Classification was completed by the researcher based on the clinical observations and interviews with both members of the couple. The persons with MND completed the following instruments with the assistance of the researcher: SIT, CETI-M, PCI and IOS. The spouses completed the CETI-M, PCI and IOS privately after clear instructions were given. The audio-recorded SIT responses were stored on the Notebook computer for later transcriptions and analysis,
 - The two subsequent visits (visit 2 and visit 3) were scheduled at 6-monthly intervals where the same measuring instruments as described for visit 1, were administered.
 - The researcher did not make any contact with participants between scheduled data collection visits. Appointments were reconfirmed telephonically just before the next visit.

- Telephonic contact was, however, maintained with the MND care worker between the scheduled visits to ensure that the researcher was informed of the health status of participants. This was essential as the progressive nature of MND impacted on the participant attrition rate in this study.
- On completion of the data collection process all participants were provided with a letter from the researcher, thanking them for participating in the study (See Appendix J).
- In cases where participants passed away, the researcher phoned the spouse to offer condolences.

d) At the end of each visit the researcher encoded and captured data after which it was checked for any capturing errors.

3.5.2.4 Data analysis and statistical procedures

The data was documented on all the relevant measuring instruments. A pre-designed column marked “For official use” was placed on the right-hand side of all measuring instruments for encoding the raw data. Encoding was done by the researcher according to the data definitions.

All the data was computerized for statistical analysis with the SAS and BMDP3D Statistical Software packages. The results were then analyzed using a variety of statistical procedures, listed in Table 3.8 below and displayed in tables and figures. Non-parametric statistics (Friedman Test, Spearman rank correlation and Wilcoxon) were selected as it is appropriate for studies where the sample size is small (Maxwell & Satake, 2006).

Table 3.8 Statistical procedures conducted

| Statistical procedures | Rationale |
|---|---|
| Factor analysis | A statistical method used to determine the relationships among several variables (Maxwell & Satake, 2006). A factor analysis was conducted on the PCI. |
| Cronbach's alpha reliability coefficient | Used as a measure to determine the internal consistency of a measure (Maxwell & Satake, 2006; McMillan & Schumacher, 2001). For this study it was specifically used to determine the reliability of the PCI for the purpose of this study. |
| Mean scores, median and standard deviations were calculated where applicable to provide information on the spread of distribution | Information was obtained on the average of all scores as well as the average variability of scores (Maxwell & Satake, 2006). |
| Friedman Test (two-way analysis of variance by ranks) | This nonparametric test was used with the repeated measures obtained from each participant across the visits (Maxwell & Satake, 2006). |
| Spearman rank correlation (Rho) | A nonparametric test used to compute the correlation on two variables with ranked scores (Maxwell & Satake, 2006). For the purpose of this study correlations were computed between speech intelligibility and communication effectiveness, communication efficiency ratio and communication effectiveness, speech intelligibility and marital communication. |
| Wilcoxon | A nonparametric test to compare the differences for pairs of scores (Maxwell & Satake, 2006). The communication effectiveness ratings and marital communication scores between persons with MND and spouses were compared at each visit. |
| Cohen's <i>d</i> (Effect size) | The effect size was calculated in order to establish the size of statistically significant differences (Cohen, 1992; Maxwell & Satake, 2006). This is supported by the notion that with stronger effects of treatment, a smaller sample size is required (Salkind, 2008). |

3.6 SUMMARY

This chapter described the methodology of the research. It included the aim of the research, description of the research design and phases. A description of the pilot study that indicated problem areas and recommendations followed. The main study was discussed with respect to participant selection criteria and description, as well as equipment and measuring instruments. Finally data collection procedures and analysis were discussed.

CHAPTER 4

RESULTS AND DISCUSSION

4.1 INTRODUCTION

The results of the study will be described and discussed in this chapter, in relation to the main aim of the study, namely to compare the deteriorating speech of persons with MND and the couples' perception of marital communication across the disease progression. This chapter commences with a presentation of the interrater reliability results. Thereafter it focuses on reporting the findings in relation to the aims of the study. Data is organized, analyzed and interpreted so that conclusions can be drawn regarding the association between the deteriorating speech of persons with MND and the couples' perception of marital communication across the disease progression.

4.2 INTERRATER RELIABILITY

Interrater reliability, only one of various types of reliability of measurement, pertains to the researcher's ability to accurately collect and record information (Maxwell & Satake, 2006; Salkind, 2008). Interrater reliability measures were included to determine the accuracy of the researcher's judgment of speech intelligibility scores (SIT) of the persons with MND, their MND Classification and ratings of functional impairment according to the ALSSS Speech Scale. Interrater reliability was also established for the CETI-M, PCI and IOS of participant group 1. Interrater reliability was determined by the researcher and two different independent raters for 20% of participant group 1 (House et al., 1981). Participants were randomly assigned to the two independent raters and were not necessarily similar.

The researcher determined the interrater agreement for the *MND Classification*, *ALSSS Speech Scale* ratings, *CETI-M* ratings, *IOS* ratings and *PCI* ratings with the

assistance of the first independent rater (the MND care worker, a registered nurse with 30-years clinical experience). The care worker accompanied the researcher on 20% of the visits, randomly selected based on her availability. At each of the visits the care worker firstly determined the disease state according to the MND Classification and rated their functional speech impairment using the ALSSS Speech Scale through clinical observation and information obtained from the couple. She also independently completed the CETI-M ratings, PCI scores and IOS ratings while the researcher conducted the interviews with the persons with MND. Interrater agreement was calculated by counting the frequency of agreements between the two raters with the following formula (House et al., 1981; Maxwell & Satake, 2006):

$$\frac{\text{Number of agreements between Rater 1 and Rater 2}}{\text{Number of agreements and disagreements between Rater 1 and Rater 2}} \times \frac{100}{1}$$

Across all measurements, the interrater agreement was 100%. Although very high, this was expected as clinical observation, interviews and direct answers to the questions of the various measuring instruments were used to obtain information from participants.

The second independent rater (the speech therapist with five years clinical experience) independently transcribed 20% of the participants' recorded SIT sentences (randomly selected) to establish the percentage of intelligible sentences of participant group 1. The percentage of the scores by the researcher and rater two that fell within the 10% range of agreement was 100%, while 78% of the scores were within the 5% range of agreement. Interrater reliability was also assessed by computing the Pearson product-moment correlations between the raters' scores. The interrater reliability coefficient indicated an average correlation of .99 for the percentage of intelligible productions. These results compare favourably with the interrater agreement of .94 obtained by Yorkston et al. (1996) during the standardization of the SIT.

It is evident that the interrater agreement for all the measuring instruments was more than 95%. This indicates a good interrater agreement score as it exceeded the 70% recommendation of McMillan and Schumacher (2001) positively contributing to the validity of the findings.

4.3 DISEASE PROGRESSION

The description of the communication abilities of persons with MND and the couples' perception of marital communication are set against the background of the progressive nature of MND.

The MND classification was used to classify participant group 1 (persons with MND) according to their functional abilities across the modalities of speech, mobility and ability to use upper limbs for activities of daily living (Riviere et al., 1998). In the early stage or State 1 (mild), there is a mild deficit in only one of three regions (speech, arms, legs) and the individual remains functionally independent in speech, ambulation, and using upper extremities for activities of daily living. In State 2 (moderate), there is a mild deficit in all three regions or a moderate to severe deficit in one region while two regions are normal or mildly affected. As the disease progresses, the individual's ability to function independently is compromised. Assistance is required in two or three regions in State 3 (severe) while at the final terminal stage, State 4, the person with MND has no functional use in at least two regions and moderate or no functional use in a third region. The disease progression of participant group 1 is reflected in Figure 4.1.

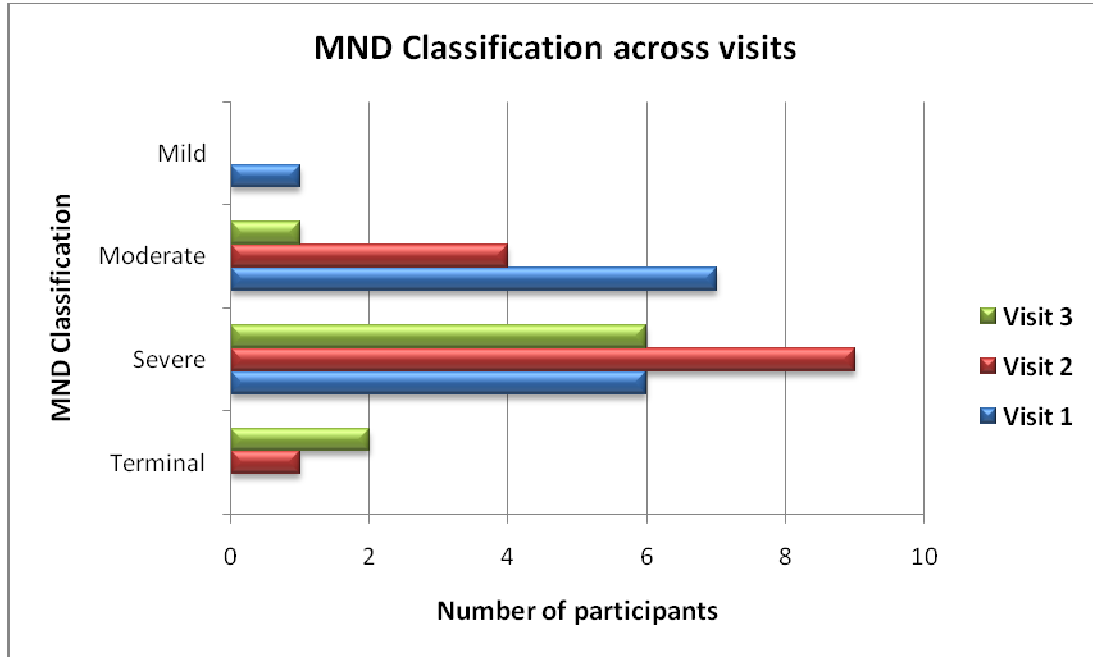


Figure 4.1 MND Classification of participants across visits

At the first visit, one participant was classified as ‘mild’, seven as ‘moderate’ and six as ‘severe’. The disease progression was evident at both the second and third visits. The number of participants classified as ‘moderate’ decreased to four at the second visit, while there was an increase in the number of participants classified as ‘severe’ to nine with one classified as ‘terminal’. Attrition of participants as a result of death shortly after the second visit decreased the sample size to only nine participants at the third visit: Of these participants only one was classified as ‘moderate’, six as ‘severe’ and two as ‘terminal’.

It is interesting to note that the average time since onset of symptoms to time of death for the five participants with MND that died shortly after the second visit were 3.2 years (range 1.0 to 5.6 years; SD – 1.8 years). Two of the participants presented with a mixed onset while the remaining three participants presented with bulbar onset. Survival duration of these participants compare with life expectancy figures of between two and five years reported in the literature (Doyle & Phillips, 2001; Logroscino et al., 2008; Mathy et al., 2000).

4.4 COMMUNICATION ABILITIES ACROSS THE DISEASE PROGRESSION

The first sub-aim addressed the communication abilities and speech intelligibility patterns of persons with MND across the disease progression. Three measures were used to describe the communication abilities of each participant with MND, namely the ALSSS Speech Scale, SIT and CETI-M.

4.4.1 ALSSS: Speech Scale

The speech function of participants with MND across the visits is summarized in Figure 4.2 with only categories recorded for participants reflected. Participants with 'detectable speech disturbance' included those whose speech changes were obvious to others or whose speech was consistently dysarthric. Participants who had to repeat messages (either occasionally or frequently) to facilitate understanding were included in the 'behavioural modifications' category. The 'use of augmentative communication' category included participants who still utilized speech in response to questions, but had to resolve intelligibility problems by using alternative means such as writing. In addition, those who had limited speech to one word responses and initiated communication non-vocally were also included in this category. The last category 'loss of useful speech' comprised participants that were either non-vocal or only used vocalizations to express emotion, affirmation and negation.

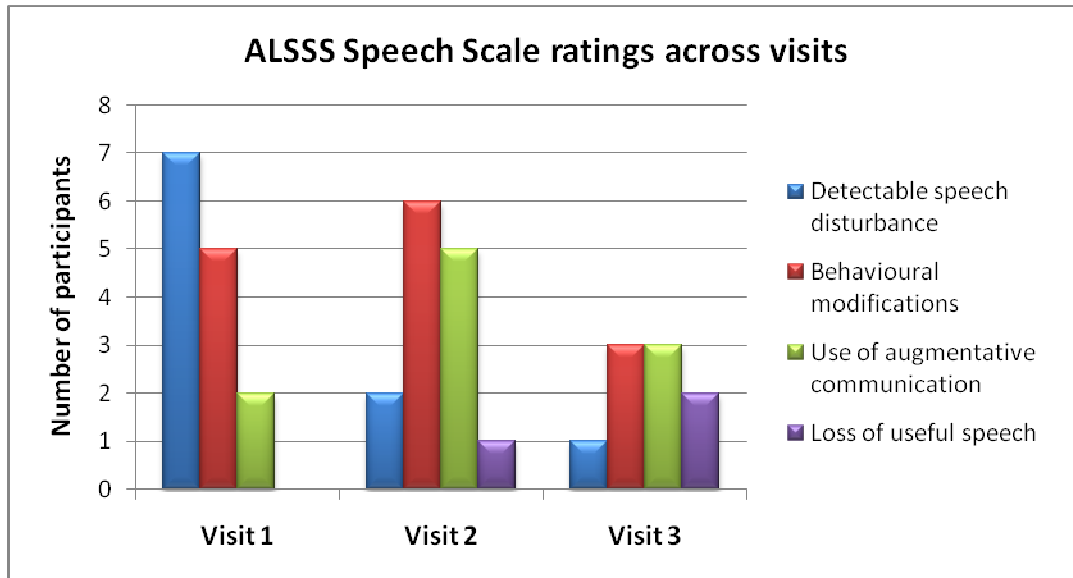


Figure 4.2 Summary of ALSSS Speech Scale ratings across visits

The progressive decline in speech function of participants with MND across all visits is evident. Seven participants reported ‘detectable speech disturbances’ at the first visit, five were required to make some ‘behavioural modifications’ and two used ‘augmentative communication strategies’ when communicating with both familiar and unfamiliar listeners. These two participants used a Lightwriter, a portable text-to-speech communication aid, to support communication with unfamiliar communication partners. Both participants operated the Lightwriter by direct selection as they had adequate hand function. In addition to the Lightwriter, they also implemented unaided AAC strategies such as facial expression, head nodding and manual gestures and low technology strategies such as alphabet boards (direct selection) to facilitate communication with their spouses.

The decline in speech intelligibility was evident at the second visit as only two participants indicated ‘detectable speech disturbances’; while six were required to implement ‘behavioural modifications’, five made use of ‘augmentative communication’ and one reported ‘loss of useful speech’. The participants who reported ‘use of augmentative communication’ mainly used unaided AAC strategies (such as facial expression and yes-or-no questions), low technology strategies (such as alphabet boards with optical direct selection using a laser pointing device

attached to their head, and writing) to support their communication. One of the two participants who initially used a Lightwriter for communication had to abandon use due to a significant decrease in hand function and mobility, making direct access to the Lightwriter impossible. The participant who reported 'loss of useful speech' continued operating the Lightwriter through direct selection for communication with unfamiliar listeners. He however preferred to use facial expression and manual gestures for communication with his spouse.

At the last visit only one participant reported a 'detectable speech disturbance', while three had to implement 'behavioural modifications', three used 'augmentative communication' and two reported 'loss of useful speech'. Participants who reported 'use of augmentative communication' and 'loss of useful speech' all facilitated communication with familiar and unfamiliar partners through facial expression, partner assisted yes-or-no questions, and/or direct optical selection alphabet boards. None of the participants made use of high technology AAC devices for communication at the last visit due to a decline in functional motor abilities.

A review of the results confirms the insidious decline in the communication abilities experienced by persons with MND across the disease progression regardless of onset type. In this study, all but one participant reported a progressive decline in speech function, which corresponds with reports in the literature that for 75% of individuals with MND intelligible verbal communication will not be possible in the final stages of the disease (Ball et al., 2001; Ball et al., 2004; Beukelman & Mirenda, 1998; Fox & Sohlberg, 2000; Murphy, 2004). The participant who reported no decline in speech function, presented with spinal onset MND which typically displays a gradual reduction in speech intelligibility over an extended period (Ball et al., 2001; Yorkston et al., 1993).

It is evident from the current study that all participants predominantly used unaided AAC strategies such as facial expression, head nodding, manual gestures and partner assisted yes-no questions to communicate with their spouses. Low technology strategies, for instance, alphabet boards with optical direct selection,

were used by the minority of participants, while only two participants made use of high technology AAC strategies for part of the data collection period. These findings support the reports in the literature that face-to-face spontaneous conversation modes are more frequently used by persons with MND despite the limitations of slow production rate, lack of permanence and the demands on the conversational partners (Fried-Oken et al., 2006; Murphy, 2004). The collaborative efforts of both conversational partners ensured that persons with MND were able to still communicate with spouses and other familiar communication partners. The importance of non-verbal efforts in maintaining the marital relationship cannot be underestimated. Couples' shared history of communicative interactions serves to increase awareness of and sensitivity to each other's non-verbal communication (Kahn, 1970; Murphy, 2004).

Despite the considerable improvement of AAC technology for persons with MND within the last decade (Beukelman et al., 2008), none of the participants in the current study reported using high technology AAC systems other than the Lightwriter. It is postulated that the variety of AAC technology available to persons with MND in South Africa compares favourably with what is used internationally, but there is a scarcity of evidence regarding its use and acceptance locally. The exorbitant costs of imported high-technology AAC systems coupled with the lack of health care funding significantly impede on the number of individuals with little or no functional speech using these systems. In addition, the shortage of adequate AAC trained personnel and a wholly inadequate AAC service delivery system in South Africa restricts these persons' access to communication (Alant, 2005; McConkey, 2005).

4.4.2 Speech intelligibility and speaking rate

The percentage of intelligible speech productions and rate of speech of the persons with MND were established with the SIT at each visit. The percentage intelligible words per minute were also calculated to determine the communication efficiency

ratio of participants in group 1. A summary of the speech intelligibility (percentage) results are shown in Table 4.1.

Table 4.1 Results of speech intelligibility scores in percentage across visits

| Participants | Visit 1 n = 14 | Visit 2 n = 14 | Visit 3 n = 9 |
|--------------------------------|--------------------|---------------------|--------------------|
| P 1 | 44 | 0 | 0 |
| P 2 | 98 | 45 | 0 |
| P 3 | 99 | 77 | 47 |
| P 4 | 97 | 93 | 23 |
| P 5 | 59 | 40 | 39 |
| P 6 | 95 | 81 | 73 |
| P 7 | 43 | 49 | 38 |
| P 8 | 77 | 65 | - |
| P 9 | 100 | 89 | 51 |
| P 10 | 89 | 78 | 55 |
| P 11 | 35 | 0 | - |
| P 12 | 80 | 79 | - |
| P 13 | 63 | 42 | - |
| P 14 | 79 | 5 | - |
| Mean | 75.58 ^a | 53.07 ^{ab} | 36.22 ^b |
| SD | 22.93 | 32.81 | 24.6 |
| Median | 79.50 | 57.00 | 39.00 |
| Cohen's <i>d</i> | 0.9168 (large) | | |
| Friedman <i>p</i>-value | 0.0005* | | |

Mean with different superscript differ significantly at the 5% level

**Significance at the 5% level*

Speech intelligibility A Friedman Test (two way analysis of variance) was employed to determine whether the change in speech intelligibility was statistically significant over time. The *p*-value of 0.0005 was significant at the 5% level, which requires pair-wise comparisons to test the nature of the significance. A summary of these results are shown in Table 4.1.

This table indicates a statistically significant decrease in speech intelligibility at the 5% confidence level between visit 1 and visit 3. This implies that there was a significant decrease in the speech intelligibility of the persons with MND across the disease progression. Cohen’s d ($d = 0.9168$) confirms that the effect of the difference between visit 1 and visit 3 is large (Cohen, 1992).

Communication efficiency ratio The communication efficiency ratio was determined by the calculating the percentage of intelligible words per minute for each participant. In order to determine whether change in communication efficiency was statistically significant over time, a Friedman Test (two way analysis of variance) was employed. The p -value of 0.0008 was significant at the 5% level, which requires pair-wise comparisons to test the nature of the significance. A summary of these results is shown in Table 4.2 below:

Table 4.2 Results of communication efficiency ratio across visits

| | Visit 1 $n = 14$ | Visit 2 $n = 14$ | Visit 3 $n = 9$ | Friedman p -value |
|-------------------------------|---------------------|---------------------|--------------------|------------------------|
| Mean | 0.52 ^a | 0.31 ^b | 0.20 ^b | 0.0008* |
| SD | 0.30 | 0.27 | 0.18 | |
| Median | 0.50 | 0.31 | 0.13 | |
| Cohen’s d | 0.5121 (medium) | | | |
| | 0.8603 (large) | | | |

Mean with different superscript differs significantly at the 5% level

** Significance at the 5% level*

This table indicates a statistically significant decrease in the communication efficiency ratio at the 5% confidence level between visit 1 and visit 2, and visit 1 and visit 3 respectively. Cohen’s d confirms that the effect size of the difference between visit 1 and visit 2 is medium ($d = 0.5121$) and between visit 1 and visit 3 large ($d = 0.8603$) (Cohen, 1992).

As is evident in the statistically significant results obtained, a reduction in speaking rate preceded the decline in speech intelligibility. While speech intelligibility

measures only showed a statistically significant difference between visit 1 and visit 3, the results of communication efficiency ratio already confirmed a statistically significant decrease in communication efficiency of persons with MND between visit 1 and visit 2. However the effect is most noticeable between visit 1 and visit 3. This confirms the findings reported in the literature that decreases in speaking rate are evident much sooner following the onset of MND symptoms than reductions in speech intelligibility (Ball et al., 2001; Ball et al., 2004; Beukelman et al., 2008; Nishio & Niimi, 2000; Yorkston et al., 1993). It has been recognized that a slow speaking rate is a deviant speech characteristic typical to MND especially in the early stages of MND (Darley et al., 1975). The degree of change in the speaking rate tends to become smaller during the later stages of MND (Nishio & Niimi, 2000).

4.4.3 Communication effectiveness

The CETI-M, the third and final measuring instrument, was used to describe the functional communication abilities (or perceived societal limitations) of the persons with MND across the disease progression. Ten communication situations ranging from speaking to familiar persons and strangers in quiet and in noise to talking on the phone were rated (See Appendix D). This rating scale was completed by both participant groups for the same communication situations at each visit. The results obtained per participant group at each visit, the comparison over time for each group as well as the difference between the two groups, and the Wilcoxon for comparing the two groups for each visit, is reported. A summary of these results is shown in Table 4.3.

Table 4.3 Communication effectiveness (CETI-M) ratings across the visits and between participant groups

| | Visit 1 <i>n</i> = 14 | | Visit 2 <i>n</i> = 14 | | Visit 3 <i>n</i> = 9 | | Cohen's <i>d</i> <i>between</i> <i>visits</i> | Friedman <i>p</i> - value |
|------------------------------------|--------------------------|-------|--------------------------|-------|-------------------------|------|---|------------------------------|
| | Mean | SD | Mean | SD | Mean | SD | | |
| PMND | 31.40 ^a | 12.04 | 24.53 ^{ab} | 10.25 | 21.00 ^b | 6.84 | 0.5821** (medium) | 0.0458* |
| Spouse | 28.53 ^a | 11.54 | 20.80 ^{ab} | 9.74 | 18.77 ^b | 9.30 | 0.6387** (medium) | 0.0151* |
| Difference | 0.6835 | | 0.2812 | | 0.1719 | | | 0.8948 |
| Wilcoxon <i>p</i>-value | 0.2578 | | 0.0980 | | 0.5078 | | | |

Mean with different superscript differs significantly at the 5% level

** Significance at the 5% level*

*** Between visit 1 and visit 3*

Communication effectiveness as rated by persons with MND A Friedman Test was employed to determine whether the change in communication effectiveness as rated by the persons with MND was statistically significant between visits 1, 2 and 3. The *p*-value of 0.0458 was statistically significant at the 5% level, which requires pair-wise comparisons to test the nature of the significance. A statistically significant decrease in communication effectiveness was found at the 5% confidence level between visit 1 and visit 3. The effect size as measured with Cohen's *d* is medium ($d = 0.5821$) (Cohen, 1992).

Communication effectiveness as rated by spouses In order to determine whether the change in the communication effectiveness of the persons with MND as rated by spouses was statistically significant between visits 1, 2 and 3 respectively, a Friedman Test was employed. The *p*-value of 0.0151 was statistically significant at the 5% level, which requires pair-wise comparisons to test the nature of the significance. Similar to the persons with MND, a statistically significant decrease in communication effectiveness was found at the 5% confidence level between visit 1

and visit 3. Cohen's d indicates that the size of the effect is medium ($d = 0.6387$) (Cohen, 1992).

Difference in CETI-M ratings between persons with MND and spouses at each visit A Wilcoxon test was used to determine if there were statistically significant differences in the way persons with MND and spouses rated the communication effectiveness of the persons with MND at each visit. The p -values (0.2578, 0.0980 and 0.5078 respectively) were not statistically significant at the 5% level (See Table 4.3).

Comparison of CETI-M ratings of persons with MND and spouses over time A Friedman Test was employed to determine whether the difference in the ratings between the two participant groups over time were statistically significant. The p -value of 0.8948 was not statistically significant at the 5% level of confidence, indicating no difference in ratings between the two participant groups over time. The mean communication effectiveness rating by each participant group are similar indicating a decrease in the communication effectiveness of the nine participants with MND at the 5% confidence level between visit 1 and visit 3.

These results correspond with findings in the literature reporting the similarity with which both the persons with MND and their spouses perceived the communication effectiveness of persons with MND at each visit within the various communication situations. These findings further support the literature, which indicates that quiet environments were more conducive to communication effectiveness than adverse communication situations (e.g. noisy environments) (Ball et al., 2001, Ball et al., 2004; Yorkston et al., 1993; Yorkston et al., 1999).

4.4.4 Speech intelligibility and communication effectiveness

A Spearman's rho correlation was calculated to determine the existence of a possible relationship between the *speech intelligibility* of the person with MND and *communication effectiveness* as rated by both participant groups across the visits.

Results of this analysis between the speech intelligibility scores of the persons with MND and the *self-ratings on the CETI-M* indicate a significant positive relationship across the visits. There was a weak positive correlation at the first two visits of $r_s = 0.4835$, and $r_s = 0.3440$ respectively, while at the last visit a strong positive correlation ($r_s = 0.5356$) was indicated. Similar results were obtained for the relationship between the speech intelligibility scores of persons with MND and the *spouse's rating on the CETI-M* with weak positive correlations at visit 1 ($r_s = 0.4813$) and visit 2 ($r_s = 0.2528$) and a strong positive correlation at visit 3 ($r_s = 0.6160$). These results therefore indicate that there is a positive relationship between the speech intelligibility scores of the persons with MND and the self- and spouse ratings of communication effectiveness across the disease progression.

In a study conducted to compare speech intelligibility and communication effectiveness across ten social situations (Ball et al., 2004), it was found that for persons with MND even a slight decrease in speech intelligibility, communication in some social situations (e.g., in a noisy environment, speaking for a long period) became difficult. Moreover, even intimate communication situations with familiar communication partners became increasingly difficult when speech intelligibility scores were less than 70%. It is important that information should be provided timeously to the persons with MND and their spouses about adverse speaking situations and strategies for repairing communication breakdown (Ball et al., 2004).

4.4.5 Communication efficiency ratio and communication effectiveness

A Spearman's rho correlation was also calculated to determine the existence of a possible relationship between the *communication efficiency ratio* (percentage of intelligible words per minute) of the persons with MND and *communication effectiveness* as rated by both participant groups at all the visits.

The results of the analysis between the communication efficiency and *self-ratings on the CETI-M* indicate a positive relationship for all visits. Although not statistically

significant, weak positive correlations were indicated at all three visits of $r_s = 0.3160$, $r_s = 0.4300$ and $r_s = 0.4202$ respectively.

The relationship between the communication efficiency and *spouse's ratings on the CETI-M* indicate a strong positive relationship at visit 1 ($r_s = 0.5743$), a weak positive correlation at visit 2 ($r_s = 0.3477$) and a strong positive relationship at the last visit ($r_s = 0.6144$).

This evident positive relationship between the communication efficiency and communication effectiveness of persons is consistent with the findings of other studies. Although a reduction in the rate of speech may typically coincide with improvements in speech intelligibility, the acceptability of speech may suffer and result in decreased communication effectiveness (Dagenais, Brown, & Moore, 2006). This finding is supported by Ball et al. (2001) and Ball et al. (2004) that found that communication effectiveness accurately predicted changes in speech at speaking rates of 200, 140 and 100 words per minute. A decreased rate of intelligible speech will make it notably more difficult for listeners to understand the speech of persons with MND, impinging on their communication effectiveness (Klasner & Yorkston, 2005).

4.5 MARITAL COMMUNICATION

The second sub-aim of the study, to describe the perception of marital communication as indicated by the couple across the disease progression, was addressed by administering the PCI and IOS at each visit to both participant groups.

4.5.1 Primary Communication Inventory

The mean marital communication scores for each participant group across the visits are presented in Table 4.4. The PCI scores have a possible range of 25 to 125 with higher scores indicative of better or more positively viewed marital communication. Navran (1967) reported that the mean scores for 'happily' married couples were 105 and for 'unhappily' married couples, 81.

Table 4.4 Marital communication across all visits and between participant groups

| | Visit 1 <i>n</i> = 14 | | Visit 2 <i>n</i> = 14 | | Visit 3 <i>n</i> = 9 | | Friedman <i>p</i> - value |
|------------------------------------|--------------------------|-------|--------------------------|-------|-------------------------|-------|------------------------------|
| | Mean | SD | Mean | SD | Mean | SD | |
| PMND | 87.99 | 14.15 | 86.00 | 12.54 | 85.22 | 18.49 | 0.8233 |
| Spouse | 87.73 | 16.02 | 83.93 | 16.91 | 79.44 | 16.74 | 0.0446* |
| Difference | 0.9134 | | 0.4966 | | 0.5078 | | 0.2359 |
| Wilcoxon <i>p</i>-value | 0.7763 | | 0.6374 | | 0.0576 | | |

**Significance at the 5% level*

Overall, the mean scores of marital communication as perceived by the persons with MND group are consistently higher than the spouse group at all three visits. It is important to note that the mean PCI scores obtained at the first visit for both these groups were below 105, the mean score for ‘happily’ married couples. These mean scores steadily decreased across the visits; at the first visit it was similar but the decrease was more marked in the spouse participant group at visit 2 and visit 3, indicating a steady decline to a score of ‘unhappily’ married.

Perception of marital communication as rated by persons with MND In order to determine whether the perception of marital communication across the visits as rated by the *persons with MND* was statistically significant, a Friedman Test was employed. The *p*-value of 0.8233 noted implies that the change was not statistically significant at the 5% level.

Perception of marital communication as rated by spouses The converse was found when looking at the change in marital communication as rated by the *spouses*. The *p*-value of 0.0446 was statistically significant at the 5% level which requires pair-wise comparisons to test the nature of the significance. A summary of these results are shown in Table 4.4 and indicates that there is not a statistically

significant decrease in the spouses' perception of marital communication at the 5% level of confidence.

Difference in marital communication scores between persons with MND and spouses at each visit A Wilcoxon test was used to determine if there were statistically significant differences in the way persons with MND and spouses rated their marital communication *at each visit*. At visit 1 the *p*-value was 0.7763, at the second visit 0.6374 and at the last visit 0.0576, indicating that it was not statistically significant at the 5% level.

Comparison of marital communication scores between persons with MND and spouses over time In addition, a Friedman Test was employed to determine whether the difference in marital communication scores between the persons with MND and the spouses were statistically significant across the disease progression. The *p*-value of 0.2359 was not statistically significant.

The findings of this study indicate that both participant groups reported mean PCI scores below the 'happily married' score of 105 at the first visit. Interestingly, no statistically significant decrease in the perception of marital communication was reported by the persons with MND and the spouses across the visits, despite the perception of marital communication as reported by the spouses declining markedly to below 81, the score indicated for 'unhappily married' couples.

It is postulated that the diagnosis of MND has devastating consequences on the functioning of the couple, and that severe psychosocial strain on this relationship is inescapable. The literature too, supports these findings that any long-term illness could significantly challenge couples' capability to openly and directly discuss, among other, the psychosocial demands of the illness, personal and relationship priorities, maintaining balanced and mutual relationships (Cutrona, 1996; Lev-Wiesel, 1988; Navran, 1967; Rolland, 1994, 1999). Communication has been found to be associated with marital adjustment as highly communicative marital relationships are reported to significantly relate to positive marital adjustment (Burlinson & Denton, 1997; Hobart & Klausner, 1959; Navran, 1967; Rolland, 1994,

1999). The quality of the marital relationship, levels of personal disclosure and communication prior to the illness determines how couples cope with the ongoing challenge of disability (Rolland, 1994; Ross & Deverell, 2004). These aspects that supported marital communication prior to the disability may now become insufficient when couples face illness and disability (Rolland, 1994). This supports the findings of the current study that the couples' perception of marital communication even at the first visit was below the 'happily married' score of 105.

Participants (persons with serious illnesses and their caregivers) in a study conducted by Fried, Bradley, O'Leary, and Byers (2005) endorsed that communication with one another about the illness is important. Caregivers reported higher levels of communication needs with their ill-partners but this desire was not shared by their ill-partners. It is postulated that the persons with MND in the current study, employed their limited needs for communication about the illness as a strategy to better cope with their debilitating illness. Similar findings are reported by Fried et al. (2005).

The dissonance in the need for communication between the ill-partner and the spouses may have a negative influence on care-givers as they have their own sets of needs throughout the ill-partners' illness that must be recognized and fulfilled. The obvious decrease in the spouses' perception of marital communication in this study, is supported by the literature on communication disabilities such as dementia and TBI (Baikie, 2002; Blais & Boivert, 2007; Savundranayagam et al., 2005). Spouses of individuals with dementia reported that communication breakdown as a result of ineffective communication had a significant negative impact on the quality of their relationship (Baikie, 2002; Savundranayagam et al., 2005). The cognitive-communicative, specific language impairment and motor speech disorders associated with TBI also negatively impact on the ability of individuals with TBI to successfully participate in marital communication (Blais & Boisvert, 2007; Wells et al., 2005). Enhanced communication in the face of serious illness is necessary to strengthen relationships between the couple (Fried et al., 2005).

The possibility that other psychosocial aspects such as depression and social isolation which accompany debilitating medical conditions can account for some of the deterioration in communication between spouses (as reported by spouses in the current study) cannot be excluded (Lev-Wiesel, 1988; Segrin & Flora, 2001). Studies conducted with persons with MND reported that depression and social isolation did not appear to directly influence quality of life (Goldstein et al., 2002). It is inevitable that the psychosocial typology of MND as described by Rolland (1994, 1999) will also determine the impact of the illness on the couple over time.

4.5.2 Inclusion of Others in the Self Scale

The perception of closeness to spouses in relation to the self was rated by both participant groups at each visit. Circles representing the 'self' and the 'other' (in this context the spouse) were represented in seven diagrams with increasing degrees of overlap between the two circles (See Appendix F). The numerical values assigned to each diagram facilitated encoding and description of the results. A '1' indicated that the individual did not perceive any feelings of closeness to their spouse, while a '7' represented a perception of complete overlap or closeness between the self and the spouse.

The IOS ratings were organized in a frequency table (See Table 4.5). The data reported is ordinal level data, and the measures of central tendency should therefore be interpreted with care. Overall the mean scores of the IOS ratings are very similar across visits for both participant groups; for persons with MND it was 5.57, 5.78 and 5.78 respectively, while for the spouses it was 5.14, 5.36 and 5.33 respectively.

Interestingly, the mean marital communication scores and perceptions of closeness as reported by the persons with MND remained relatively constant across the visits. Their spouses, however, reported that their perceptions of closeness to their partners remained constant despite a statistically significant decrease in their perceptions of marital communication between visit 1 and visit 3.

Table 4.5 Frequency table for IOS results

| Couple | Persons with MND | | | Spouse | | |
|-------------|--------------------------|--------------------------|-------------------------|--------------------------|--------------------------|-------------------------|
| | Visit 1 <i>n</i> = 14 | Visit 2 <i>n</i> = 14 | Visit 3 <i>n</i> = 9 | Visit 1 <i>n</i> = 14 | Visit 2 <i>n</i> = 14 | Visit 3 <i>n</i> = 9 |
| 1 | 7 | 7 | 7 | 7 | 7 | 6 |
| 2 | 7 | 7 | 7 | 7 | 7 | 7 |
| 3 | 6 | 6 | 6 | 7 | 7 | 6 |
| 4 | 5 | 6 | 4 | 1 | 1 | 1 |
| 5 | 5 | 6 | 7 | 5 | 5 | 5 |
| 6 | 7 | 6 | 6 | 7 | 7 | 7 |
| 7 | 6 | 5 | 5 | 7 | 5 | 7 |
| 8 | 5 | 5 | - | 4 | 6 | - |
| 9 | 7 | 4 | 6 | 4 | 5 | 4 |
| 10 | 4 | 7 | 4 | 5 | 5 | 5 |
| 11 | 4 | 7 | - | 7 | 7 | - |
| 12 | 7 | 3 | - | 3 | 3 | - |
| 13 | 5 | 6 | - | 1 | 3 | - |
| 14 | 3 | 6 | - | 7 | 7 | - |
| Mean | 5.57 | 5.78 | 5.78 | 5.14 | 5.36 | 5.33 |
| SD | 1.34 | 1.19 | 1.20 | 2.25 | 1.92 | 1.94 |

Two important trends were further identified, namely the consistency and distribution of IOS ratings across the visits. The consistency of ratings are described in relation to those that remained constant and those that decreased, increased or fluctuated between visits (See Figure 4.3).

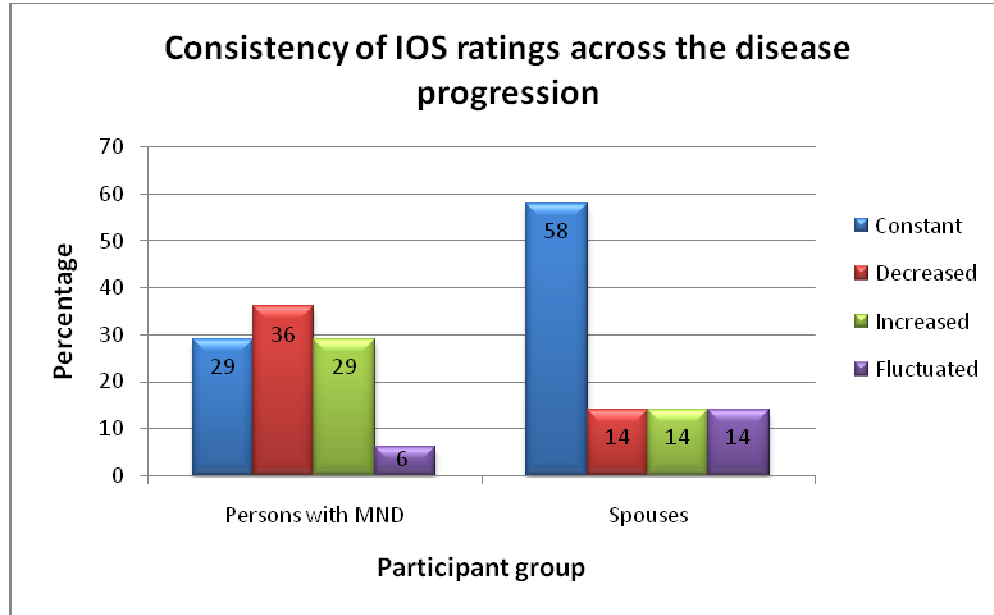


Figure 4.3 Consistency of IOS ratings (percentage) across disease progression

It is interesting to note that despite lower marital communication scores, the perception of closeness to their spouse remained constant for the majority of participants across the visits (29% of the persons with MND and 58% of the spouses). A decrease in the perception of closeness between visit 1 and visit 3 was reported by 36% of the persons with MND and 14% of the spouses. Twenty-nine percent (29%) of persons with MND and 14% of spouses reported an increase of perception of closeness between visit 1 and visit 3, whilst fluctuating perceptions of closeness were reported for 6% of the persons with MND and 14% of the spouses across the visits.

The second trend, distribution of ratings, was identified with the clustering of all the ratings into three groups; low (1, 2, 3), average (4, 5) and high (6, 7). The results are presented in Figure 4.4. The majority of participants in both participant groups (62% and 51% respectively) indicated high ratings of perceived closeness to their spouse despite the fact that the mean marital communication and speech intelligibility scores decreased across the disease progression. Average ratings were indicated by 30% of persons with MND and spouses, whilst only 11% of

spouses and 5% of the persons with MND indicated low ratings of perceived closeness to their spouses.

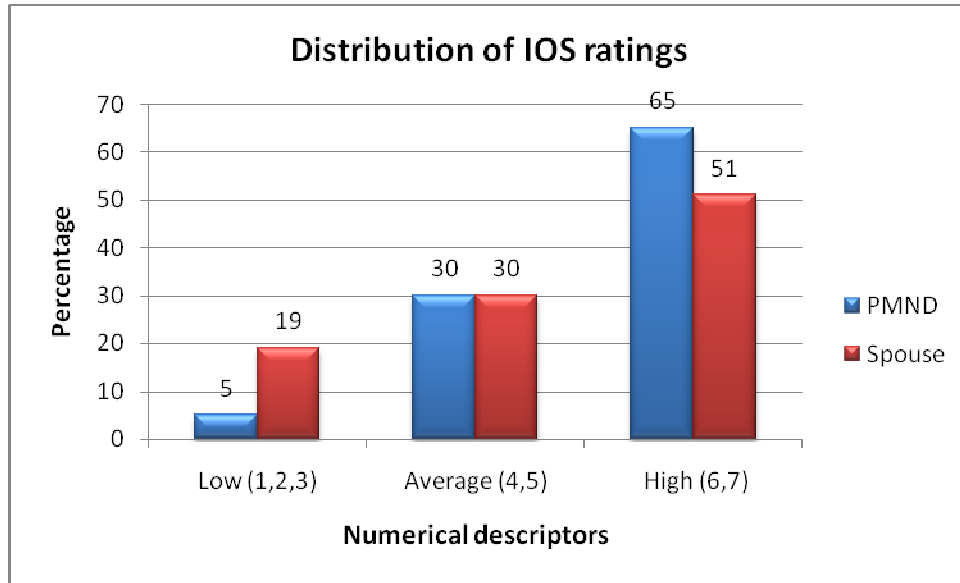


Figure 4.4 Distribution of IOS ratings

It is postulated that the ill-partners' ever increasing dependency in all activities of daily living and spouses' escalating caregiving role often result in the blurring of emotional and physical boundaries and greater perceptions of interdependence between the couple. This is supported by the literature on the IOS that the quantity and variety of interaction (or 'behaving close') is an important aspect of this measure (Aron et al., 1992). The provision of care by the spouse offers many opportunities for them to demonstrate supportiveness, commitment, kindness and love (Aron et al., 1992; Cutrona, 2004). This is in contrast to reports by Kowal et al. (2003) who found that as the persons with chronic illness became more dependent, spouses reported significant negative changes in their perceptions of closeness. In the current study, a small percentage of spouses (11%), however, did experience a sense of limited closeness to their partners with MND as is evident in their ratings of "1" on the IOS Scale. Living with a serious chronic illness (both as spouse and individual diagnosed with the illness) inevitably heighten feelings associated with

loss and couples either react by pulling away or clinging to their spouse in a fused way (Rolland, 1994).

4.6 SPEECH INTELLIGIBILITY AND MARITAL COMMUNICATION

The main research aim, to determine whether there is an association between the deteriorating speech of persons with MND and the couples' perception of marital communication, was addressed by employing Spearman's correlation. The positive relationship between speech intelligibility, communication efficiency and communication effectiveness was established and discussed earlier in this section. Therefore, only the relationship between speech intelligibility and marital communication will be expanded on in this section.

The correlation between speech intelligibility and marital communication for *persons with MND* of $r_s = 0.2440$ ($p = 0.4006$) at visit 1, $r_s = -0.0441$ ($p = 0.8811$) at visit 2 and $r_s = 0.2983$ ($p = 0.4356$) at visit 3 were found not to be significant ($p > 0.01$). This indicates the persons with MND perception of marital communication is not influenced by the decrease in speech intelligibility.

A similar correlation was found for the *spouse group* at all visits. The correlation between speech intelligibility and marital communication of $r_s = 0.2352$ ($p = 0.4183$) at visit 1, $r_s = -0.1367$ ($p = 0.6412$) at visit 2 and $r_s = 0.3598$ ($p = 0.3415$) at visit 3 were found not to be significant ($p > 0.01$). Similarly, to the findings of persons with MND, spouses' perception of marital communication is not influenced by their partner's decreased speech intelligibility.

This most significant finding of the study, that the relationship between the deteriorating speech of persons with MND and the couples' perception of marital communication was not statistically significant across the visits, was unexpected. The hypothesis that marital communication as perceived by the couple will decrease as the speech intelligibility of persons with MND decline is consequently rejected.

It is accepted that when speech intelligibility becomes compromised, persons with MND must expend much greater effort to communicate and thus verbal communication is often kept to the minimum to conserve energy (Murphy, 2004). It is evident that notwithstanding the decline in verbal communication, couples still communicated. As the disease progressed, the majority of persons with MND made use of unaided AAC strategies and aided low technology AAC to facilitate communication with their spouses. Spouses accepted an increasing share of the communication burden in the conversations to facilitate meaning. The past shared experiences and familiarity with each other as a couple is postulated to also facilitate the spouse's ability to better interpret facial expressions, gestures, vocalizations and thus the needs of their ill-partner (Cutrona, 2004). This ability of spouses to understand the communicative intent and meaning was perceived by the persons with MND as important in the maintenance of social closeness. The findings of a longitudinal study focusing on communication between persons with MND and their closest communication partners support the findings of the current study, that the use of low technology AAC is essential for couples to maintain their most intimate relationship, marriage (Murphy, 2004). Reports in the literature allude to the importance of both verbal and non-verbal communication in the maintenance of marital communication (Beach & Arias, 1989; Cutrona, 2004; Kahn, 1970; Navran, 1967) but the value of non-verbal communication in maintaining social closeness in the face of decreased verbal communication can, however, not be underestimated and is supported by the findings of previous studies (Fried-Oken et al., 2006; Murphy, 2004).

The timing of referral for AAC assessment and intervention therefore still remains one of the most important clinical decision-making issues in MND (Beukelman et al., 2008) that can contribute to the maintenance of social closeness (Murphy, 2004).

The negative aspects of decreased speech intelligibility and use of AAC were also reported by participants. One of the spouse-participants reported that she found communication with her spouse frustrating and tiring especially after a long day at work: "I do not have the energy to try and understand what he wants to tell me"

(Spouse of participant 5). She purposefully avoided communicating with her husband, decreasing the opportunity for them as a couple to maintain social closeness within their marital relationship. The lack of motivation that this spouse displayed, contributes to the feelings of anger and frustration experienced by both members of the couple. This finding is supported by reports in the literature that where couples had not developed strategies to compensate for communication difficulties, increased tension, anger and frustration abound (Murphy, 2004).

The decreased opportunities for intimate talking invoked sadness in many couples, as touchingly expressed by the spouse of participant 3: "I miss our conversations; we used to be so close..." The sadness experienced by this spouse, corresponds with findings that decreased social satisfaction and perceived loss of intimacy was predicted by the changes in communication as a result of MND (Goldstein et al., 2002). However, the acceptance of increasingly compromised speech intelligibility that predictably limits verbal communication was pertinently expressed by participant 3: "I sometimes want to tell my wife about something interesting I have seen or heard, but more and more I now keep it to myself. I have accepted this." Adjustment to the inevitable symptoms of the illness is pivotal in coping with MND (Charmaz, 1995; Rolland, 1994, 1999).

4.7 CONCLUSION

This chapter highlighted the results of the research and were organized, analyzed and described as it relates to the aims of the research. The reliability measures of the data collection instruments and procedures were presented. The results supported the progressive decline in communication abilities of persons with MND regardless of type of onset using speech intelligibility, speaking rate and communication effectiveness measuring instruments. Marital communication and perceptions of closeness revealed that both participant groups reported that their perceptions of closeness remained relatively constant despite reported decreases in marital communication. The hypothesis that marital communication will decrease

in accordance with declining speech intelligibility was rejected. In the discussion, the reasons for these findings were postulated.

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

This chapter contains an overview of the rationale for the current research. It then provides a summary of the results in relation to the main aim of the study that examined the association between the deteriorating speech of persons with MND and the couples' perception of marital communication. Conclusions are provided, and a detailed critical evaluation including the consideration of the limitations of the study follows. Finally, clinical implications are discussed and recommendations made for future research.

5.2 OVERVIEW OF THE RATIONALE AND SUMMARY OF RESULTS

The onset of a progressive, fatal illness such as MND unremittingly challenges the ability of the individuals diagnosed with MND and their spouses to adjust to the physical, communication and psychosocial aspects of the illness. Social roles performed and responsibilities assumed by both members of the couple within the marital relationship continuously change. Communication that allows for daily interactions, decision-making and expression of emotions, thoughts and feelings is essential for couples to manage these challenges experienced. One of the most profound changes, the loss of speech, will inexorably influence their ability to adequately maintain their relationship. The dearth of information on the way in which marital communication is affected by illnesses with progressive communication disabilities provided a compelling rationale for the current study to investigate how persons with MND and their spouses perceive changes in their marital communication in relation to the deteriorating speech of persons with MND.

Data on the communication abilities and speech intelligibility patterns of participants with MND, and the couples' perception of marital communication was

obtained using objective and subjective measures. The research comprised two phases; the development phase, included the selection of measuring instruments, a pilot study and participant selection. The main study comprised three visits to the participants' homes, at six-monthly intervals over a 12-month period. The results of the study revealed the following:

- *Interrater reliability*: The interrater agreement for the MND Classification, ALSSS Speech Scale, CETI-M, PCI and IOS was 100%, while the interrater agreement for the SIT was .99 as determined using the Pearson product-moment correlation. These findings compare well with reports in the literature, and confirm that the rating system used was consistent. This contributes to the validity of the study.
- The communication abilities of the participants as it relates to the first sub-aim, namely *describing the communication abilities and speech intelligibility patterns* across the disease progression confirm reports in the literature. The progressive decline in speech abilities is inevitable in the majority of cases despite the type of onset. The results further indicate that the decreased speaking rate and communication effectiveness was evident before the decline in speech intelligibility was noted. As expected, a positive relationship was found across the disease progression between the *speech intelligibility and communication effectiveness* of persons with MND, and *their communication efficiency ratio and communication effectiveness* as rated by both participant groups.
- The second sub-aim, describing the perception of marital communication as indicated by the couples across the disease progression produced unexpected results. Interestingly, no statistically significant difference was reported by the persons with MND and the spouses. The descriptive analysis of the IOS results revealed that for the both participant groups their perceptions of closeness remained relatively constant across the visits.
- The results of the relationship between the deteriorating speech of persons with MND and the couples' perception of marital communication did not reveal

a significant positive relationship. Indicating that the couples' perception of marital communication was not influenced by decreased speech intelligibility.

Overall, the results support the supposition that communication between couples will invariably deteriorate as a result of progressively reduced speech intelligibility is not necessarily valid. The fundamental importance of communication in marriage is highlighted by Johnson (2000): "Honest and effective communication is crucial for any healthy relationship and even more so when one of the partners is an augmented communicator" (p. 47). It is well established that AAC strategies can preserve the ability to develop and maintain intimate, rewarding relationships even in the face of profound physical disabilities (Prentice, 2000).

5.3 EVALUATION OF THE STUDY

- The current research comprised a preliminary effort to deal the apparent dearth of information on the impact of progressive communication disabilities as a result of MND on marital communication as perceived by *both* members of the couple.
- The small sample size is one of the primary limitations of this study. Despite efforts by the researcher and care worker of the MND Association of South Africa, the unpredictable nature of MND and the unique circumstances of the individual couples impinged on the numbers of participants who could be included in the study. The use of alternative statistical measures, such as Cohen's *d*, however, supports the notion that meaningful effect sizes (in this study either medium or large) moderate the need for larger sample sizes (Salkind, 2008).
- The participants were representative of the broader MND population in South Africa in terms of age, gender, onset type and race. The findings can thus be generalized to the broader MND population in South Africa.

- The reliability of measures used in this study is well-known, and in the case of the PCI, established specifically for the purposes of this study. The reliability and validity of the data was further heightened by determining the interrater agreement for all the measures completed by the persons with MND.
- Although all data collection sessions were audio-recorded to enhance reliability it was ineffective in capturing communication interactions of the participants with MND that made use of AAC. Video-recordings of sessions would have been more effective for recording the non-verbal communication interaction of participants.
- Every attempt was made to minimize the Hawthorne effect. Participants were informed prior to data collection that there were no correct or incorrect answers to the questions. Each member of the couple completed the measuring instruments privately. The researcher assisted participants with MND who were unable to write to complete the instruments based on their verbal and gestured responses.
- The research design did not make provision for the retrospective measurement of marital communication and closeness prior to the onset of the MND. Information on the marital relationship prior to the onset of the disease would have contributed to understanding the complexity of the situation and the role that speech intelligibility plays in this regard.
- The current research did not attempt to differentiate between marital communication and marital satisfaction in the presence of a progressive communication disorder. The association between these two aspects would have provided valuable insight into the actual mean marital communication

(PCI) scores obtained in this study that for all visits were below the mean scores for 'happily' married couples as indicated by Navran (1967).

5.4 CLINICAL IMPLICATIONS

- The most important clinical implication of this study is that marital communication is not influenced by the deteriorating speech of persons with MND. Even in the face of loss of speech, communication as a means of facilitating and maintaining the marital relationship is particularly pertinent to persons with MND and their spouses.
- MND is often viewed by healthcare providers as only having behavioural consequences such as increasing dependence and self-care needs which require practical support. Although providing relief for this relentless physical deterioration is important, the exclusive focus on physical aspects is limited and results in a serious underestimation of the significance of communication in maintaining independence and interpersonal relationships despite physical limitations.
- Health professionals should take a holistic approach to communication intervention and not only address the communication needs of the individuals with MND, but also consider the needs of their spouses. These identified needs should be addressed with the implementation of AAC strategies tailor-made for each couple, as to facilitate the maintenance of intimate marital communication.
- The applicability of low technology and unaided AAC strategies for persons with MND should not be underestimated. Speech-language pathologists can play an important role in the implementation of effective communication strategies for couples based on low technology and unaided AAC.

- All these factors underscore the importance of timely provision of information, intervention, training and support to individuals living with MND and their spouses to ensure successful intimate communication for the couple.

5.5 RECOMMENDATIONS FOR FUTURE RESEARCH

The results revealed a variety of interesting trends. Preliminary answers and many more questions were raised that will need to be answered in the following type of future research:

- The replication of this study on a larger sample of persons with MND and their spouses, preferably followed longitudinally and/or using different interval periods, would expand the research in the field of marital communication and MND.
- This study can further be replicated on other populations experiencing progressive communication disabilities such as Parkinson's disease, Primary Progressive Aphasia and Multiple Sclerosis. It would also be interesting to replicate this study on populations with progressive cognitive communication disorders such as Alzheimer's disease and Huntington's disease.
- As marital communication is embedded in socio-cultural contexts, it is recommended that similar research be conducted using various cultural groups.
- As evidence suggests that the quality of the relationship prior to the onset of illness is a critical determinant of the extent to which chronic illness disrupts the marital relationship (Baikie, 2002; Cutrona, 1996; Rolland, 1994), it is suggested that prospective studies are conducted that investigate the impact of speech intelligibility and marital communication in MND.

- Employing qualitative research design (e.g. focus groups, case study method) to investigate the perceptions' of marital communication in relation to the declining speech intelligibility of persons with MND could provide invaluable in-depth information that could be further explored and analyzed to aid in understanding this complex situation that couples face.
- Further research should also attempt to determine the factors that mediate the relationship between marital communication and marital satisfaction, especially in the presence of progressive communication disability. These insights may be used to help couples improve their communication and marital satisfaction despite communication disabilities associated with MND.
- No information is available on the use and acceptance of AAC by persons with MND in South Africa. Obtaining such information would be invaluable to inform the establishment of an appropriate AAC service delivery system to people with MND and their families.

5.6 SUMMARY

This chapter summarized the rationale and the results of the research as described in Chapter 4. By means of a critical evaluation of the research, combined with a discussion of the study's strengths and weaknesses, the validity of the study is established. The clinical implications of the research were pointed out.

Given the dearth of information on the impact of progressive communication disabilities such as MND on marital communication, the groundwork has been laid for future more in-depth research to replicate, refine, and expand the current study in various ways that could be generalized beyond this specific population.

REFERENCES

- Abrahams, S., Goldstein, L. H., Al-Chalabi, A., Pickering, A., Morris, R. G., Passingham, R. E., et al. (1997). Relation between cognitive dysfunction and pseudobulbar palsy in amyotrophic lateral sclerosis. *Journal of Neurology, Neurosurgery, and Psychiatry*, *62*, 464-472.
- Abrahams, S., Leigh, P. N., & Goldstein, L. (2005). Cognitive change in ALS: A prospective study. *Neurology*, *64* (7), 1222-1226.
- Alant, E. (2005). AAC technology for development. In A. Alant, & L. L. Lloyd (Eds.), *Augmentative and alternative communication and severe disabilities: Beyond poverty* (pp. 192-220). London: Whurr Publishers.
- Aron, A., & Fraley, B. (1999). Relationship closeness as including other in the self: Cognitive underpinnings and measures. *Social Cognition*, *17* (2), 140-160.
- Aron, E., Aron, E.N., & Smollan, D. (1992). Inclusion of other in the self scale and the structure of interpersonal closeness. *Journal of Personality and Social Psychology*, *63* (4), 596-612.
- Aron, A., Aron, E. N., Tudor, M., & Nelson, G. (1991). Close relationships as including other in the self. *Journal of Personality and Social Psychology*, *60* (2), 241-253.
- Baikie, E. (2002). The impact of dementia on marital relationships. *Sexual and Relationships Therapy*, *17* (3), 289-299.

- Ball, L. J., Beukelman, D. R., & Pattee, G. L. (2004). Communication effectiveness of individuals with amyotrophic lateral sclerosis. *Journal of Communication Disorders, 37*, 197-215.
- Ball, L. J., Beukelman, D. R., Ullman, C., Maassen, K., & Pattee, G. L. (2005). Monitoring speaking rate by telephone for persons with amyotrophic lateral sclerosis. *Journal of Medical Speech-Language Pathology, 13* (4), 233-238.
- Ball, L. J., Willis, A., Beukelman, D. R., & Pattee, G. L. (2001). A protocol for the identification of early bulbar signs in amyotrophic lateral sclerosis. *Journal of the Neurological Sciences, 191* (1-2), 43-53.
- Beach, S. H., & Arias, I. (1989). Assessment of perceptual discrepancy: Utility of the primary communication inventory. *Family Process, 22*, 309-316.
- Beukelman, D. R., & Garrett, K. L. (1988). Augmentative and alternative communication for adults with acquired severe communication disorders. *Augmentative and Alternative Communication, 4* (2), 104-121.
- Beukelman, D. R., & Mirenda, P. (1998). *Augmentative and alternative communication: Management of severe communication disorders in children and adults* (2nd ed.). Baltimore: Paul H. Brookes.
- Beukelman, D. R., & Mirenda, P. (2005). *Augmentative and alternative communication: Supporting children and adults with complex communication needs* (3rd ed.). Baltimore: Brookes Publishing Company.
- Beukelman, D. R., & Yorkston, K. M. (1998). Augmentative and alternative communication application for persons with severe acquired communication

disorders: An introduction. *Augmentative and Alternative Communication*, 5 (1), 42-48.

Beukelman, D. R., Ball, L. J., & Fager, S. (2008). An AAC personnel framework: Adults with acquired complex communication needs. *Augmentative and Alternative Communication*, 24 (3), 255-267.

Blais, M. C., & Boisvert, J. (2007). Psychological adjustment and marital satisfaction following head injury. Which critical personal characteristics should both partners develop? *Brain Injury*, 21 (4), 357-372.

Brintnell, E. S., Madill, H. M., Montgomerie, T. C., & Stewin, L. L. (1992). Work and family after injury: Do female and male client perspectives differ? *Career Development Quarterly*, 41, 145-160.

Brooks, B. R.; Miller, R. G.; Swash, M.; Munsat, T. L. (2003). *El Escorial Revisited: Revised Criteria for the Diagnosis of Amyotrophic Lateral Sclerosis*. Retrieved February 28, 2009, from World Federation of Neurology Research Group on Motor Neuron Diseases: <http://www.wfnals.org/guidelines/1998elescorial/elescorial1998.htm>

Burleson, B. R., & Denton, W. H. (1997). The relationship between communication skill and marital satisfaction: Some moderating effects. *Journal of Marriage and the Family*, 59, 884-902.

Charmaz, K. (1995). The body, identity, and self: Adapting to impairment. *Sociological Quarterly*, 36 (4), 657-681.

Cheung, J., & Hocking, P. (2004). Caring as worrying: The experience of spousal carers. *Journal of Advanced Nursing*, 47 (5), 475-482.

- Chiò, A., Gauthier, A., Montuschi, A., Calvo, A., Di Vito, N., Ghiglione, P., et.al. (2004). A cross sectional study of determinants of quality of life in ALS. *Journal of Neurology, Neurosurgery and Psychiatry*, 75, 1597-1601.
- Cohen, J. (1992). A power primer. *Psychological Bulletin*, 112, 155-159.
- Cutrona, C. (1996). *Social support in couples*. Thousand Oaks: Sage Publications.
- Cutrona, C. E. (2004). A psychological perspective: Marriage and the social provisions of relationships. *Journal of Marriage and Family*, 66, 992-999.
- Dagenais, P. A., Brown, G. R., & Moore, R. E. (2006). Speech rate effects upon intelligibility and acceptability of dysarthric speech. *Clinical Linguistics and Phonetics*, 20 (2/3), 141-148.
- Darley, F. L., Aronson, A. E., & Brown, J. R. (1975). *Motor speech disorders*. Philadelphia: W. B. Saunders Company.
- Darley, F., Aronson, A., & Brown, J. (1969). Clusters of deviant speech dimensions in the dysarthrias. *Journal of Speech and Hearing Disorders*, 12, 462-496.
- DePaul, R., & Kent, R. D. (2000). A longitudinal case study of ALS: Effects of listener familiarity and proficiency on intelligibility judgements. *American Journal of Speech-Language Pathology*, 9 (3), 230-240.
- Diamanti, T. (2000). Get to know me. In M. B. Krezman, & C. J. Williams (Eds.), *Beneath the surface: Creative expressions of augmented communicators* (pp. 98-99). Toronto: ISAAC Press.

- Dickson, S., Barbour, R. S., Brady, M., Clark, A. M., & Paton, G. (2008). Patients' experiences of disruptions associated with post-stroke dysarthria. *International Journal of Language and Communication Disorders*, 43 (2), 135-153.
- Doyle, M., & Phillips, B. (2001). Trends in augmentative and alternative communication use by individuals with amyotrophic lateral sclerosis. *Augmentative and Alternative Communication*, 17 (3), 167-178.
- Doyle, M., Kennedy, M. R., Jausalaitis, G., & Phillips, B. (2000). AAC and Traumatic Brain Injury. In D. R. Beukelman, K. M. Yorkston, & J. Reichle (Eds.), *Augmentative and alternative communication for adults with acquired neurological disorders* (pp. 271–304). Maryland: Brookes Publishing Company.
- Duffy, J. (1995). *Motor speech disorders: Substrates, differential diagnosis and management*. Baltimore: Mosby.
- Fong, G. Y., Cheng, T. S., Lam, K., Cheng, W. K., Mok, K. Y., Cheung, C. M., et al. (2005). An epidemiological study of motor neuron disease in Hong Kong. *Amyotrophic Lateral Sclerosis*, 6 (3), 164-168.
- Fox, L. E., & Sohlberg, M. M. (2000). Meaningful communication roles. In D. R. Beukelman, K. M. Yorkston, & J. Reichle (Eds.), *Augmentative and alternative communication for adults with acquired neurological disorders* (pp. 3-24). Baltimore: Paul H. Brookes.
- Freed, D. (2000). *Motor speech disorders: Diagnosis and treatment*. San Diego: Singular Publishing.

- Fried, T. R., Bradley, E. H., O'Leary, M. A., & Byers, A. L. (2005). Unmet desire for caregiver-patient communication and increased caregiver burden. *Journal of the American Geriatrics Society, 53* (1), 59-63.
- Fried-Oken, M., Fox, L., Rau, M. T., Tullman, J., Baker, G., Hindal, M., et al. (2006). Purposes of ACC device use for persons with ALS as reported by caregivers. *Augmentative and Alternative Communication, 22* (3), 209-221.
- Ganzini, L., Johnston, W. S., & Hoffman, W. F. (1999). Correlates of suffering in amyotrophic lateral sclerosis. *Neurology, 52*, 1434-1440.
- Gelinas, D. F. (1999). Conceptual approach to diagnostic delay in ALS: A United States perspective. *Neurology, 53* (Suppl 5), S17-S19.
- Goldstein, L. H., Adamson, M., Jeffrey, L., Down, K., Barby, T., Wilson, C., et al. (1998). The psychological impact of MND on patients and carers. *Journal of the Neurological Sciences, 160* (Suppl.1), S114-S121.
- Goldstein, L. H., Atkins, L., & Leigh, P. N. (2002). Correlates of quality of life in people with motor neuron disease (MND). *ALS and other motor neuron diseases, 3*, 123-129.
- Gordon, K. C., Baucom, D. H., Epstein, N., Burnett, C. K., & Rankin, L. A. (1999). The interaction between marital standards and communication patterns: How does it contribute to marital adjustment? *Journal of Marital and Family Therapy, 25* (2), 211-223.
- Gottman, J. M., & Porterfield, A. L. (1981). Communicative competence in the nonverbal behavior of married couples. *Journal of Marriage and Family, 43* (4), 817 – 824.

- Hillel, A.D., Miller, R. M., Yorkston, K., McDonald, E., Norris, F.H., & Konikow, N. (1989). Amyotrophic lateral sclerosis severity scale. *Neuroepidemiology*, 8 (3), 142-150.
- Hillemacher, T., Gräbel, E., Tigges, S., Bleich, S., Neundörfer, B., Kornhuber, J., et al. (2004). Depression and bulbar involvement in amyotrophic lateral sclerosis. *ALS and other motor neuron disorders*, 5, 245-249.
- Hobart, C. W., & Klausner, W. J. (1959). Some social interactional correlates of marital role disagreement, and marital adjustment. *Marriage and Family Living*, 21 (3), 256-263.
- House, A., House, B., & Campbell, M. (1981). Measures of interobserver agreement: Calculation formulas and distribution effects. *Journal of Behavioral Assessment*, 3 (1), 37-57.
- Hunt, C. K. (2003). Concepts in caregiver research. *Journal of Nursing Scholarship*, 35 (1), 27-32.
- Hustad, K. (1999). Optimizing communicative effectiveness. In K. M. Yorkston, D. R. Beukelman, E. A. Strand, & K. R. Bell (Eds.), *Management of motor speech disorders in children and adults* (2nd ed., pp. 483-542). Austin: ProEd.
- Hustad, K. C. (2008). The relationship between listener comprehension and intelligibility scores for speakers with dysarthria. *Journal of Speech, Language and Hearing Research*, 51, 562-573.
- Hustad, K. C., & Cahill, M. A. (2003). Unfamiliar listener's evaluation of speech supplementation strategies for improving the effectiveness of severely dysarthric speech. *Augmentative and Alternative Communication*, 4, 213-220.

- Johnson, P. L. (2000). If I do say so myself. In M. Fried-Oken, & J. H. Bersani (Eds.), *Speaking up and spelling it out* (pp. 47-56). Maryland: Paul H. Brookes.
- Kahn, M. (1970). Non-verbal communication and marital satisfaction. *Family Process*, 9, 449-456.
- Katz, J. (2002). Ill-health. In N. Thompson (Ed.), *Loss and grief: A guide for human service practitioners* (pp. 149-161). Hampshire: Palgrave.
- Kinsella, G., Cooper, B., Picton, C., & Murtagh, D. (1998). A review of the measurement of caregiver and family burden in palliative care. *Journal of Palliative Care*, 14 (2), 37-45.
- Klasner, E. R., & Yorkston, K. M. (2005). Speech intelligibility in ALS and HD dysarthria: The everyday listener's perspective. *Journal of Medical Speech-Language Pathology*, 12 (2), 127-140.
- Kotchoubey, B., Lang, S., Winter, S., & Birbaumer, N. (2003). Cognitive processing in completely paralyzed patients with amyotrophic lateral sclerosis. *European Journal of Neurology*, 10, 551-558.
- Kowal, J., Johnson, S. M., & Lee, A. (2003). Chronic illness in couples: A case for emotionally focused therapy. *Journal of Marital and Family Therapy*, 29 (3), 299-310.
- Lasker, J. P., & Bedrosian, J. L. (2000). Acceptance of AAC by adults with acquired disorders. In D. R. Beukelman, K. M. Yorkston, & J. Reichle (Eds.), *Augmentative and alternative communication for adults with acquired neurologic disorders* (pp. 107-136). Baltimore: Paul H. Brookes.

- Leigh, P. N., Abrahams, S., Al-Chalabi, A., Ampong, M. A., Goldstein, L. H., Johnson, J., et al. (2003). The management of motor neurone disease. *Journal of Neurology, Neurosurgery and Psychiatry*, 74 (Suppl IV), iv32-iv47.
- Lev-Wiesel, R. (1988). Spouses' perceptions of each other's coping ability with possible stressful life events and marital quality. *Contemporary Family Therapy*, 20 (2), 211-220.
- Lewis, J. M. (1998). For better or worse: Interpersonal relationships and individual outcome. *American Journal of Psychiatry*, 155 (5), 582-589.
- Light, J. (1988). Interaction involving individuals using augmentative and alternative communication systems: State of art and future directions. *Augmentative and alternative communication*, 4, 66-82.
- Light, J. (1989). Toward a definition of communicative competence for individuals using augmentative and alternative communication systems. *Augmentative and Alternative Communication*, 5 (2), 137 – 144.
- Light, J. (1997). "Communication is the essence of human life": Reflections on communicative competence. *Augmentative and Alternative Communication*, 13, 61-70.
- Light, J. C., Arnold, K. B., & Clark, E. A. (2003). Finding a place in the 'social circle of life'. In J. C. Light, D. R. Beukelman, & J. Reichle (Eds.), *Communicative competence for individuals who use AAC: From research to effective practice*. Baltimore: Paul H. Brookes Publishing Co.

- Linebaugh, C. W., Kryzer, K. M., Oden, S., & Myers, P. S. (2008). Reapportionment of communicative burden in aphasia: A study of narrative interaction. *Aphasiology*, 20 (1), 84-96.
- Lloyd, L. L., Fuller, D. R., & Arvidson, H. H. (1997). Introduction and overview. In L. L. Lloyd, D. R. Fuller, & H. H. Arvidson (Eds.), *Augmentative and alternative communication: A handbook of principles and practices* (pp. 1-17). Needham Heights: Allyn & Bacon, Inc.
- Locke, J. L. (1998). Where did all the gossip go? Casual conversation in the information age. *ASHA*, 40,26–31.
- Logroscino, G., Traynor, B. J., Hardiman, O., Chio, A., Couratier, P., Mitchell, J. D., et al. (2008). Descriptive epidemiology of amyotrophic lateral sclerosis: New evidence and unsolved issues. *Journal of Neurology, Neurosurgery and Psychiatry*, 79, 6-11.
- Lubinsky, R. (1997). Perspectives on aging and communication. In R. Lubinsky, & D. J. Higginbotham (Eds.), *Communication technologies for the elderly: Vision, hearing and speech* (pp. 1-22). San Diego: Singular Publishing.
- Luterman, D. (1996). *Counseling persons with communication disorders and their family* (3rd ed.). Austin: Pro-Ed.
- Lyon, J. G. (1998). *Coping with aphasia*. San Diego: Singular Publishing Group Ltd.
- Madill, H. M., Brintnell, E. S., Macnab, D., Stewin, L. L., & Fitzsimmons, G. W. (1989). The delicate balance: Working and family role. *International Journal for the Advancement of Counseling*, 11, 219-230.

- Mathy, P. (2005). *Explorations in using a notebook computer as a clinical speech sampling and analysis tool*. Retrieved September 15, 2005, from www.madonna.org/institute/Software/pmathyreport.htm
- Mathy, P., Yorkston, K. M., & Gutmann, M. L. (2000). AAC for individuals with amyotrophic lateral sclerosis. In D. R. Beukelman, K. M. Yorkston, & J. Reichle (Eds.), *Augmentative and alternative communication for adults with acquired neurological disorders* (pp. 183-232). Baltimore: Paul H. Brookes.
- Maxwell, D.L. & Satake, E. (2006). *Research and statistical methods in communication sciences and disorders*. New York: Thomson Delmar Learning.
- McConkey, R. (2005). Service delivery in low-income countries. In E. Alant, & L. L. Lloyd (Eds.), *Augmentative and alternative communication and severe disabilities: Beyond poverty* (pp. 131-154). London: Whurr Publishers.
- McLeod, J. E., & Clarke, D. M. (2007). A review of psychosocial aspects of motor neurone disease. *Journal of the Neurological Sciences*, 258, 4-10.
- McMillan, J. H., & Schumacher, S. (2001). *Research in education: A conceptual introduction* (5th ed.). New York: Addison Wesley Longman.
- Michallet, B., Tètreault, S., & Le Dorze, G. (2003). The consequences of severe aphasia on the spouses of aphasic people: A description of the adaptation process. *Aphasiology*, 17 (9), 835-859.
- Miglioretti, M., Mazzini, L., Oggioni, G. D., Testa, L., & Monaco, F. (2008). Illness perceptions, mood and health-related quality of life in patients with amyotrophic lateral sclerosis. *Journal of Psychosomatic Research*, 65, 603-609.

- Mitsumoto, H. (1997). Diagnosis and progression of ALS. *Neurology*, 48 (Suppl 4), S2-S8.
- Murphy, J. (2004). "I prefer contact this close": Perceptions of AAC by people with motor neuron disease and their communication partners. *Augmentative and Alternative Communication*, 20 (4), 259-271.
- Murray, J. M., Manela, M. V., Shuttleworth, A., & Livingston, G. A. (1997). Caring for an older spouse with psychiatric illness. *Aging and Mental Health*, 1 (3), 256-260.
- Nalini, A., Thennarasu, K., Gourie-Devi, M., Shenoy, S., & Kulshreshtha, D. (2008). Clinical characteristics and survival pattern of 1153 patients with amyotrophic lateral sclerosis: Experience over 30 years from India. *Journal of the Neurological Sciences*, 272, 60-70.
- National Joint Committee for the Communicative Needs of Persons with Severe Disabilities. (1992). Guidelines for meeting the communicative needs of persons with severe disabilities. *ASHA*, 34 (Suppl.7), 1-8.
- Navran, L. (1967). Communication and adjustment in marriage. *Family Process*, 6, 173-184.
- Neary, D., Snowden, J. S., & Mann, D. M. (2000). Cognitive change in motor neurone disease/amyotrophic lateral sclerosis (MND/ALS). *Journal of the Neurological Sciences*, 180 (1-2), 15-20.
- Nishio, M., & Niimi, S. (2000). Changes over time in dysarthric patients with amyotrophic lateral sclerosis (ALS): A study of changes in speaking rate and

maximum repetition rate (MRR). *Clinical Linguistics and Phonetics*, 14 (7), 485-497.

O'Connor, E. J., McCabe, M. P., & Firth, L. (2008). The impact of neurological illness on marital relationships. *Journal of Sex and Marital Therapy*, 34, 115-132.

Prentice, J. (2000). With communication anything is possible. In M. Fried-Oken, & J. H. Bersani (Eds.), *Speaking up and spelling it out* (pp. 208-214). Baltimore: Paul H. Brookes.

Rhoades, G. K., & Stocker, C. M. (2006). Can spouses provide knowledge of each other's communication patterns? A study of self-reports, spouses' reports, and observational coding. *Family Process*, 45, 499-511.

Riviere, M., Meininger, V., Zeisser, P., & Munsat, T. (1998). An analysis of extended survival in patients with amyotrophic lateral sclerosis treated with riluzole. *Archives of Neurology*, 55 (4), 526-528.

Rolland, J. S. (1994). In sickness and in health: The impact of illness on couples' relationships. *Journal of Marital and Family Therapy*, 20 (4), 327-343.

Rolland, J. S. (1999). Chronic illness and the family life cycle. In B. Carter, & M. McGoldrick (Eds.), *The expanded family life cycle: Individual, family, and social perspectives* (3rd ed., pp. 492-551). Needham Heights: Allyn & Bacon.

Rolland, J. S. (2005). Cancer and the family: an integrative model. *Cancer*, 104 (Suppl 11), 2584-2595.

- Ross, E., & Deverell, A. (2004). *Psychosocial approaches to health, illness and disability. A reader for health care professionals*. Pretoria: Van Schaik Publishers.
- Salkind, N. J. (2008). *Exploring research*. New Jersey: Prentice Hall.
- Sapey, B. (2002). Disability. In N. Thompson (Ed.), *Loss and grief: A guide for human service practitioners* (pp. 139-148). Hampshire: Palgrave.
- Savundranayagam, M. Y., Hummert, M. L., & Montgomery, R. J. (2005). Investigating the effects of communication problems on caregiver burden. *The Journals of Gerontology, 60B* (1), S48-S55.
- Segrin, C., & Flora, J. (2001). Perceptions of relational histories, marital quality, and loneliness when communication is limited: An examination of married prison inmates. *The Journal of Family Communication, 1* (3), 151-173.
- Strong, M. J., Grace, G. M., Orange, J. B., Leeper, H. A., Menon, R. S., & Aere, C. (1999). A prospective study of cognitive impairment in ALS. *Neurology, 53* (8), 1665-1670.
- Stuart, S., Lasker, J. P., & Beukelman, D. R. (2000). AAC message management. In D. R. Beukelman, K. M. Yorkston, & J. Reichle (Eds.), *Augmentative and alternative communication for adults with acquired neurologic disorders* (pp. 25-54). Baltimore: Paul H. Brookes.
- Tönsing, K. M., Alant, E., & Lloyd, L. L. (2005). Augmentative and alternative communication . In E. Alant, & L. L. Lloyd (Eds.), *Augmentative and alternative communication and severe disabilities: Beyond poverty* (pp. 30-67). London: Whurr Publishers.

- Trail, M., Nelson, N. D., Van, J. N., Appel, S. H., & Lai, E. C. (2004). Major stressors facing patients with amyotrophic lateral sclerosis (ALS): a survey to identify their concerns and to compare with those of their caregivers. *ALS and other motor neuron disorders*, 5, 40-45.
- Wells, R., Dywan, J., & Dumas, J. (2005). Life satisfaction and distress in family caregivers as related to specific behavioural changes after traumatic brain injury. *Brain Injury*, 19 (13), 1105-1115.
- Williams, B. (2000). More than an exception to the rule. In M. Fried-Oken, & H. Bersani (Eds.), *Speaking up and spelling out: Personal essays on augmentative and alternative communication* (pp. 245–254). Baltimore: Paul H. Brookes.
- Worms, P. M. (2001). The epidemiology of motor neurone disease: a review of recent studies. *Journal of the Neurological Sciences*, 191, 3-9.
- Yorkston, K. M., Beukelman, D. R., Strand, E. A., & Bell, K. R. (1999). *Management in motor speech disorders in children and adults* (2nd ed.). Austin: Pro-Ed.
- Yorkston, K. M., Beukelman, D. R., & Tice, R. (1996). *Sentence Intelligibility Test for Windows*. Lincoln: Institute for Rehabilitation Science and Engineering, Madonna Rehabilitation Hospital.
- Yorkston, K. M., Miller, R. M., & Strand, E. A. (1995). *Management of speech and swallowing disorders in degenerative disease*. Tuscon: Communication Skill Builders.
- Yorkston, K. M., Strand, E., Miller, R. M., Hillel, A. D., & Smith, K. (1993). Speech deterioration in amyotrophic lateral sclerosis: Implications for the timing of intervention. *Journal of Medical Speech-Language Pathology*, 1 (1), 35-46.

Young, J. M., & McNicoll, P. (1998). Against all odds: positive life experiences of people with advanced amyotrophic lateral sclerosis. *Health and Social Work, 23*, 35-43.

Yunusova, Y., Weismer, G., Kent, R. D., & Rusche, N. M. (2005). Breath-group intelligibility in dysarthria: Characteristics and underlying correlates. *Journal of Speech, Language and Hearing Research, 48* (6), 1294-1310.

APPENDICES

APPENDIX A

CLASSIFICATION OF MOTOR NEURON DISEASE

Riviere, M., Meininger, V., Zeisser, P., & Munsat, T. (1998). An analysis of extended survival in patients with amyotrophic lateral sclerosis treated with riluzole. *Archives of Neurology*, 55, 526-528.

STATE 1 (MILD)

- Recently diagnosed
- Mild deficit in only 1 of 3 regions (speech, arm, leg)
- Functionally independent in speech, upper extremities of daily living and ambulation

STATE 2 (MODERATE)

- Mild deficit in all 3 regions OR
- Moderate to severe deficit in 1 region, while 2 regions are normal or mildly affected

STATE 3 (SEVERE)

- Needs assistance in 2 or 3 regions
- Speech is dysarthric and/or patient needs assistance to walk and/or needs assistance with upper extremities of daily living

STATE 4 (TERMINAL)

- Non-functional use of at least 2 regions and moderate or non-functional use of the third region

APPENDIX B

AMYOTROPHIC LATERAL SCLEROSIS SEVERITY SCALE (ALSS): SPEECH SCALE

Hillel, A.D., Miller, R. M., Yorkston, K., McDonald, E., Norris, F.H., & Konikow, N. (1989). Amyotrophic lateral sclerosis severity scale. *Neuroepidemiology*, 8(3), 142-150.

NORMAL SPEECH PROCESSES

- 10 – **Normal speech** – Individual denies any difficult speaking. Examination demonstrates no abnormality
- 9 – **Nominal speech abnormality** – Only the individual with ALS or spouse notices speech has changed. Maintains normal rate and volume.

DETECTABLE SPEECH DISTURBANCE

- 8 – **Perceived speech changes** – Speech changes are noted by others, especially during fatigue or stress. Role of speech remains essentially normal.
- 7 – **Obvious Speech abnormalities** – Speech is consistently impaired. Affected are rate, articulation, and resonance. Remains easily understood.

BEHAVIOURAL MODIFICATIONS

- 6 – **Repeats messages on occasion** – Rate is much slower. Repeats specific words in adverse listening situations. Does not limit complexity or length of message.
- 5 – **Frequent repeating required** – Speech is slow and laboured. Extensive repetition or a ‘translator’ is commonly needed. Person probably limits the complexity or length of messages.

USE OF AUGMENTATIVE COMMUNICATION

- 4 – **Speech plus augmentative communication** – Speech is used in response to questions. Intelligibility problems need to be resolved by writing or a spokesperson.
- 3 – **Limits speech to one word response** – Vocalizes one word response beyond yes/no, otherwise writes or uses spokesperson. Initiates communication non-vocally.

LOSS OF USEFUL SPEECH

- 2 – **Vocalizes for emotional expression** – Uses vocal inflection to express emotion, affirmation and negation.
- 1 – **Non-vocal** – Vocalization is effortful, limited in duration, and rarely attempted. May vocalize for crying or pain.
- X – **Tracheostomy**

APPENDIX C

SENTENCE INTELLIGIBILITY TEST (SIT) SAMPLE SENTENCES

(ACTUAL SHORT TEST FORM)

Yorkston, K. M., Beukelman, D. R., & Tice, R. (1996). *Sentence Intelligibility Test for Windows*. Lincoln: Institute for Rehabilitation Science and Engineering, Madonna Rehabilitation Hospital.

File: Sample SIT

Date: 20/4/2009

Examiner:

Agency:

Comment:

- 5 A. We brought a brown chair.
- 6 A. I was in love with it.
- 7 A. Old telephone booths aren't easy to find.
- 8 A. The defendant is either guilty or not guilty.
- 9 A. He could never understand people who complained about age.
- 10 A. Aptitude tests indicated that he would do well in accounting.
- 11 A. In that certainty lies a great peace and a great joy.
- 12 A. Those things are only as good as the people who use them.
- 13 A. Adoring fans reached out to touch the players, who sat atop open vehicles.
- 14 A. The children were now daring each other to feats of wild speed and recklessness.
- 15 A. A special meal cooked for friends is as loving a gift as anything you buy.

APPENDIX D

MODIFIED COMMUNICATION EFFECTIVENESS INDEX (CETI-M)

Yorkston, K. M., Beukelman, D. R., Strand, E. A., & Bell, K. R. (1999). *Management in motor speech disorders in children and adults (2nd Ed.)*. Austin: Pro-Ed.

| | | | | | | | | |
|---|----------------------|---|---|---|---|---|----------------|------------------------------|
| <p>Please evaluate how effectively you communicate in these situations. Read the item describing each of the situations and decide how successful you communicate. If you think the communication is <u>very effective</u>, circle the 7. If the communication <u>doesn't occur at all</u>, circle the 1. Circle any number on the scale that best describes communication in that situation.</p> | | | | | | | | |
| | Not at all effective | | | | | | Very effective | |
| Having a conversation with familiar persons in a quiet environment | 1 | 2 | 3 | 4 | 5 | 6 | 7 | V3 <input type="checkbox"/> |
| Having a conversation with strangers in a quiet environment | 1 | 2 | 3 | 4 | 5 | 6 | 7 | V4 <input type="checkbox"/> |
| Having a conversation with a familiar person over the phone | 1 | 2 | 3 | 4 | 5 | 6 | 7 | V5 <input type="checkbox"/> |
| Having a conversation with young children | 1 | 2 | 3 | 4 | 5 | 6 | 7 | V6 <input type="checkbox"/> |
| Having a conversation with a stranger over the phone | 1 | 2 | 3 | 4 | 5 | 6 | 7 | V7 <input type="checkbox"/> |
| Having a conversation while traveling in a car | 1 | 2 | 3 | 4 | 5 | 6 | 7 | V8 <input type="checkbox"/> |
| Having a conversation with someone at a distance | 1 | 2 | 3 | 4 | 5 | 6 | 7 | V9 <input type="checkbox"/> |
| Having a conversation with someone in a noisy environment | 1 | 2 | 3 | 4 | 5 | 6 | 7 | V10 <input type="checkbox"/> |
| Speaking or having a conversation before a group | 1 | 2 | 3 | 4 | 5 | 6 | 7 | V11 <input type="checkbox"/> |
| Having a long conversation with someone (over an hour) | 1 | 2 | 3 | 4 | 5 | 6 | 7 | V12 <input type="checkbox"/> |

APPENDIX E

PRIMARY COMMUNICATION INVENTORY (PCI)

Below is a list of items on communication between you and your spouse. Using the scale described here, tick the column which best represents the extent to which you and your spouse behave in the specified way.

| | Never | Seldom | Occasionally | Frequently | Very frequently |
|--|-------|--------|--------------|------------|-----------------|
| How often do you and your spouse talk over pleasant things that happen during the day? | 1 | 2 | 3 | 4 | 5 |
| How often do you and your spouse talk over unpleasant things that happen during the day? | 1 | 2 | 3 | 4 | 5 |
| Do you and your spouse talk over things you disagree about or have difficulties over? | 1 | 2 | 3 | 4 | 5 |
| Do you and your spouse talk about things in which you are both interested? | 1 | 2 | 3 | 4 | 5 |
| Does your spouse adjust what s/he says and how s/he says it to the way you seem to feel at the moment? | 1 | 2 | 3 | 4 | 5 |
| When you start to ask a question, does your spouse know what it is before you ask it? | 1 | 2 | 3 | 4 | 5 |
| Do you know the feelings of your spouse from his/her facial and bodily gestures? | 1 | 2 | 3 | 4 | 5 |
| Do you and your spouse avoid certain subjects in conversation? | 1 | 2 | 3 | 4 | 5 |
| Does your spouse explain or express himself/herself to you through a glance or a gesture? | 1 | 2 | 3 | 4 | 5 |
| Do you and your spouse discuss things together before making an important decision? | 1 | 2 | 3 | 4 | 5 |
| Can your spouse tell what kind of day you have had without asking? | 1 | 2 | 3 | 4 | 5 |
| Your spouse wants to visit some close friends or relatives. You don't particularly enjoy their company. Would you tell him/her this? | 1 | 2 | 3 | 4 | 5 |
| Does your spouse discuss matters of sex with you? | 1 | 2 | 3 | 4 | 5 |



| | Never | Seldom | Occasionally | Frequently | Very frequently |
|---|-------|--------|--------------|------------|-----------------|
| Do you and your spouse use words which have special meaning not understood by outsiders? | 1 | 2 | 3 | 4 | 5 |
| How often does your spouse sulk or pout? | 1 | 2 | 3 | 4 | 5 |
| Can you and your spouse discuss your most sacred beliefs without feelings of restraint or embarrassment? | 1 | 2 | 3 | 4 | 5 |
| Do you and your spouse talk about things in which you are both interested? | 1 | 2 | 3 | 4 | 5 |
| You and your spouse are visiting friends. Something is said by the friends which causes you to glance at each other. Would you understand each other? | 1 | 2 | 3 | 4 | 5 |
| How often can you tell as much from the tone of voice of your spouse as from what s/he actually says? | 1 | 2 | 3 | 4 | 5 |
| How often do you and your spouse talk with each other about personal problems? | 1 | 2 | 3 | 4 | 5 |
| Do you feel that in most matters your spouse knows what you are trying to say? | 1 | 2 | 3 | 4 | 5 |
| Would you rather talk about intimate matters with your spouse than with some other person? | 1 | 2 | 3 | 4 | 5 |
| Do you understand the meaning of your spouse's facial expression? | 1 | 2 | 3 | 4 | 5 |
| If you and your spouse are visiting friends or relatives and one of you starts to say something, does the other take over the conversation without the feeling of interrupting? | 1 | 2 | 3 | 4 | 5 |
| During the marriage, have you and your spouse, in general, talked most things over? | 1 | 2 | 3 | 4 | 5 |

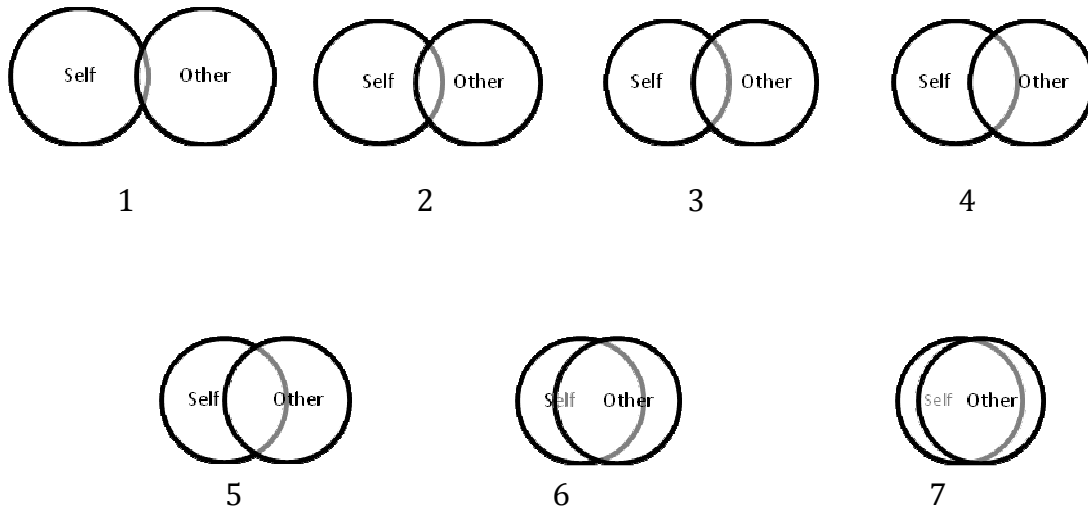
Navran, L. (1967). Communication and adjustment in marriage. *Family Process*, 6, 173-184.

APPENDIX F

INCLUSION OF OTHERS IN THE SELF (IOS) SCALE

Aron, E., Aron, E.N., & Smollan, D. (1992). Inclusion of other in the self scale and the structure of interpersonal closeness. *Journal of Personality and Social Psychology*, 63(4), 596-612.

“Please circle the picture below which best describes your relationship with your spouse”

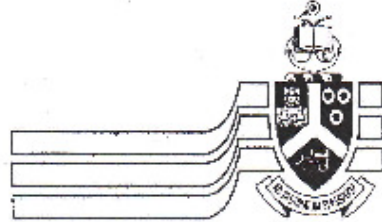




APPENDIX G

UNIVERSITY ETHICS APPROVAL

Members:
Research Proposal and Ethics Committee
Dr P. Chiroro, Dr M-H Coetzee, Prof C Delpoit,
Dr JEH Grubler, Prof KL Harris, Ms H Klupper,
Prof E Krüger, Prof B Louw (Chair), Prof A Mamba,
Prof D Prinsloo, Prof G Prinsloo, Dr E Taljard,
Prof A Wessels, M-FG Wolmarans



University of Pretoria

Research Proposal and Ethics Committee
Faculty of Humanities

7 February 2006

Dear Professor Alant

Project: *Partner's perspective: Communication challenges and quality of life in Motor Neuron Disease*
Researcher: K Joubert
Supervisor: Prof E Alant
Department: CAAC
Reference number: 85367169

Thank you for the application you submitted to the Research Proposal and Ethics Committee, Faculty of Humanities.

I have pleasure in informing you that the Research Proposal and Ethics Committee formally approved the above study on 25 January 2006. The approval is subject to the candidate abiding by the principles and parameters set out in her application and research proposal in the actual execution of the research.

The Committee requests you to convey this approval to Mrs Joubert.

We wish you success with the project.

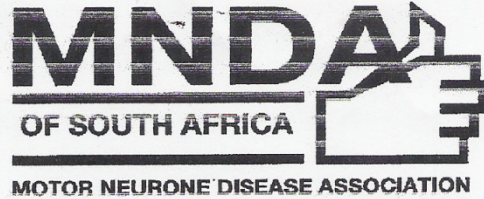
Sincerely

Prof Brenda Louw
Chair: Research Proposal and Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA



APPENDIX H

WRITTEN PERMISSION: MND ASSOCIATION OF SOUTH AFRICA



P.O. BOX 789,
HOWARD PLACE
7450

24 November 2005

The Centre for Augmentative and
Alternative Communication

To Whom it May Concern

Student : Karen Joubert

The Motor Neurone Disease Association supports the research that Karen Joubert proposes to undertake.

We hereby give permission for her to interview MND Patients and their carers on the condition that the patient agrees, gives an informed consent and the ethical committee approves her research.

Dr Peter Vurgarellis
Chairperson

Cape Town
Tel: +27(21) 631 - 6130
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Email: mndaalsa@global.co.za

Member of the International Alliance
ALS/MND Associations
Website: www.alsmndalliance.org.

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Cell: 082 - 878 - 3716
Email: keth@futurejhb.co.za

Affiliated to the Hospice Association of Southern Africa Fundraising Number : NPO 003-462
PATRON: AVIVA PELHAM (M.MUS.) CHAIRMAN: DR. PETER VURGARELLIS

APPENDIX I

PARTICIPANT INFORMED CONSENT FORM

CENTRE FOR AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

Faculty of Education / Fakulteit Opvoedkunde
UNIVERSITY OF PRETORIA
Lynnwood Road, Pretoria, 0002



Enquiries: Karin Joubert
Tel: (011) 411-3526 or (011) 793-6604
Fax: (011) 792-4054
E-mail: karinjoubert@absamail.co.za

INFORMED CONSENT

Speech Intelligibility and Marital Communication in Motor Neuron Disease

AIM OF THE RESEARCH:

I am a Doctoral student conducting research in the field of Motor Neuron Disease (MND). The aim of the research is to determine the association, if any between the deteriorating speech of persons with motor neuron disease and their partners' perception of marital communication

I would like to obtain your permission (both the person with MND and partner of person with MND) to participate in this study. Participation will involve 3 sessions over a period of 12 months. Each session will include the following:

- Completion of questionnaires with specific biographical and medical information pertaining to the person with MND that should take approximately 15 minutes to complete.
- Completion of questionnaires pertaining to communication effectiveness, intelligibility and marital communication of life by both the person with MND and the partner of the person with MND that should take approximately 45 minutes to complete.

POTENTIAL BENEFITS AND RISKS

There is no direct benefit or financial gain to participating in this research. However, the information gathered from you and other participants in the study will be used to provide valuable information to guide interventionists in enhancing quality of life for both the partners and people with MND through the identification,

development and evaluation of supports and services. Feedback on the results of the research will be made available to the MND Association and interested participants.

There are no risks involved should you take part in this study.

PARTICIPANT'S RIGHTS

Should you choose to participate please note that:

- Your participation in this research is *voluntary*; you are free to choose to participate or not to participate
- You may decide to withdraw from the research process at any time, since there is *no penalty* for withdrawing or refusing to participate
- All data will be destroyed should the participant wish to withdraw from the research
- Anonymity will be ensured as there will be no identifying information on the questionnaires and in publications
- All information will be treated with the utmost *confidentiality*. The information will be kept safely in locked cabinets and after completion of the research it will be stored for a period of 5 years at the University of Pretoria Research Archives at the Department of Statistics.
- As this study is required for the partial fulfilment of a Ph.D. degree, the academic supervisor as well as external examiners will have access to the information obtained. Results will be published as a thesis and in relevant academic publications.
- If you agree to participate you need to *sign* this informed consent form as part of your agreement to participate

For any further information or questions about this research project, you are welcome to contact the researcher – Karin Joubert – at Tel: (011) 411-3526; (011) 793-6604 or Cell: 072 1779 655.

Thank you

KARIN JOUBERT

Ph.D. Student

I, _____ agree to participate in the as study outlined above

Participant signature: _____ Date: _____
(Person with MND)

I, _____ agree to participate in the as study outlined above

Participant signature: _____ Date: _____
(Spouse of person with MND)

Researcher signature: _____ Date: _____

APPENDIX J

LETTER OF THANKS FOR RESEARCH PARTICIPANTS

CENTRE FOR AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

Faculty of Education / Fakulteit Opvoedkunde
UNIVERSITY OF PRETORIA
Lynnwood Road, Pretoria, 0002



Enquiries: Karin Joubert
Tel: (011) 411-3526 or (011) 793-6604
Fax: (011) 792-4054
E-mail: karinjoubert@absamail.co.za

20 December 2008

Dear _____

Thank you very much for agreeing to participate in my study on Motor Neuron Disease. The information that you provided has been invaluable to my study, and I am very grateful for all your personal experiences that you shared with me. The time that you have both given towards my research project is much appreciated.

Should you have any further queries please do not hesitate to contact me on 072 1779 655.

Kind regards

Karin Joubert



APPENDIX K

TITLE REGISTRATION FORM

Ons verw: Mr P Woost / 83337100
Tel: 012 420 2736
Faks: 012 420 2656
E-pos: petru.woost@u-p.ac.za



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Fakulteit Geesteswetenskappe

08 Junie 2009

Mev K Joubert
Pousie 400
BROMHOFF
2154

Geachte mev Joubert

TITEL REGISTRASIE: STUDIERIGTING – PHD AANVULLENDE EN ALTERNATIEWE KOMMUNIKASIE

Dit is vir my in gereed om u mee te deel dat die volgende goedkeuring is:

ONDERWERP: Speech intelligibility and marital communication in Motor Neuron Disease

PROMOTOR: Prof J Bornman

MEDEPROMOTOR: Prof E Alant (UP Extra-ordinary Professor)

NEEM ASSEBLIEF KENNIS VAN DIE INLIGTING HIERONDER GENOEM EN DIE AANGEHEGTE VEREISTES.

1. **REGISTRASIE:**
 - (a) U moet vir minstens een akademiese jaar regstreek vir die graad voordat u toegeskat kan word om u proefskrif in te dien.
 - (b) U registrasie moet jaarliks voor Aan van elke akademiese jaar maan word luidel u aan al die vereistes van die graad voldoen het. Geen herregistrasie sal na 31 Maan reinnar word nie. U sal slegs peroglig woor op die leiding van u leorinde en u jaarlks bewys van registrasie aan hom voorle.
2. **KENNISGEWING VOOR INDIENING:**
Dit is in vereiste dat u my ten minste drie maande voor die tyd in kennis stel van u waarneming in u proefskrif in te dien.
3. **GOEDKEURING VIR INDIENING:**
Vir eksamenoeleindes moet u voldoende eksimplare vir elke eksaminator indien, tesame met in skriftelike verdkanning van u leor dat u wry die indiening van die proefskrif goedkeur sowel as in verklaring deur u, wat voor in Kommissore van Ede goukan word, wat by Studenteadministrasie ingehandig word.
4. **DATUM VAN EKSAMEN:**
U wry wendelik versook om my in kennis te stel van die datum van u doktrale eksamen indien dit oors na indiening van die proefskrif aigekom word.

Die nuwe

012 DEKAAN: FAKULTEIT GEESTESWETENSAPPE