

**Message banking: Comparing perceptions of persons with Motor Neuron
Disease, significant others and speech-language pathologists**

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ABSTRACT

Facing the reality of a diagnosis of Motor Neuron Disease (MND) and preparing for the possibility of losing one's ability to speak is extremely challenging. The aim of this study was to determine and compare the perceptions of ten persons with MND (PMNDs), 11 significant others (SOs) and 17 speech-language pathologists (SLPs) about message banking, a process where messages are pre-recorded so as to use them in a speech-generating device. A quantitative, non-experimental, multi-group, posttest-only survey design was used. The 38 participants listened to a short presentation of what message banking entails and how it is done and then individually completed a questionnaire about their perceptions. Data was compared between the three participant groups to investigate the similarities and differences between them. Results indicated that most PMNDs and SOs reported they had never heard of AAC or message banking. SLPs knew only a little about AAC. Only 43% of SLPs were currently using AAC strategies for PMNDs. AAC methods that were most recommended for PMNDs were gestures, letter boards or communication boards. Participants agreed most with the statement that message banking was a good idea for PMNDs in general, although only 80% of PMNDs and 36% of SOs showed an interest in doing message banking for themselves or their loved one with MND. SLPs showed 100% interest in doing message banking with their patients with MND. PMNDs ranked messages important for message banking in descending order namely: social closeness, needs and wants, social etiquette and sharing information. SOs mostly agreed but thought that messages about needs and wants were more important to bank than were messages about social closeness. The SOs also thought that sharing information was more important than social etiquette, which was different to what PMNDs thought. In conclusion, all participants confirmed an awareness of AAC and message banking, although participants' perception about AAC and message banking differed somewhat. They also had slightly differing views about the categories of messages that were important to bank during message banking.

Keywords: amyotrophic lateral sclerosis, augmentative and alternative communication, communication purposes, message banking, motor neuron disease, multi-group posttest-only survey, significant others, speech-language pathologists.

OPSOMMING

Om die werklikheid van 'n diagnose van Motorneuronsiekte (MNS) in die gesig te staar en om voor te berei vir die verlies van spraak is uiters uitdagend. Die doel van hierdie studie was om vas te stel wat die bewustheid en persepsies van 10 persone met MNS, 11 betekenisvolle ander en 17 spraak-taaltherapeute (STT'e) oor die berging van boodskappe is. Om 'n boodskap te bank behels 'n proses waar boodskappe vooraf gestoor word om later in 'n elektroniese spraakhulpmiddel gebruik te word. 'n Kwantitatiewe, pre-eksperimentele, multi-groepontwerp wat uitsluitlik as 'n na-toets toegepas word, is gebruik. Die 38 deelnemers het na 'n kort aanbieding oor boodskapberging geluister. Die aanbieding het die definisie van boodskapberging behels, asook 'n verduideliking van hoe dit gedoen word. Daarna het die deelnemers elkeen individueel 'n vraelys voltooi. Data is vergelyk tussen die drie belangegroepe om ooreenkomste en verskille tussen die groepe te bestudeer. Resultate het aangedui dat die meeste persone met MNS en betekenisvolle ander nog nooit van AAK of boodskapberging gehoor het nie. STT'e het slegs 'n bietjie oor AAK geweet. Slegs 43% van STT'e gebruik tans AAK-strategieë vir persone met MNS. Die AAK-strategieë wat die meeste vir persone met MNS aanbeveel word, sluit gebare, letterborde of kommunikasieborde in. Deelnemers het saamgestem dat die berg van boodskappe oor die algemeen 'n goeie idee vir persone met MNS is. Slegs 80% van persone met MNS, en 36% van betekenisvolle ander het daarin belang gestel om boodskappe vir hulself of hul geliefde met MNS te berg. Alle STT'e het belangstelling getoon om boodskappe, met hul pasiënte met MNS te bank. PMNS het gekies om boodskappe oor die volgende (in dalende volgorde) te bank: *sosiale nabyheid; persoonlike behoeftes en begeertes; sosiale etiket*, en die *deel van inligting*. Betekenisvolle ander het meestal hiermee saamgestem, maar gedink dat boodskappe oor *behoeftes en begeertes* belangriker is as boodskappe oor *sosiale nabyheid*. Die betekenisvolle ander was verder van mening dat die *deel van inligting* belangriker is as *sosiale etiket*, wat verskil het van as persone met MNS se opinie. Ten slotte het deelnemers ooreenstemmende bewustheid oor AAK en die berging van boodskappe gehad. Hul persepsies het egter ietwat van mekaar verskil oor AAK en die belangrikheid daarvan om boodskappe te berg. Deelnemers het verskillende sienings gehad oor die kategorieë van boodskappe wat gestoor behoort te word.

Sleutelwoorde: aanvullende en alternatiewe kommunikasie, amiotrofiese laterale sklerose, boodskapberging, kommunikasiedoeleindes, motorneuronsiekte, multi-groepontwerp uitsluitlik as na-toets, spraak-taalterapeute, versorgers.

CHAPTER 1: PROBLEM STATEMENT AND RATIONALE

1.1 INTRODUCTION

This chapter provides an orientation to the study. The problem statement is discussed, outlining the rationale for the study. Next, definitions of terms used in the context of this study are provided, as well as a list of the abbreviations used. The chapter is concluded with an outline of each of the chapters.

1.2 PROBLEM STATEMENT AND RATIONALE

“My head is a mess. I stand up, walk across to the window, run my hands through my hair and stare out into the middle distance. My mind goes blank. I don’t know what to do. I’m 29 years old and I have just been given a death sentence.” (Aikman, 2014, p. 1)

Gordon Aikman was 29 years old when he was diagnosed with Motor Neuron Disease (MND). He compared receiving the diagnosis of MND to receiving a death sentence. MND is a neurodegenerative condition where the nerve cells that allow a person to move, breathe and speak progressively degenerate. Understandably, such a diagnosis is one that instantly changes the reality of the person diagnosed (Mathy, Yorkston & Guttman, 2000). The heavy burden of what the disease entails can be devastating news to the person and his or her family and loved ones.

Persons diagnosed with MND (PMND) have to face a variety of changes as the disease progresses, including physical, cognitive and speech changes. Research shows that 95% of those diagnosed with MND will lose the ability to meet their daily communication needs with their natural speech (Mckelvey, Evans, Kawai & Beukelman, 2012). Research has also suggested that the majority of individuals will benefit from some type of Augmentative and Alternative Communication (AAC) system to assist with effective communication (Yorkston, Miller & Strand, 1995). In fact, AAC is vital in the management of the PMND. When communication becomes impaired, AAC can assist with more effective

palliative care and can also improve the person's quality of life by assisting with decision making, optimising functioning and allowing for opportunities for personal growth (Bongioanni, 2012).

Unfortunately, using AAC has not been without challenges for PMNDs (Murphy, 2004). Despite the potential of AAC, it does not work successfully for many PMNDs and hence there must be a much more concentrated focus on what is available, how different devices work, as well as what training and support can be provided to both PMNDs and their significant others (SOs). For example, the need to maintain social closeness is not always sustained when AAC technologies or systems are used. The use of a computerised voice in particular makes it difficult to maintain social closeness, because the natural inflection and intonation of a person's voice cannot be translated over a speech-generating device (SGD) (Brownlee, 2014).

Message banking is a relatively new intervention strategy that could facilitate more effective communication for PMNDs, as it could allow social closeness to be sustained. Message banking is an early communication intervention option for PMNDs pioneered by John Costello at the Boston Children's Hospital (Costello, 2014). It involves the digital recording and storing of words, phrases, sentences, personally meaningful sounds and stories, often referred to as "legacy messages", by using a person's own voice, natural inflection and intonation before his/her intelligibility becomes significantly affected. As such, message banking allows a person to use a SGD with pre-recorded messages in his/her own voice. When their speech starts deteriorating or becomes completely unintelligible, PMNDs can retrieve and "speak" these messages by using a variety of high-technology AAC systems.

Deciding to start message banking can in itself be an overwhelming process, as PMNDs have to decide what the important messages are that they would like to bank. Guidance from a speech-language pathologist (SLP) about possible vocabulary and/or messages to bank for future use is of cardinal importance. Murphy (2004) states that the advice given to PMNDs in terms of the possible vocabulary they could store in the device is crucial for effective AAC technology use. Unfortunately, research regarding message banking as an applicable and preferred AAC strategy for PMNDs is currently still limited.

Message banking could maintain social closeness between the PMND and his/her significant others (SOs) as it allows for recording legacy messages (Costello, 2014). According to Light (1988) the need for social closeness may well increase throughout the lifespan, making it particularly important for older adults (Light, 1988). She further states that social closeness is often neglected in intervention as greater focus is placed on the communication of needs and wants, and on information transfer.

The importance of maintaining social closeness throughout the progression of MND is highlighted by Joubert and Bornman (2012) and Murphy (2004). Communication, especially for maintaining social closeness, is an interpersonal process where meaning is not created in isolation but in partnership. Hence, intervention to improve communicative competence should not focus only on the PMND but also on the SO, as this reciprocal partnership is what is necessary to maintain social closeness (Light & McNaughton, 2014).

The support of a close caregiver, SO, spouse, partner, family member, child or friend is vital during the process of message banking. Research findings confirm the importance of collaborative effort between a person with communication difficulties and his/her SO, resulting in their shared responsibility for communication (Calculator, 1998; Murphy, Marková, Collins & Moodie, 1996). SOs may give valuable assistance in identifying frequently used messages that are a natural part of the social identity of their loved one with MND (Costello, 2014). The successful use of message banking therefore depends to a large degree on the awareness, concerns, skills and preferences of the SO.

Message banking is best accomplished with the support of SLPs who provide the PMND with guidance about using or considering the use of AAC. This includes providing a framework of communication purposes, as well as categories and themes of messages that could be considered during message banking.

This study aims to determine the perceptions about message banking of SLPs and compare them to those of PMNDs and their SOs. PMNDs and their SOs are more likely to depend on the SLPs for guidance about how and when to proceed and what vocabulary or messages to record during message banking. This study will determine perceptions about message banking as well as possible

messages of importance by comparing the perspectives of PMNDs, SOs and SLPs.

1.3 DEFINITION OF TERMS

The following terms that are frequently used in this study are clarified to provide the reader with context.

1.3.1 Augmentative and alternative communication

Augmentative and alternative communication (AAC) refers to an area of research, as well as clinical and educational practice. AAC involves attempts to study and, when necessary, compensate for temporary or permanent impairments, activity limitations and participation restrictions of individuals with severe disorders of speech-language production and/or comprehension, including spoken and written modes of communication (ASHA, 2001). AAC further endeavours to compensate for the impairment and disability patterns of individuals with little or no functional speech such as persons diagnosed with MND (Beukelman & Mirenda, 2005; Lloyd, Fuller & Arvidson, 1997). AAC strategies employed by PMNDs to enhance or facilitate communication include a variety of unaided strategies (e.g. gestures and facial expressions), aided low-technology strategies (e.g. topic and alphabet cues, alphabet boards) and high-technology strategies (e.g. computer systems with digitised or synthetic speech) (Beukelman, Ball & Fager, 2008; Fried-Oken et al., 2006).

1.3.2 Communication purposes

Light (1988) defined four purposes of communication, namely (i) communication of needs and wants; (ii) information transfer; (iii) social closeness; and (iv) social interaction. Communication of needs and wants focuses less on the participants and more on the end goal (Light, 1988). For the purpose of information transfer, the focus is placed more on the message. For social closeness, the interaction with the partner is what is most important. Social interaction aims to perform the designated roles of conversation.

1.3.3 Dysarthria

Dysarthria is the collective name for a group of speech disorders that result from disruptions in muscular control (e.g. weakness, slowness, or incoordination) of the speech mechanism due to impairment of the central or peripheral nervous system. This term includes co-occurring neurogenic disorders in all the basic processes of speech, namely 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, 2005).

1.3.4 Motor Neuron Disease (MND)

MND, known as amyotrophic lateral sclerosis (ALS) in Europe and in the United States of America is a rare but rapidly progressive neurological condition categorised by motor neuron degeneration of the central nervous system, and in some cases, front temporal impairment (Hardiman, van den Berg & Kiernan, 2011). MND is used as an umbrella term for degenerative neurological diseases that affect the motor neurons in the brain and spinal cord (Murphy, 2004). MND could therefore affect all four limbs, swallowing, speech and breathing (Young & McNicoll, 1998).

1.3.5 Message banking

Message banking is a relatively new intervention option for PMND where the voice of a person is recorded as he/she speaks any meaningful sentences, stories, sounds or legacy messages that are associated with the PMND. These messages are then later accessed in a SGD and will be spoken in the voice of the PMND.

1.3.6 Person with MND (PMND)

For the purposes of this study, the term 'person with MND' (PMND) refers to a person diagnosed with MND by a neurologist. He/she could have a bulbar, spinal, mixed or unspecified diagnosis of MND.

1.3.7 Significant other (SO)

For the purposes of this study, the term 'significant other' (SO) refers to a family member, close friend, spouse or child who knows the PMND well. This SO should spend a minimum of 5 hours per week with the PMND.

1.3.8 Speech-language pathologist (SLP)

For the purposes of this study, the term 'speech-language pathologist' (SLP) refers to both speech-language therapists (as the profession is known in South Africa) and speech-language pathologists (as the profession is known internationally). The American Speech-Language-Hearing Association (ASHA) defines the scope of practice for the SLP as the assessment, management and remediation of speech-language and swallowing disorders. SLPs offer expert knowledge of communication difficulties and assist people with the most appropriate and effective modes for communicating in various social settings so as to maximise their quality of life (ASHA, 2001).

1.4 ABBREVIATIONS

| | | |
|--------|---|---|
| AAC | - | Augmentative and Alternative Communication |
| ALS | - | Amyotrophic Lateral Sclerosis |
| ASHA | - | American Speech-Language-Hearing Association |
| BCI | - | Brain-Computer Interface |
| CPD | - | Continuing Professional Development |
| ETCS | - | Eye Tracking Computer System |
| HPCSA | - | Health Professionals Council of South Africa |
| LNFS | - | Little or No Functional Speech |
| MND | - | Motor Neuron Disease |
| MNDASA | - | Motor Neuron Disease Association of South Africa |
| NGO | - | Non-Governmental Association |
| PBP | - | Progressive Bulbar Palsy |
| PMA | - | Progressive Muscular Atrophy |
| PMND | - | Person with MND |
| SASLHA | - | South African Speech-Language-Hearing Association |

| | | |
|-----|---|-----------------------------|
| SGD | - | Speech-Generating Device |
| SLP | - | Speech-Language Pathologist |
| SO | - | Significant Other |

1.5 CHAPTER OUTLINES

Chapter 1 provides an overview of the problem statement and justification for the study. This chapter also includes definitions of commonly used terms in the study, a list of abbreviations, and a summary of what each chapter entails.

Chapter 2 provides the conceptual framework and literature review for this study. It starts with providing a description of the impact of MND on the PMND's physical, cognitive and speech abilities. Alternative communication and MND are discussed, as well as AAC strategies and technologies currently used for PMNDs. In a systematic review of the literature on this subject, 19 articles are systematically reviewed to determine the AAC strategies currently used for PMNDs. Perceptions about the existing AAC strategies are discussed from the view of the PMNDs, their SOs and the SLP. The chapter concludes with implications for the importance of message banking as a new early intervention AAC strategy for PMNDs.

Chapter 3 describes the methodology used in this study. The aims, sub aims and research design are discussed in this chapter, followed by a presentation and critical evaluation of the pilot study. This is followed by a description of the main study. Finally a detailed description is provided of the three participant groups, equipment, measuring instruments and data collection procedures. The data analysis methods and statistical analysis conclude Chapter 3.

Chapter 4 provides the results for each sub aim set and presents a critical discussion of the results on completion of the study. Data is organised, analysed and interpreted to allow the researcher to draw conclusions about how perceptions about message banking compare between PMNDs, SOs and SLPs, as well as the specific communication purposes that are important for message banking across these participant groups. A discussion of the factors that contributed to the outcomes concludes the chapter.

Chapter 5 presents the conclusions of the study as well as a critical evaluation of its strengths and weaknesses. Clinical implications and future recommendations are discussed.

1.6 SUMMARY

Chapter 1 provided and described the problem statement, rationale as well as the purpose of the study. It included a definition of terms used in the context of the research, together with an explanation of the abbreviations used. The chapter concluded with an outline of the different chapters.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

A diagnosis of MND is one that instantly changes the reality of the person diagnosed (Mathy et al., 2000). The burden of what the disease entails can be overwhelming to the PMND and his/her family and loved ones. The purpose of this chapter is firstly to provide an overview of the available literature regarding the use of AAC strategies for people diagnosed with MND, and secondly to discuss the perceptions about these AAC strategies for PMNDs.

This chapter serves as a conceptual framework for the study and starts off with a description of MND and how it affects the individual diagnosed. Emphasis is placed on how the individual's communication will be affected throughout the disease progression. The current AAC strategies used to aid the communication of PMND are described. Next follows a discussion of the prevailing perceptions of PMNDs, their SOs and SLPs about current AAC strategies. This chapter concludes by highlighting the paucity of research into the perceptions of PMNDs, their SOs and SLPs regarding message banking, seeing that it is a relatively new, early option AAC strategy for this population.

2.2 DESCRIPTION OF MND

MND, known as amyotrophic lateral sclerosis (ALS) in Europe and in the United States of America, is a rare but rapidly progressive neurological condition characterised by motor neuron degeneration of the central nervous system, and in some cases, front temporal impairment (Hardiman et al., 2011). ALS is also known as Lou Gehrig's disease, Progressive Muscular Atrophy (PMA), Progressive Bulbar Palsy (PBP), and Progressive Lateral Sclerosis, which are all subtypes of MND (Murphy, 2004). MND is used as an umbrella term for degenerative neurological diseases that affect the motor neurons in the brain and spinal cord (Murphy, 2004). According to Young and McNicoll (1998), MND could affect all four limbs, swallowing, speech and breathing. It is steadily progressive with an average course of two to three years (Young & McNicoll,

1998; Doyle & Phillips, 2001). However, more recent data proves prolonged survival due to more effective management strategies, including Riluzole, percutaneous gastrostomy, mechanical ventilation, tracheostomy, and comprehensive care (Pupillo, Mesinna, Logroscino & Beghi, 2014). Nowadays survival for up to 10 years is not unexpected for ALS, as longer survival is predicted by younger age, spinal onset, male gender, and suspected ALS (Pupillo et al., 2014).

Both the etiology of and a cure for MND are currently unknown. The majority of people who develop MND are between the ages of 45 to 65 years (Murphy, 2004). There is no conclusive evidence that MND is more prevalent in any specific geographical area, class or occupation (Murphy, 2004). It is estimated that 3000 people are currently living with MND in South Africa (Henning, 2012; MNDA.org, 2012), based on the prevalence of 6 in 100 000 people who suffer from MND internationally.

PMNDs are typically diagnosed with either of two types of MND – bulbar or spinal MND. These forms are identified by location of pathology and clinical presentation (Robarge, 2009). In MND, the term “bulbar” signifies neuronal damage in the “bulb” area of the brain stem, which is responsible for controlling common motor functions critical for speech (Robarge, 2009). Consequently patients who are diagnosed with bulbar or brainstem forms of the disease often exhibit difficulties with speaking, swallowing and chewing (Robarge, 2009).

In contrast, patients diagnosed with the spinal form of MND often initially experience disturbances of the motor signals to muscles that result in muscle weakness, muscle atrophy, and hyperactive reflexes. Individuals with the spinal form of MND commonly complain of stumbling or tripping while running or walking, and they experience difficulty with simple motor tasks such as buttoning a shirt (Robarge, 2009). These patients may at first not experience any communication problems, however in the later stages of MND communication changes are not uncommon (Robarge, 2009).

Patients can also have a mixed diagnosis of bulbar and spinal MND. The complexity and variation of this disease requires a multidisciplinary approach to determine the appropriate interventions for a particular patient and his/her family members or caregivers (Robarge, 2009). The interdisciplinary team

should ideally include physicians, SLPs, occupational therapists, physiotherapists, nutritionists, social workers, counsellors and professionals familiar with assistive technology. Beside these professionals, other critical members of this team include the PMNDs, their caregivers and family members or SOs (Robarge, 2009).

2.3 THE IMPACT OF MND ON THE INDIVIDUAL AND HIS/HER FAMILY

During the early stages of the disease, specific symptoms include atrophy of muscles, weight loss, fatigue and fasciculation (Doyle & Phillips, 2001). The effects on physical, cognitive and speech abilities are discussed below.

2.3.1 Physical abilities

Muscle deterioration affects the PMND's daily functioning (Doyle & Phillips, 2001). Muscle deterioration can cause individuals to experience difficulty with swallowing, speaking, breathing, moving, and managing fine motor tasks for self-care. Death is most often caused by respiratory failure (Doyle & Phillips, 2001). This progressive deterioration requires a constant process of adapting to the loss of a specific physical function before another presents itself (Mathy et al., 2000; Joubert & Bornman, 2012).

Deterioration of physical abilities often has an impact on the AAC strategies that can be used. The selection of specific AAC system features depends on an individual's upper extremity function and mobility (Doyle & Phillips, 2001). Evaluation of these factors by an occupational therapist or physiotherapist determines optimal physical access to AAC, including specific information regarding the layout of the AAC display (e.g. size of the targets, display size, and positioning or mounting of the display). The mobility status of the PMND will influence inter alia the size and portability of the AAC display that will be used (Doyle & Phillips, 2001).

2.3.2 Cognitive abilities

In the past it was believed that a diagnosis of MND did not affect cognitive abilities and that this was one of the reasons why PMNDs were regarded as excellent candidates for AAC (Doyle & Phillips, 2001; Murphy, 2004; Zago, Poletti,

Morelli, Doretta & Silani (2011). More recent literature, however, reports that between 15 and 41% of PMNDs experience a frontal temporal dementia (Zago et al., 2011). Over the past decade evidence has proved that some PMNDs have measurable cognitive and behavioural deficits that can have practical consequences on their ability to operate a communication device, especially in the final stages of MND (Hanson, 2011; Zago et al., 2011). Cognitive difficulties will affect the individual's ability to learn how to use new AAC systems, specifically high-technology AAC systems.

2.3.3 Speech abilities

Research shows that 95% of those diagnosed with MND will lose the ability to meet their daily communication needs with their natural speech (Beukelman, Fager, Nordess, 2011; Mckelvey et al., 2012). As the disease progresses, the majority of PMNDs experience a motor speech disorder of mixed dysarthria, specifically flaccid-spastic dysarthria (Duffy, 2005). A PMND's speech could be compromised for various reasons: if breathing is affected, volume can be reduced, voice becomes weak and fewer words will be produced per breath. If the vocal chords are affected, the voice can sound monotonous and have a low pitch. If the soft palate is affected, speech can become hyper nasal. Weakness of the tongue and lips affects articulation and speech becomes slower and imprecise (Strong, Grace, Orange & Leeper, 1996). The speech of a PMND is often characterised by slow, effortful, short phrases, imprecise consonants, hyper nasal quality, inappropriate pauses, reduced pitch range and loudness, as well as a strained-strangled voice (Duffy, 2005).

2.4 THE IMPACT OF MND ON THE FAMILY AND SOs

Not only PMNDs, but also their families need to adapt in order to cope with a variety of changes during the progression of the disease, including changes and adaptations for communication. These adaptations are essential for the PMND to remain as independent and functional as possible (Fried-Oken et al., 2006; Murphy, 2004). There is a need for both communication partners to adapt to this changing situation by acquiring new communication strategies to manage the growing speech disability of the PMND.

It is estimated in literature that primary carers of PMNDs spend 9.5 hours per day caring for a PMND even when there is paid assistance available (Ng, Kee, Amatya & Khan, 2011). It is also advised that perceptions of carers should be investigated as this will allow that the SOs' needs are also met in the management of the PMND (Ng et al., 2011).

An examination of literature shows that the conservation of effective communication is crucial in allowing PMNDs to remain at home and maintain a good quality of life (Bach, 1993). Carrol-Thomas (1995) recommends that successful communication is vital for both psychosocial and physical adjustment of the PMND and his/her SOs. Furthermore, a means of communication is vital to maintain social closeness, provide information, make decisions, and indicate basic wants and needs (Ball et al., 2010).

2.5 AAC STRATEGIES CURRENTLY USED FOR PMNDs

The speech of a PMND will decline at varying rates and in different patterns. Research has proved that the majority of individuals will benefit from some type of AAC system (Yorkston et al., 1995) and that AAC is vital in the management of the PMND. AAC refers to a variety of strategies that facilitate communication for people who are unable to communicate effectively by using only their speech mechanism (Stern, 2008). When overall communication becomes impaired, AAC can meet the needs of palliative care and can improve the person's quality of life by assisting with decision making, optimising function and allowing for opportunities for personal growth (Bongioanni, 2012).

2.5.1 Systematic literature search

In order to identify current AAC strategies used by PMND, a systematic search was conducted to determine the AAC strategies currently used by PMNDs.

The terms searched were "Neurodegenerative Disease", OR "Degenerative Conditions" OR "Motor Neuron Disease", OR "Amyotrophic Lateral Sclerosis", OR "Lou Gehrig's Disease" AND "Communication Strategies", OR "Communication Intervention", OR "Augmentative and Alternative Communication".

The following data bases were searched, i.e. Medline, Ebsco Host and Proquest. Additional articles were found through hand searches and inclusion

criteria were the following: (i) published in English, (ii) peer-reviewed (iii) articles (iv) published between the years 1994 and 2015. These articles described AAC strategies currently used by PMND. The prisma diagram in Figure 2.1 graphically depicts the process.

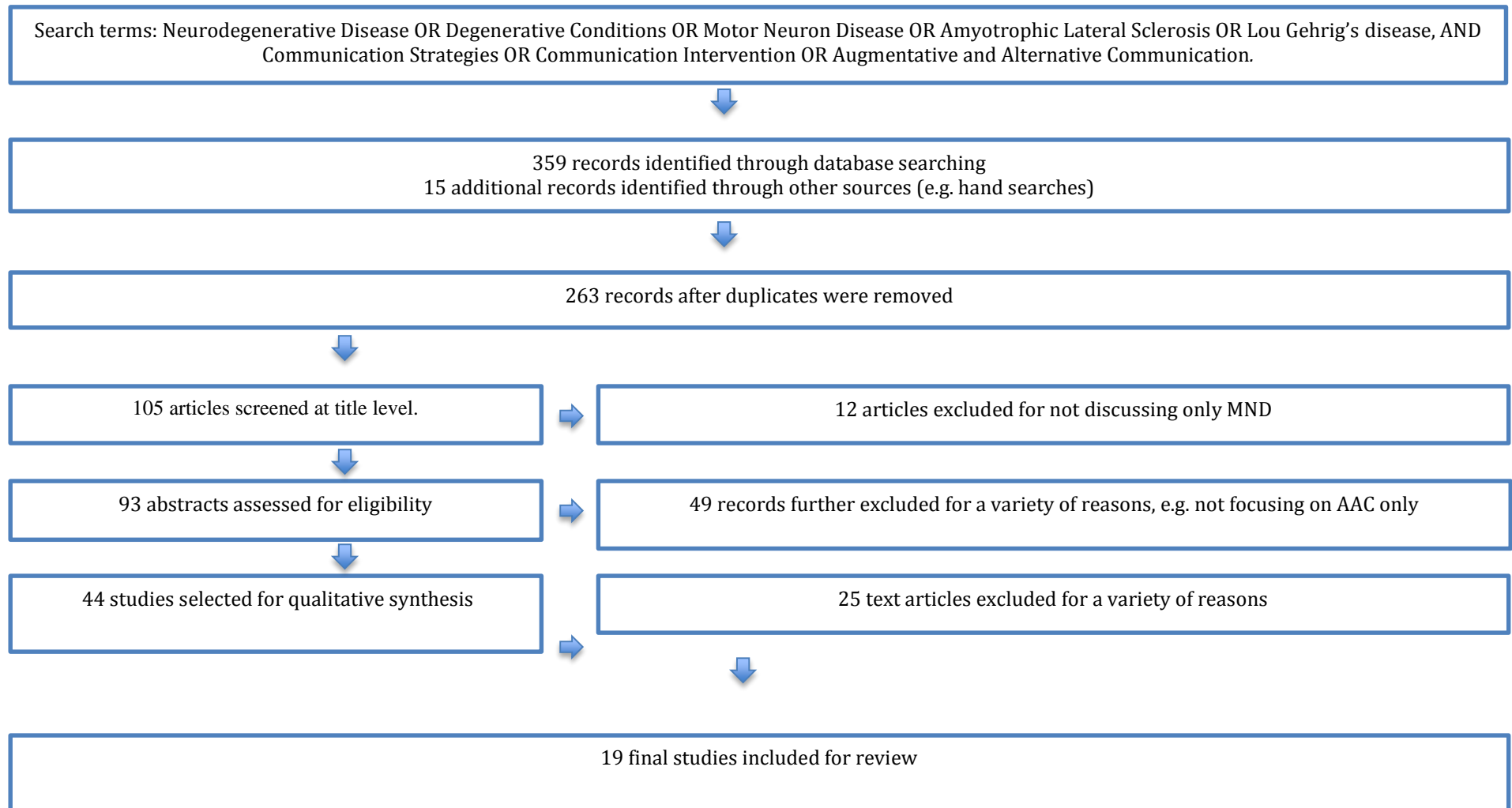


Figure 2.1: Search process for studies included in the systematic literature search

2.5.2 Results of the systematic search

The results of the search based on the previously mentioned keywords and databases were as follows: 359 articles were identified through database searching and 15 articles were identified via searching bibliographies of related articles. Altogether 263 articles were selected for review, of which 105 were screened at title level. Twelve articles were excluded at title level and the abstracts of 93 articles were screened for eligibility. A further 49 articles were excluded for various reasons such as (i) not having an abstract; (ii) not specifically mentioning AAC strategies; and (iii) only including a general discussion about communication for the PMND. A total of 44 studies were selected for qualitative synthesis, of which 25 articles were excluded for various reasons. Finally, 19 articles were selected to be included in the literature review about the current AAC strategies used by PMND. These 19 articles are shown in Appendix A. Specific themes were identified from these articles in terms of the AAC strategies used with PMNDs and are discussed in the sections that follow. The method for identifying, analysing and reporting patterns (themes) within data was thematic analysis (Braun & Clarke, 2006). The approach to this analysis method comprised, identifying themes from the data (inductive approach), and from the researchers prior theoretical knowledge of the research study (a priori/deductive approach) (Ryan and Bernard, 2003). The researcher identified the themes, which was independently checked by the supervisor. Discrepancies were discussed until consensus was reached. Figure 2.2 illustrates the themes identified.

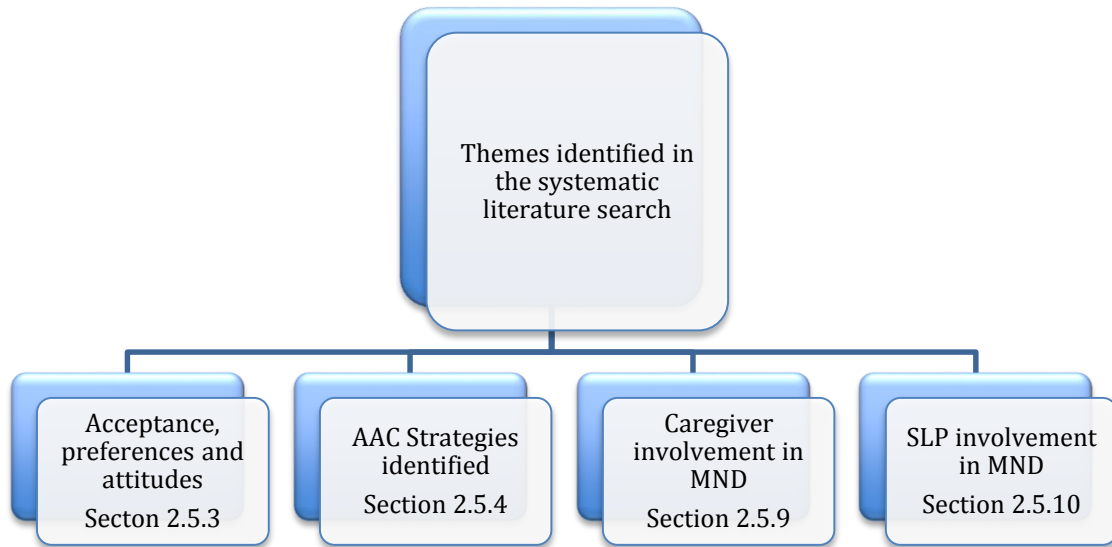


Figure 2.2: Themes identified from the systematic literature search

2.5.3 AAC acceptance, preference, success and attitudes

In order to determine the acceptance, preference, success and attitudes of PMNDs, SOs and SLPs towards AAC, the perceptions of these participants should be investigated. There has been immense excitement about the possible benefits that technology holds for people with little or no functional speech (LNFS) (Hanson, 2011; Murphy, 2004). However, there is not yet consensus in literature about the success of using AAC for PMNDs as using technology does not come without complications for everyone. Having access to a specific piece of technology does not imply that one is competent to use it. It has often been said that providing a person with a piano does not turn him/her into a pianist and the same applies to AAC technology.

A number of studies have concentrated on acceptance, preference, success and attitudes towards AAC. Ball, Beukelman and Pattee (2004) reviewed the use of AAC for PMNDs over the course of four years. In their descriptive study, they investigated the acceptance of AAC of 50 PMNDs. They found that of the 50 participants, 96% accepted AAC. Altogether 90% of them accepted the technology immediately, 6% needed a little while to get used to the idea, and only two participants (4%) rejected AAC. Thus, the acceptance of AAC technology was high among PMNDs in the study by Ball et al. (2004). In their review of the

literature, Beukelman, Fager, Ball and Dietz (2007) also found that AAC acceptance and use had increased for PMND in the past decade. They found, however, that there were not many studies investigating what specific AAC strategies were suggested, preferred or utilised during the disease progression for PMNDs.

Murphy (2004), on the other hand conducted a qualitative case study in which 15 PMNDs and their closest communication partners were investigated over a 3-year period. During data collection, participants were free to talk about any topic they wished. Video recordings captured the use and interplay of different modes of communication, including speech, non-verbal methods, and AAC. The researchers found that AAC strategies were less successful than expected, due to the following: (i) difficulties learning to use high-technology devices; (ii) a need for social closeness that may be a challenge when communicating via an AAC device; and (iii) a lack of training. A critical issue in this study was that participants had received very little input about how to use their devices. A lack of training to ensure that the PMNDs and their SOs understand the device and its functions (e.g. storing phrases, changing the voice and using prediction) is catastrophic for the implementation of AAC.

Similarly Beukelman, Yorkston and Dowden (1985) stated that no matter how advanced technology is, it can never replace the voice, fingers or legs of the PMND. Given his/her steady decline in physical functioning, a PMND often displays little tolerance for any technology that requires extensive new learning (Beukelman et al., 1985; Doyle & Phillips, 2001). It is essential that professionals receive adequate training, time and funding if they are expected to provide the input and backup that are required for PMNDs and their families to use technology successfully (Wendt, 2002).

Richter, Ball, Beukelman, Lasker and Ullman (2003) – in a 3x3 group-repeated-measures experimental design – investigated attitudes towards components of AAC that were used to tell stories by people with ALS. They did so by investigating the attitudes of three groups of listeners (PMNDs, caregivers, and unfamiliar listeners) toward three communication modes (unintelligible natural speech, communication notebook, and synthesised speech). Nine stimulus videotapes were created, each containing three different narratives

delivered in three different communication modes by a male speaker with MND. After viewing each of the videotapes, the listeners responded to a questionnaire. The results confirmed a strong preference for AAC strategies (i.e. communication notebook with synthesised speech) to unintelligible natural speech.

In a single subject case report conducted by Ray (2015), the real-life challenges of using AAC are discussed from the perspective of the PMND. The aim of this study was to summarise the communication needs and AAC intervention strategies used for this PMND. The latter was monitored throughout the assessment and intervention phases. From Ray's report it is evident that the specific PMND wished to attempt multiple modalities when using AAC strategies to supplement his communication. The PMND wished to improve his communication by using a variety of no-technology, low-technology and high-technology strategies that ranged from gestures and verbal speech to AAC devices. He used typing for 10% of his communication purposes and used pre-stored messages for 20% of the time. A combination of gestures and natural speech were used 60% of the time.

Furthermore, Hanson (2011), in an evidence-based review of 713 papers that investigated the AAC options for PMND, echoed that AAC technology and strategies are often combined for the best effect. Similarly, the review by Beukelman et al. (2007) reported that a variety of low- and high-technological AAC strategies were used for PMNDs. A number of studies that discussed the AAC strategies used by PMNDs are discussed in Section 2.5.4.

2.5.4 AAC strategies identified

PMNDs are an extremely diverse group and they demonstrate a wide range of needs and preferences for communication strategies used throughout the stages of MND (Brownlee & Bruening, 2012). The specific strategies identified as important are discussed for each stage, followed by a more general discussion of other strategies that can likely be used during either stage of the diagnosis, depending on the individual's personal symptoms. The specific strategies preferred during the various stages of MND are presented in Figure 2.3.

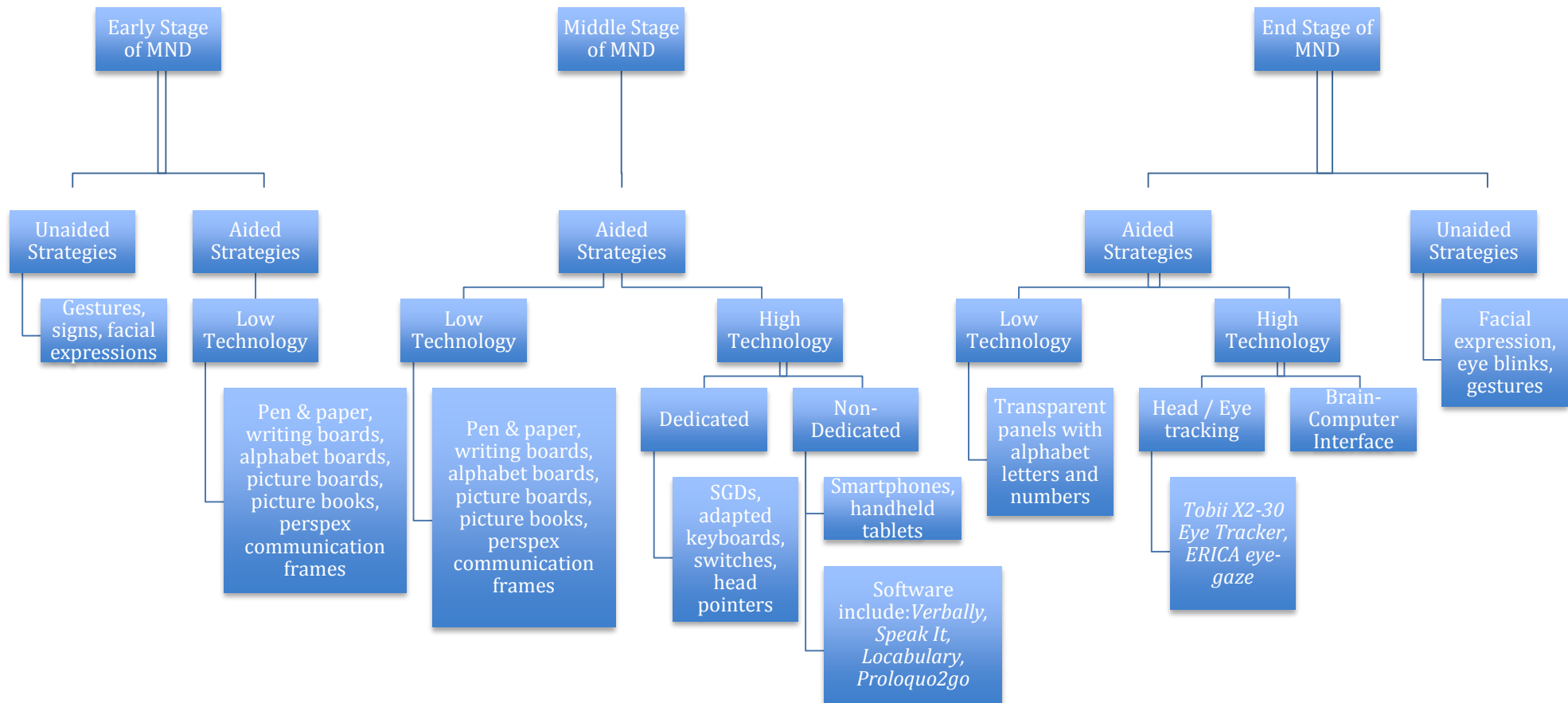


Figure 2.3: AAC strategies used at various stages of MND

2.5.5 AAC strategies for early stages of MND

Yorkston, Strand, Miller, Hillel and Smith (1993) found that intervention in the early stage of MND is advantageous in a number of ways, as it presents the opportunity (i) to develop a relationship with the PMND and family; (ii) to offer information regarding the disease at a pace with which the family and PMND can cope; (iii) to help educate the PMND and his/her family to become informed consumers of medical and technological services.

Yorkston et al. (1993) further stated that the introduction of AAC techniques and devices is determined by how functional or intelligible the speaker is. They suggested that exploring AAC options should begin when the PMND's speaking rate has slowed and his/her intelligibility has become compromised in various listening conditions. AAC intervention may be initiated when the speech rate has dropped to 50% of normal on sentence or paragraph reading tasks (Yorkston, Beukelman & Tice, 1996). In addition to speech intelligibility and rate measures, the environment, familiarity of the communication partner and topic all have an influence on a speaker's intelligibility (Doyle & Philips, 2001; Yorkston, Strand & Kennedy, 1996).

AAC strategies are often described in two broad categories – unaided AAC and aided AAC. Unaided AAC is also referred to as no-technology AAC approaches. These can include gestures, manual signs, head nodding and shaking, facial expressions and using the eyes to communicate (e.g. eye pointing or eye blinks). Typically, unaided strategies are performed using only the person's body and no external aid is necessary (Brownlee & Bruening, 2012). Unaided strategies are valuable for the person in the earlier stages of MND when speech is only slightly compromised and limbs can be engaged to enhance communication with gestures and manual signs. Doyle and Phillips (2001) investigated trends in AAC use by PMNDs and discovered that the four individuals who formed part of their study relied more heavily on unaided or low-technology approaches in the initial stages of the disease. Aided low technology or light technology systems do not require a power source to be operated. Examples of these include a pen and paper, a writing board, an alphabet board, symbol boards or picture books and Perspex communication frames (E-tran frames). These systems typically require little training for users to learn how to operate them. They can however include battery-operated devices with a limited number of voice output messages that can be accessed by selecting a symbol or word

(Brownlee & Bruening, 2012). In this initial phase when speech intelligibility starts to decrease, it was not surprising to find that most participants relied on unaided communication or low-technology AAC to augment their communication (Doyle & Phillips, 2001). As the disease progressed, unaided strategies became more challenging to use and aided strategies were likely to be needed.

Bloch and Clarke (2013), in a study investigating handwriting as an AAC strategy used by PMNDs, used conversational analysis to investigate how handwriting is used as a communicative strategy. As part of the process they also investigated how communication partners responded to these written communication attempts. They found that handwriting was a very effective tool for those PMNDs who still had efficient motor control for writing. They hypothesised that handwriting was less problematic than other forms of AAC because it was a more familiar modality with clearer transition boundaries like physically handing over a writing pad to convey the message (Bloch & Clark, 2013). Although some PMNDs retain their ability to write throughout the course of their disease, the ability to write can be expected to be affected as the disease advances towards the spinal nerves (Brownlee & Bruening, 2012). Notwithstanding the high need for non-electronic aids, the literature on MND tends to focus more on electronic AAC strategies.

2.5.6 AAC strategies for middle stages of MND

As the severity of MND progresses and the physical access that low or light technology requires becomes too difficult to operate, more advanced technology can be used for continued communication. Doyle and Phillips (2001) reported that the participants in their study became increasingly dependent on high-technology options during the middle stage of the disease. In this stage, some persons with MND may wish to participate in end-of-life planning. Communication needs can become more complex at this point and require more sophisticated messages consistent with the high-tech systems described by Doyle and Phillips (2001) for middle stage MND (Brownlee & Bruening, 2012).

High-technology dedicated AAC strategies include any system that requires a power source such as a speech-generating device (SGD). These devices usually involve computer-based communication via computer-generated displays (Robarge, 2009). High-technology systems require some training for effective use. These devices typically

provide more access options, allowing for alteration once the patient becomes unable to independently use his/her limbs. They could include a variety of adapted keyboards, switches or head pointers to access the high-technology devices. High-technology devices can be symbol-based, text-based, and text-to-speech devices, which may all be modified to compensate for any physical or cognitive limitations experienced by the individual with MND (Robarge, 2009).

Examples of high-technology non-dedicated AAC devices include smartphones or handheld tablets with voice output communication apps such as *Verbally*, *Speak It*, *Locabulary*, *Proloquo2go*. These communication apps allow one to type a written message for the device to speak it on your behalf. PMNDs who have hand and finger function successfully use communication apps (Brownlee, 2014). Some PMNDs successfully use personal computers with voice output software. If a PMND can no longer use his/her hands to type, a head mouse and on-screen keyboard can be operated through head movements (Brownlee, 2014). Electronic SGDs that are dedicated speech devices are higher in cost but can be accessed by the PMND in several ways, such as by using the hands, head, or a switch placed wherever the person has consistent voluntary movement under his/her control (Brownlee, 2014).

Literature points out that PMNDs are good candidates for high-technology AAC devices including SGDs, due to the fact that many do not have impairments with cognition, language or spelling (Doyle & Philips, 2001; Murphy, 2004). Speech output on these high-technology devices varies significantly. The voice of the SGD can be synthesised, concatenated or digital (Lloyd et al., 1997).

Synthesised speech devices use computer-generated speech (Stern, 2008). Synthesised devices allow the user to use pre-programmed phrases or words, as well as to spell out novel thoughts in a computerised voice (Brownlee, 2014). An example of a communication app that uses a synthetic voice is the app *Verbally*, available for Apple devices. Current research shows that the SOs who care for PMNDs have expressed concern about the quality of speech synthesis (Mckelvey et al., 2012).

In a critical review of four articles investigating the perceptions of listeners, Brown (2011) found that the mode or voice of communication affects the attitudes of the listeners who are communicating with the PMND. Lund and Light (2007) highlighted cultural issues and commented on the fact that SGDs using synthetic voices do not have two languages available at a time, making it difficult for multilingual families, which is

particularly relevant in a multilingual South African context. Murphy (2004) states that because PMNDs have used their normal voices for speech throughout their lives they find it hard to accept an alternative synthetic voice. Participants also commented that no device could ever replace the human voice. Speech synthesis options on assistive communication devices do not reflect the user's vocal quality or personality.

Concatenated speech is a synthetic speech that is comprised of prerecorded, human phonemes. It is an emerging technology that is bound to replace synthesis by rule (Stern, 2008), but due to the high cost associated with it at present, it is not widely used in AAC systems.

Digitised speech refers to prerecorded messages in human speech and as such it can be used in voice banking or message banking (Stern, 2008). Digital voices use recorded human speech in AAC software so that selected phrases or words will be spoken with the natural voice allowing users to communicate emotion and personality (Brownlee, 2014). In contrast to synthetic voices, digitised speech uses the person's own unique voice and personality can be captured within recordings of the person's own voice. This strategy also allows the user to record the words or phrases in any language that he/she wishes. Examples of apps that use digitised voices include *Proloquo2go* – available on Apple products. Although more natural sounding, digital devices are restrictive because they can only speak the words or phrases pre-stored on the device. They do not allow for free thinking or the creation of novel messages and take up a lot of memory space to be stored (Brownlee, 2014).

2.5.7 AAC strategies for end stage MND

Although recent research about changes in communication needs and strategies during MND progression suggests that newer technologies may make it possible for people with end stage MND to continue communicating effectively further into the disease progression (Ball et al., 2010; Beukelman et al., 2011), additional research is needed in this regard (Brownlee & Bruening, 2012; Doyle & Phillips, 2001).

In recent years, strides have been made in terms of head- and eye-tracking control for AAC technology (Robarge, 2009). Head tracking and eye-gaze tracking are among several options available for PMNDs with limited mobility (Beukelman et al., 2011; Robarge, 2009). Limited mobility is often associated with the later stages of MND. Reliable eye movement can be used in computer-based systems for communication and

other technological applications for environmental control, e-mail and Internet access (Ball et al., 2010; Brownlee & Bruening, 2012). Both the *Tobii X2-30 Eye Tracker* and the *ERICA eye-gaze* are small digital systems that connect to a computer and allow the computer to be operated by the user's eyes. The eyes of a PMND are typically not affected by MND, but those with co-occurring visual or eye problems could unfortunately have difficulty operating an eye tracker effectively.

Spataro, Ciriaco, Manno and La Bella (2014) attempted to explore the effectiveness of communication by using the eye-tracking computer system (ETCS) in persons with end-stage MND. They suggested that for people with severe motor impairment, a variety of eye gaze strategies can be used to allow them to communicate effectively using only their eyes when no other mobility is viable any more. These options range from transparent panels with alphabet letters and numbers to high-tech systems. The ETCS is currently one of the most advanced devices for communication in patients with anarchic/quadruplegic MND. In addition to the vocal synthesis, ETCS devices also allow for Internet connection, webmail, and access to social networks. Light and Mc Naughton (2012; 2014) admit that in the past 25 years communication has evolved from mostly face-to-face interaction to social media usage that allows for communication on a much wider platform.

Spataro et al. (2014) performed a telephone survey with 30 patients with advanced MND who were using ETCS devices to communicate. They found that 100% of participants used the ETCS for accessing communication software, 73% used them for browsing the Internet and e-mailing, and 42.3% used them for communicating via social networks. Almost one in four (23%) patients did not use the ETCS regularly and reported fatigue when using eye-gaze. The study by Spataro et al. (2014) concluded that ETCS was a valuable tool for PMNDs who use AAC as it can be operated with good performance. (The development of oculomotor impairment may limit the functional use of ETCS devices.)

In a different study conducted by Ball et al. (2010), which also describes the communication patterns of 15 PMNDs, the results also indicated that 100% of participants used the Eye-gaze Response Interface Computer Aid (ERICA) for face-to-face interaction, 43% for group interaction, 71% for phone calls, 79% for emails and 86% for internet access.

An ETCS requires precise oculomotor activity. Since the head must be held still for the system to operate effectively, building up sentences and commands on the keyboard could be very fatiguing. An ETCS device represents an important tool for AAC in persons with advanced, near locked-in, MND (Ball et al., 2010). A limitation of ETCS is that it actually relies only on eye movements (Spataro et al., 2014). This technology offers a practical system of access to communication systems and is among the only existing functional options for PMNDs to gain access to a communication system when all other motor skills have degraded and other access options have been exhausted (Ball et al., 2010).

Brain-computer interface (BCI) technology permits people with severe stages of MND who are unable to use eye trackers to use brain signals instead of muscles to communicate and control their environments (Wolpaw & Wolpaw, 2012). Most BCIs use electrical signals recorded from the scalp, the cortical surface, or within the brain. These signals are analysed and translated into control commands for an output device, for example a mouse or keyboard for communication or robotic arm for movement (McCane et al., 2015).

According to Doyle and Phillips (2001) spontaneous and novel communication apparently become restricted and difficult in the end stages of ALS so that low-technology approaches for a limited set of messages are easier. They also recommend that AAC access methods should be investigated to examine if they would influence longer high-technology AAC use.

In the Brownlee and Bruening (2012) study, caregivers were asked to reflect on the communication strategies used by individuals as they moved into the final stage of MND. They reported that there was limited use of AAC technology and perhaps not enough use of simpler, unaided, or low-technology communication systems. Instead, speech remained a preference when the person could still talk, and other simpler or less effortful communication strategies (gestures or eye-blinks) were not used effectively (Brownlee & Bruening, 2012).

Despite the revolutionary advances in technology, Doyle and Phillips (2001) reported an interesting finding, namely that participants who used high-technology strategies in the middle phase of MND returned to low-technology approaches during the end stage of the disease. Overall, the participants regressed back to low technology due to reduced motor skills, reduced communication topics and fewer communication

partners. Unaided approaches were also preferred in the end stages of the disease because participants were mainly concerned with communicating basic wants and needs. Doyle and Phillips (2001) added that their results did not imply that end-stage MND patients rejected high technology completely, but that these methods were reserved for specific communication topics or partners. Therefore, in the final stage, closer to death, there may be more focus on saying goodbye and on meeting basic physical needs, often with a return to unaided or low-technology communication strategies (Brownlee & Bruening, 2012; Doyle & Phillips, 2001). This may be due to the more “intimate” nature of unaided or low-technology systems in which messages require more co-construction and closer proximity of both partners.

2.5.8 Additional AAC strategies reported for PMNDs

Yorkston et al. (1993) found that individuals with ALS could be grouped into different groups, each reflecting different AAC needs. Individuals with bulbar ALS who were ambulatory and had poor speech but adequate hand function, used low-technology AAC approaches such as writing or an alphabet board to either augment speech or as an alternative to it (Yorkston et al., 1993). These individuals also used small, dedicated SGDs for specific communication situations or needs. Individuals with spinal ALS who were confined to bed and who had poor speech and hand function used a range of low-technology AAC approaches as well as switches to access high-technology options such as dedicated or integrated (i.e. computer-based or multipurpose) communication devices. All individuals with ALS could use unaided AAC approaches such as gestures, facial expressions, and yes or no responses to meet specific needs (Doyle & Philips, 2001).

In agreement with this study, Mathy (1996) followed 24 individuals with ALS and found that those with spinal ALS used integrated systems, while those with bulbar ALS used dedicated devices. However, the results of the study should be interpreted cautiously, given that equipment was provided based on availability in the programme’s loan pool. Mathy (1996) found that all 12 persons with spinal ALS who participated in her study chose to use a high-technology approach to tell stories, and six of the 12 persons with bulbar ALS also chose to use a high-technology approach to tell stories.

To confirm the results of her previous study, Mathy and others (2000) surveyed 36 persons with MND and confirmed that the initial MND symptoms influenced their use

of AAC techniques. Participants with initial spinal symptoms were more likely to use high technology, while participants with bulbar symptoms were more likely to depend on handwritten messages and made frequent use of low-technology AAC approaches. Mathy et al. (2000) further reported that quick needs were frequently communicated via low-technology AAC, while high-technology AAC was used for in-depth conversations. They also determined that unaided and low-technology strategies were used across environments and positions (e.g. in a wheelchair or in bed), whereas high-technology systems were primarily used in one environment, often the home (Doyle & Phillips, 2001; Mathy et al., 2000)

Brownlee and Bruening (2012) surveyed 625 family members or caregivers about communication topics used by PMNDs. They discovered that the following options were provided to describe the AAC strategies that PMNDs used to communicate: talking, writing, gestures, letter boards, communication devices, eye-blinks, hand squeeze, sounds, partner-assisted scanning, and flash cards. Some caregivers also reported that their PMND had no means of communication (Brownlee & Bruening, 2012).

The study by Brownlee and Bruening (2012) also reported that communication methods remained reasonably consistent across partners, with talking used most commonly, followed by writing, gestures, and then electronic communication devices. The most popular topics for communication were physical needs, caregiving issues, and family issues. The least discussed topics were spiritual, death and dying issues.

2.5.9 Caregiver involvement in MND

Research findings document the importance of collaborative efforts between a person with communication difficulties and his/her SOs, as these result in shared responsibility between them for effective communication (Calculator, 1998; Murphy et al., 1996). PMNDs are typically cared for by informal (unpaid) caregivers (Krivickas, Shockley & Mitsumoto, 1997). It is vital for PMNDs to communicate effectively and efficiently with their SOs, family and medical staff about a diversity of topics in multiple settings (Mckelvey et al., 2012). Therefore family members and SOs should be encouraged to take part in the PMND's early rehabilitation. The role of the family will increase as the disease progresses, the PMND becomes weaker and his/her requirements for assistive devices change (Bongioanni, 2012; Brownlee & Bruening, 2012).

MND affects each individual differently and can have a devastating impact on family, caregivers and friends (Murphy, 2004). Baxter, Enderby, Evans and Judge (2012) highlight the importance of family members' involvement in the implementation of any AAC system. Family perceptions and attitudes toward technology could be a barrier or facilitator to implementation. Murphy (2004) suggests that the use of AAC depends on the awareness of the partners' concerns, skills and preferences about AAC. Similarly, Ball and Lasker (2013) report that adults with communication difficulties may benefit from partner-supported techniques. Therefore, training of partners to support the effective use of specific strategies is essential.

It has been said that communication is a collective effort and therefore therapy needs to be provided as such. Therapy should not concentrate solely on the PMND but must always involve the person's communication partner or partners (Murphy, 2004). Ball and Lasker (2013) state that it is imperative that all members of the AAC team agree on the value of the AAC technology and strategies and that these relatively simple partner-supported strategies must be taught explicitly to the SOs of the person with MND.

2.5.10 SLP involvement in MND

SLPs play an important role in monitoring speech changes, providing assistance with making choices about communication options, and educating clients, health care providers and family members (Brownlee & Bruening, 2012). Hence it is crucial for the SLP to consider the abilities and expectations of the PMND and SOs in suggesting AAC systems and technology.

The fast progression of the disease necessitates clinical interventionists like SLPs to anticipate communication changes and teach new and compensatory techniques in advance (Bongioanni, 2012). Murphy (2004) suggests that PMNDs and their communication partners may benefit from SLP intervention during the following stages after diagnosis: (i) at or soon after diagnosis – to provide information and to emphasise the fact that help will be available if and when needed; (ii) when speech deterioration becomes evident – to explain the speech mechanism and suggest ways for both partners to maintain/preserve interaction; (iii) when speech is more effortful and less intelligible – to suggest possible strategies to augment interaction and resolve misunderstandings; (iv) when speech is largely unintelligible – to suggest alternative methods of

communication. Moss et al. (1996) consider the importance of early acknowledgment of communication difficulties in order to enable the PMND to make decisions before the disease becomes life threatening or debilitating. Depending on the individual person, it may be valuable to suggest AAC strategies and systems early enough for the person to receive adequate training before fatigue makes new learning too strenuous.

Clinical decision making is a complex process as screening, referral, assessment, acquisition of technology, and training in the use of such technology must occur in a timely manner (Beukelman et al., 2011; Bongioanni, 2012; Hanson, 2011). Often PMNDs, SOs and SLPs wait to implement AAC until speech deteriorates. Unfortunately once this starts happening, it often progresses so rapidly that effective training is not possible (Beukelman et al., 2011). It is therefore fundamental that SLPs are trained to implement AAC strategies such as message banking as early as possible. Before any form of AAC is initiated, it is imperative that the PMND be encouraged to reflect on and discuss his/her own goals for therapy. Professionals may possibly set goals without truly understanding the opinions of the PMND or aspects in his/her life that might affect his/her ability to accept and effectively use AAC strategies and systems (Murphy, 2004).

Fried-Oken et al. (2006) and Murphy (2004) recommend that in the process to understand how PMNDs use AAC strategies and systems, it may be helpful to reflect on the purpose of communication. In her landmark paper, Light (1988) defined four main purposes of human communication: (i) to meet a person's needs and wants; (ii) to share new information; (iii) for social closeness; (iv) for social etiquette.

In a study involving 34 SOs who cared for PMNDs, Fried-Oken et al. (2006) reported that the persons suffering from MND used AAC to get their needs met, to achieve social closeness and to share information. Fried-Oken et al. (2006) stated that the communication of needs and wants focused less on the interaction between participants and more on the end goal (Light, 1988). Messages relating to needs and wants could be predictable to a certain extent. However, for the purpose of information transfer, the focus should be placed more on the message, which is a more challenging purpose of communication as such messages are less predictable than the mere communication of needs and wants. Information transfer depends on the ability to construct novel messages in response to conversation (Light, 1988). The third purpose of communication – to maintain social closeness – is even more problematic to achieve, as the messages are usually not predictable and interaction with each other is the most

important aspect (Light, 1988). The last purpose of communication – to conform to social conventions – revolves around fulfilling designated turns in an acceptable manner with less focus on developing interaction (Light, 1988). It is often said that the loss of social closeness is devastating to the PMND, as he/she can no longer fulfil the same social roles as before (Murphy, 2004; Joubert & Bornman, 2012).

As a consequence, SLPs should be knowledgeable and sensitive about the above purposes of communication when they give advice to PMNDs and their SOs about AAC strategies and systems.

2.6 IMPLICATIONS FOR MESSAGE BANKING

From the above literature review it was clear that no information was available regarding the acceptance or preference of or attitudes towards message banking as an AAC strategy for PMNDs. Several authors nonetheless acknowledge the importance of improving technology (Bocker, Seibold & Neundorfer, 1990; Vaughan & Wolpaw, 1996) for use by PMNDs. Message banking is one such technological improvement.

Communication is associated with humanity and personal identity and has often been claimed as a basic human right (Shadden, Hagstrom & Koski, 2009). The loss or anticipated loss of speech and communication can be like the loss of humanity, and having to face this loss when confronted with a terminal illness is even more challenging (Brownlee & Bruening, 2012).

Message banking is a relatively new intervention strategy that could allow for more effective communication for PMNDs. The term “message banking” should not be confused with the term “voice banking” as these definitions differ somewhat. Voice banking is a process where large inventories of your speech sounds are recorded to create a synthetic or computer voice that sounds like your own voice (Costello, 2014). Message banking in turn comprises of recording whole messages and storing these for later use.

Murphy (2004) states that the advice given to people in terms of the possible vocabulary they could store in the device is a crucial consideration in introducing an AAC device. For the process of message banking, guidance about possible vocabulary and messages to bank for future use are of equal importance.

Time must be taken to talk through the kind of messages the person might want to have access to on his/her communication system. This will depend on many factors,

not least of which is the stage of the illness. Stuart, Lasker and Beukelman (2000) describe four stages of MND illness: vigilance; relinquishing care to others; enduring self; and new sense of self. They further claim that different types of vocabulary are needed at each stage. In order for message banking to be successful, PMNDs would need guidance to think about the different messages that could be necessary during different stages. For example, if a PMND is experiencing the stage of vigilance, he/she might need a phrase to the following effect: *"Can I have time alone please?"*. During the stages of relinquishing care, a phrase might be needed to communicate, *"please put my collar inside, not outside my jacket"*. The stages of enduring self might require phrases to express feelings *"I used to... but now..."*. The stage of new sense of self might want to include personal stories and narratives to explain new situations to others. Stuart et al. (2000) add that at all stages of progression through the disease the PMNDs might need vocabulary to conserve 'small talk' – to help maintain and nurture their personal relationships, to gossip, to reduce conflict, to tell and respond to jokes. They may or may not want to ask questions about their medical condition or discuss wishes for their medical treatment as they become more ill.

Costello (2014) is of opinion that the ultimate goal of message banking is to record legacy messages. Legacy messages are any phrases, words or sounds that have a personal meaning to only the PMND and his/her loved ones. Such a message could be anything ranging from an invented pet name for a loved one, to a comment with a sarcastic undertone, delivered with the persons' unique voice, intonation and prosody (Costello, 2014). Legacy messages could potentially allow PMNDs to maintain social closeness throughout the progression of MND.

It is imperative therefore that a collaborative approach towards providing message banking to PMNDs is adopted. The important role of the PMND, SO and SLP in ensuring adequate planning for message banking in the early stages of MND may ensure the improved management of communication among all involved.

The current study therefore aims to determine and compare the perceptions of SLPs about message banking with those of SOs and PMNDs. The latter are more likely to depend on the SLPs for guidance about how and when to proceed and what vocabulary or messages to record during message banking. The study will also determine possible messages of importance by comparing the perspectives of PMNDs, SOs and SLPs.

2.7 SUMMARY

Chapter 2 provided an overview of MND in terms of its influence on communication and speech. Perceptions regarding AAC strategies and systems as held by a variety of participants were investigated. The relevant literature was investigated to gain insight into the current AAC strategies used for PMNDs. The chapter concluded that there was a void in the literature on perceptions of message banking as an AAC strategy for PMNDs.

CHAPTER 3: METHODOLOGY

3.1 INTRODUCTION

In this chapter the research methodology used in the study is discussed. Firstly, the main aim and sub-aims are identified, followed by a discussion of the research design, the development phase and the main study. The development phase commences with a discussion of the materials developed, participant identification and the pilot study. The main study follows with data collection for PMNDs, SOs and SLPs. Data analysis and interpretation conclude this chapter.

3.2 RESEARCH AIMS

3.2.1 Main aim

The main aim of the study was to determine and compare the perceptions of three participant groups (PMNDs, their SOs and SLPs) about AAC in general, message banking and the most important communication purposes of message banking.

3.2.2 Sub-aims

The main aim was delineated as follows:

- To determine and compare the awareness and perceptions of PMNDs, SOs and SLPs regarding AAC with reference to (i) sources of information about AAC; (ii) AAC candidacy for PMNDs; and (iii) current AAC strategies used by PMNDs and recommended by SLPs.
- To determine and compare the awareness and perceptions of PMNDs, SOs and SLPs regarding message banking with reference to (i) sources of information about message banking; (ii) the timing of message banking; (iii) the relevance of message banking, and (iv) positive and negative perceptions about message banking.
- To determine and compare the interest of PMNDs, SOs and SLPs in message banking.
- To determine and compare the communication purposes (categories of messages) that PMNDs, SOs and SLPs consider as important for message banking

in the voice of the PMND. This involves (i) messages that PMNDs and SOs want to bank and (ii) categories of messages to bank in the voice of the PMND.

3.3 RESEARCH DESIGN

The present study used a comparative non-experimental survey design. This type of descriptive design allows phenomena to be described (e.g. perceptions of message banking) without manipulating the conditions (McMillan & Schumacher, 2014). A survey is a cost- and time-effective method of obtaining data at one point in time (McMillan & Schumacher, 2014). In this study the researcher determined and compared perceptions about message banking of PMNDs, their SOs and SLPs. A questionnaire was used to determine participants' perceptions about message banking. Participants listened to a short presentation of what message banking entails and then individually completed a questionnaire about their perceptions.

Data was compared between the three participant groups, as a comparative design allows for analysis across the groups of similarities and differences of the phenomenon being studied. The disadvantage of using a survey design is the potential negative effect that low literacy levels or difficulties with reading and writing may have on the study (Blair, Czaja & Blair, 2014). Another limitation of this design is a lack of control over threats to internal validity, such as loss of participants and response bias (McMillan & Schumacher, 2014).

3.4 RESEARCH PHASES

The research comprised two phases as outlined in Table 3.1, namely Phase I – the development phase and Phase II – the main study.

Table 3.1: Research phases

| RESEARCH PHASES | | |
|---|--|--|
| Phase I: Developmental Phase (Section 3.4.1) | | |
| 1.1. Development of materials | 1.2. Pilot study | 1.3. Participant identification |
| This phase aimed to develop appropriate materials and measuring instruments to be used in the study. | The pilot study aimed to determine the feasibility of this study in terms of measurements, procedures and data analysis. | During this phase potential participants were recruited. |
| (Section 3.4.1.1) | (Section 3.4.1.2) | (Section 3.4.1.3) |
| Phase II: Main Study (Section 3.4.2) | | |
| 2.1 Data collection for PMNDs | 2.2. Data collection for SOs | 2.3. Data collection for SLPs |
| Data collection for the PMNDs was completed at two support group meetings of the Motor Neuron Association of South Africa (MNDASA). | Data collection for the SOs was completed at two support group meetings of the MNDASA. | Data collection for the SLPs was completed at a South African Speech-Language-Hearing Association (SASLHA) Workshop on Motor Neuron Disease (MND). |
| (Section 3.4.2.1) | (Section 3.4.2.1) | (Section 3.4.2.1) |

3.4.1 Developmental phase

The main purpose of the development phase was to develop the materials and measuring instrument used in the study. Currently no measures are available to determine perceptions with regard to message banking. A measuring instrument (questionnaire) was developed for three participant groups with minor adaptations in respect of the specific group. The complementary (second) purpose of the developmental phase was to recruit potential participants for the study and to subsequently conduct a pilot study to test the newly developed measuring instrument.

3.4.1.1 Development of Materials and Measuring Instrument

The following materials and instruments were developed for the purpose of this study: (i) a message banking presentation; (ii) a message banking pamphlet; (iii) a biographical information questionnaire; and (iv) a message banking questionnaire.

3.4.1.1.1 *Development of Message Banking Presentation*

Message banking is a relatively new, early intervention option for PMND. As such, the majority of participants would be unfamiliar with the construct and therefore they needed basic information about message banking before their perceptions of it could be determined. No strictly informative message banking presentations were available online or in the published literature. Although videos of personal experiences with message banking were available (<https://www.youtube.com/watch?v=qUcpyAQpmiM>) (Costello, 2014), these were likely to influence the perceptions of the participants and could thus create a Hawthorne effect.

The researcher consequently developed her own script for the presentation to inform participants about what message banking is, and how it is done (Appendix B). The script, which was designed to guide the narration of the presentation, was strictly adhered to during the recording of the presentation. The video used the app “Adobe Voice” on the Apple iPad™. This presentation included the scripted audio clip with accompanying images (e.g. images of SGDs) to inform participants on the nature of message banking and how it is done. The result was a short 6 minute and 52 second video presentation about message banking, which prompted participants to start thinking about their own perception of the concept of message banking. By using a video presentation, the procedural integrity of the study was increased, as all participants were exposed to exactly the same information.

3.4.1.1.2 *Development of a Message Banking Pamphlet*

The message banking pamphlet was designed to provide the participants with a hard copy of the electronic video presentation. This ensured that they could take information home with them. The design of the pamphlet was guided by the format of the message banking presentation. The exact information that was used in the scripted message banking presentation appears in the pamphlet (Appendix C).

3.4.1.1.3 *Development of Biographical Questionnaires*

Three separate biographical questionnaires were developed to gather participants’ biographical information as the researcher was interested in different biographical aspects of the three participant groups – the severity of symptoms currently experienced by PMNDs; the relationship of the SO to the PMND; and the number of years

that the SLP had been practising as a qualified SLP (Appendix D-F).

3.4.1.1.4 *Development of a Message banking Questionnaire*

This questionnaire was developed to determine the participants' perceptions of message banking. The same questionnaire was used for all three participant groups, with minor adaptations where necessary. The questionnaire comprised three sections. Section 1 focused on perceptions of AAC, including awareness and current use of AAC strategies. Section 2 focused on perceptions about message banking, including awareness about message banking, perceived relevance of message banking, and interest in message banking. Section 3 focused on communication aims for which message banking could be used, including messages that are important for message banking, and categories of communication where it would be crucial to have messages available in one's own voice (Appendix G-I). The *Communication Device Use Checklist* developed by Fried-Oken et al. (2006) was also included in the message banking questionnaire as the authors recommended that it was an applicable checklist to identify differences between the expectations of SOs and PMNDs. The *Communication Device Use Checklist* had acceptable reliability or internal consistency with the following Chronbach's alpha values: basic needs (.92); new information (.82); and social closeness (.87). No Chronbach's alpha values were reported for social etiquette. Minor adaptations were made to the *Communication Device Use Checklist* (Fried-Oken et al., 2006) based on the results of the pilot study (Section 3.4.1.2).

Expert Panel

After completion, the materials and measuring instruments were distributed to an AAC expert panel for review. This panel consisted of three SLPs with PhD degrees and more than 10 years' experience in AAC. Their suggested changes and recommendations about the measuring instruments were incorporated to improve the latter's face validity. After incorporation of the expert panel's comments and suggestions (Appendix J), a pilot study was conducted.

3.4.1.2 Pilot study

A pilot study was conducted in the Western Cape. The selection criteria and procedures used for the pilot study were the same as outlined in the main study. The objectives, measures and equipment, procedures, results and recommendations made on completion of the pilot study are outlined in Table 3.2 for the PMNDs and their SOs, and in Table 3.3 for the SLPs.

3.4.1.2.1 Objectives

The objectives of the pilot study were to determine the feasibility of the proposed study in terms of (i) the recruitment of participants; (ii) the appropriateness of the materials and measures developed for the study; (iii) the appropriateness of the recording equipment, and (iv) the appropriateness of the data collection procedures. The results of the pilot study were used to improve the data collection procedures and to reduce threats to internal and external validity. The objectives of the study are set out in Tables 3.2 and 3.3.

3.4.1.2.2 Participants

Three participants with MND, their three SOs and three SLPs were included in the pilot study. Participants who had MND and their SOs were members of MNDASA and met the selection criteria as outlined for the main study (Section 3.4.1.3). The SLPs were members of SASLHA and appeared on its database, while they also met similar selection criteria as outlined for the main study (Section 3.4.1.3). The selection criteria for the main study were adapted after conducting the pilot study. The pilot study was conducted at a central meeting point for all participants involved.

Table 3.2: Objectives, procedures, results and recommendations of pilot study for PMNDs and their SOs

| Objectives | Procedures | Results | Recommendations |
|--|--|---|---|
| 1. To evaluate the effectiveness of the recruitment procedures. | Participants were recruited from the database of MNDASA. | The participant selection process through MNDASA was appropriate. Additional participants might nevertheless be needed in the main study. | Participants for the main study will be recruited from MNDASA as well from additional sources, such as the personal database of a neurologist (the chairperson of the MNDASA) if necessary. |
| a. To evaluate the effectiveness of the selection criteria for PMNDs. | | | |
| b. Diagnosed with MND by a neurologist before June 2015. | Determined via biographical information. | All participants were diagnosed before June 2015. | No changes recommended. |
| c. Live in the Western Cape. | Determined via biographical information. | All participants were living in the Western Cape. | No changes recommended. |
| d. Literate in English. | Determined via biographical information. | All participants were literate in English. | No changes recommended. |
| e. Able to complete a questionnaire by means of intelligible verbal responses. | The researcher completed the <i>Staging of Dysarthria System</i> (Mathy et al., 2000) for each participant to determine his/her speech intelligibility. Participants with no useful speech were excluded from the study. | Participants fatigued easily when they had to give verbal responses. Many requested to complete the questionnaire in writing, as this would be less tiring and allow for more time to reflect on their answers. | The selection criterion will be changed to: “ <i>Participants should have legible handwriting.</i> ” Participants will not be excluded from the study if they have no useful speech according to the <i>Staging of Dysarthria System</i> (Mathy et al., 2000). Participants will now be requested to complete the biological information questionnaire in writing. Those who are able to write independently and legibly will be included in the study. |

| Objectives | Procedures | Results | Recommendations |
|--|---|--|---|
| f. MND severity classified as mild, moderate or severe. | The researcher completed the <i>Classification of Motor Neuron Disease</i> (Riviere et al., 1998) for each participant to determine the severity of his/her MND symptoms. | The <i>Classification of MND</i> by Riviere et al. (1998) was a good measure and was sensitive enough to classify severity. | The measure will be used in the study. Only PMNDs with mild, moderate or severe states (where writing is unaffected in the severe state) as determined by Riviere et al. (1998) will be included in the study. Patients classified as terminal and therefore unable to write will be excluded from the study. |
| g. Must be able to identify at least one significant other (spouse, partner, family member, child, or friend) who spends a minimum of five hours per day with the PMND and consents to take part in the study. | PMNDs identified SOs before the study and explained how they were related when they completed the biographical information questionnaire. | PMNDs who were independent in all aspects of daily living did not always have an SO assigned as primary caregiver who spent five hours a day with them. Some PMNDs with more severe states of MND had only a paid caregiver who spent five hours per day with them. | The PMND must be able to identify an SO who could potentially be assigned the role of primary caregiver to the PMND and who currently spends no less than three hours per <u>week</u> with the PMND. For those PMNDs who do not have an unpaid SO, a paid SO will be included in the study. If both are available, preference will be given to the unpaid caregiver. |
| 2. To evaluate the clarity of terms, statements and questions in the measuring instruments. | As participants completed the questionnaire, they were asked to identify unclear statements encountered in terminology for the materials and measuring instrument. | Participants shared valuable suggestions to improve the clarity of terms and questions. This informed the researcher of necessary changes. | Changes to individual questions are explained below. |
| a. Biographical information questionnaire | The participants suggested changes to the following items: | Question 5: Participants suggested changing the word “unspecified” to “other”. | Question 5: What is the nature of your MND diagnosis? <ul style="list-style-type: none"> • Bulbar • Spinal • Mixed • Other |
| | | Question 7: Participants suggested separating cell phone use. | Question 7: Do you require assistance with the following activities of daily living? <ul style="list-style-type: none"> • Using your cell phone for calls. • Using your cell phone for sending messages. |

| Objectives | Procedures | Results | Recommendations |
|---|--|---|--|
| a. Biographical information questionnaire (continued) | The participants suggested changes to the following items: | Question 13: Participants suggested adding “understand” to the possible proficiencies. | Question 13: What other languages are you proficient in? <ul style="list-style-type: none"> • Language <ul style="list-style-type: none"> • Speak • Read • Write • Understand |
| | | Question 18: Wording changed to eliminate possible confusion. | Question 18: Please select if you are currently receiving any of the following: <ul style="list-style-type: none"> • Speech Therapy • Occupational Therapy • Physiotherapy • Other |
| | | Question 19: Provide a “Yes / No” option for ease of answer. | Question 19: Have you consulted a speech-language pathologist after your diagnosis of MND? <ul style="list-style-type: none"> • Yes • No |
| | | Question 23: Additional question added to determine patient’s own view of his/her ability to communicate. | Question 23: Have you experienced any changes in your speech? Please explain. |
| a. Message banking questionnaire | Participants were asked to identify unclear statements in terminology in the measuring instrument. | Question 1: First provide the definition, then ask the question. | Question 1: Augmentative and Alternative Communication (AAC) refers to the use of less frequently used modes of communication to either supplement or replace your speech. These AAC strategies include writing, gestures, signs, communication boards and electronic devices such as speech-generating devices that can help you to communicate effectively when your speech deteriorates. Have you ever heard of AAC before today? |

| Objectives | Procedures | Results | Recommendations |
|--|--|--|---|
| c. Message banking questionnaire (continued) | The participants suggested changes to the following items. | Question 2: Participants suggested adding the J9 foundation* as an option. | Question 2: Where /from whom did you hear about AAC? (Added the following category) <ul style="list-style-type: none"> • The J9 foundation |
| | | Question 4: Participants suggested that the question should be changed to list all possible methods of communication, not only AAC. Speaking, social media, SMS / WhatsApp and other options were added. | Question 4: Which of these methods are you currently using to help with your communication? (Added the following categories) <ul style="list-style-type: none"> • Speaking • Social media • Email • Phone call • SMS • WhatsApp |
| | | Question 5: Question changed to include the same answers as Question 1. This was done to gain more insight into PMNDs' and SOs' perceptions about message banking. | Question 5: Before today, have you ever heard about message banking? <ul style="list-style-type: none"> • Never heard of message banking • Heard of message banking, but do not know anything about it • Know a little about message banking • Know a fair amount about message banking • Know a lot about message banking |
| | | Question 6: Additional question added to determine where they heard about message banking. | Question 6: Where / from who did you hear about message banking? <ul style="list-style-type: none"> • A speech-language pathologist • The Internet • The media • The Motor Neuron Disease Association of SA • The J9 foundation • Other |

| Objectives | Procedures | Results | Recommendations |
|--|--|---|--|
| c. Message banking questionnaire (continued) | The participants suggested changes to the following items. | Questions 7 & 8: Participants suggested a change in order from general to specific. | Question 7: Please select to what extent you agree with these statements and provide a reason for your answer: <ul style="list-style-type: none"> • Message banking is a good idea for <u>others</u> with MND. <ul style="list-style-type: none"> • I strongly agree • I agree • I am unsure • I disagree • I strongly disagree |
| | | Questions 7 & 8: Participants suggested a change in order from general to specific. | Question 8: Please select to what extent you agree with these statements and provide a reason for your answer: <ul style="list-style-type: none"> • Message banking is a good idea for <u>me</u>. <ul style="list-style-type: none"> • I strongly agree • I agree • I am unsure • I disagree • I strongly disagree |
| | | Question 10: Changed to allow all participants to convey both positive and negative perceptions about message banking. | Question 10: Which of these perceptions do you agree with regarding message banking? (All participants will now complete this question, not only those who were not interested in message banking.) |
| | | Questions 12 & 15: Change order because participants had difficulty suggesting their own messages after seeing the list of categories presented in question 12. | Question 12: Please write down 12 to 15 of your own messages that you would like to bank. Write these messages in your own words. |

| Objectives | Procedures | Results | Recommendations |
|---|---|---|---|
| c. Message banking questionnaire (continued) | The participants suggested changes to the following items. | Question 15: The wording of this question was changed because participants felt that all categories were important. Question will now focus more on a computer voice versus their personal voice. | Question 15: Wording was changed: <ul style="list-style-type: none"> • We communicate for various reasons listed below. Given limited time it is not always possible to record everything in one's own voice. Read the various types of messages in the table below. Please indicate if you would be satisfied with a computer voice saying these messages or would it be important to have it in your own voice? Remember there are no right and wrong answers. I want to know what you would prefer. |
| | | Question 15: Participants identified additional categories: | Question 15: The following categories were added: <ul style="list-style-type: none"> • Messages to children • Messages about end of life • Messages about finances • Being rude |
| | | Question 15: Some participants felt that category columns were redundant. | Question 15: Category column was removed. |
| | | Question 15: Participants felt that most categories were important or very important – this would therefore not provide valuable information. | Question 15: Answer options were changed from a 4-point Likert scale to two options: <ul style="list-style-type: none"> • Computer Voice • Personal Voice |
| | | Questions 13 & 14 were redundant, difficult to answer and did not yield valuable information. | Questions 13 & 14 were removed. |
| 3. To evaluate the clarity and ease of understanding of the materials used in the study. This included: | Following data collection for the pilot study, participants were engaged in a group discussion. | The participants were satisfied with all terminology used. | No changes were recommended by the participants. |

| Objectives | Procedures | Results | Recommendations |
|--|---|---|--|
| a. Message banking presentation b. Message banking pamphlet | Terms for the message banking presentation and message banking pamphlet were discussed. | Participants were satisfied with terminology used in the message banking presentation and pamphlet. | No changes were recommended by the participants. |

** The J9 Foundation is a countrywide NGO that supports PMNDs and their families. Joost van der Westhuizen, a prominent South African rugby player founded this foundation and consequently it attracts significant media coverage and interest.*

Table 3.3: Objectives, procedures, results and recommendations of the pilot study with SLPs

| Objectives | Procedures | Results | Recommendations |
|---|--|---|--|
| 1. To evaluate the effectiveness of the recruitment procedure as well as the selection criteria for SLPs. | The SLPs in Cape Town were recruited from the SASLHA database. | The SASLHA database was effective to identify potential participants. | No changes recommended. |
| a. Working with adult neurological disorders. | SLPs who listed their speciality as “AAC”, “Dysarthria” or both were selected, as these are the closest categories that imply working with adult neurological disorders. | Very few SLPs in Cape Town were listed on the SASLHA directory as specialising in “AAC” or “Dysarthria”. | Participants will now be recruited if they enrolled to attend the SASLHA (Zone 3) workshop on MND. These participants will be given the opportunity to take part in data collection at the workshop. |
| b. Practising in the Western Cape. | Biographical information. | Effective | No changes recommended. |
| c. Literate in English. | Determined based on biographical information. | Effective | No changes recommended. |
| 2. To evaluate the clarity of terms and instructions and questions used. | Following data collection of the pilot study, participants were engaged in a group discussion about the terms, instructions and questions used in the study. | Participants shared valuable suggestions to improve the clarity of terms and questions, which informed the researcher of necessary changes. | Individual changes to questions are explained below. |
| a. Biographical questionnaire | The participants suggested changes to the following items. | Question 3: Participants suggested that a rating of proficiency in their first language be included. | Question 3: First Language will be included in the table to specify proficiency in this language too. |

| Objectives | Procedures | Results | Recommendations |
|---|--|--|--|
| a. Biographical questionnaire (continued) | The participants suggested changes to the following items. | Question 4: "What language are you <i>proficient</i> in?" The word " <i>proficient</i> " needed clarification as to whether it pertained to proficiency to communicate or proficiency as a speech-language pathologist in that language. | Question 4: The phrase "... able to provide speech-language therapy in" was added. |
| | | Question 5: Participant suggested adding "highest" to the question "Please select your level of qualification". | Question 5 was changed to: "Please select your highest level of qualification." Question 5: Honours degree was added to the table. |
| | | Question 6: Preferred to add the following additional criteria: | Question 6: Rows added to the table included: <ul style="list-style-type: none"> • Name of university • Name of qualification • Year enrolled • Year completed |
| | | Question 7: Queried whether community service should be counted. | Question 7: Wording changed to "Number of years practising including community service". |
| | | Question 9: The word " <i>where</i> " should be replaced. | Question 9: The word " <i>where</i> " was changed to "in what". |

| Objectives | Procedures | Results | Recommendations |
|---|--|--|---|
| b. Biographical questionnaire (continued) | The participants suggested changes to the following items. | Question 8: "Where are you currently working?" needed clarification. | Wording changed to: "In what sector are you currently working?" A column was added to list the options: <ul style="list-style-type: none"> ▪ Private Sector <ul style="list-style-type: none"> • Hospital • Rehabilitation unit • Outpatient clinic ▪ Public Sector <ul style="list-style-type: none"> • Hospital • Rehabilitation unit • Outpatient clinic. ▪ Tertiary Institution ▪ Other (please specify) |
| | | Question 13: Provide an estimation of how many patients you have seen with MND within the timeframe selected. | Question 13: Add section B. Estimated number of patients seen with MND: <ul style="list-style-type: none"> ▪ Less than 10 ▪ Less than 50 ▪ Less than 100 |
| | | Question 14: The word "dysphagia" needed clarification. Question 14: Suggested that the category "other" should be added. | Question 14: The word "dysphagia" was changed to "dysphagia management". Question 14: The category "other" was added as a separate row. |
| b. Message banking questionnaire | Following data collection in the pilot study, participants were engaged in a group discussion about the terms, instructions and questions used in the study. | Question 1: The word "training" was substituted for "knowledge and experience". The option "colleagues" was added to the answer selection. | Question 1: Please select where you received your AAC knowledge and experience from: <ul style="list-style-type: none"> • ... • Colleagues |
| | The participants suggested changes to the following items. | Question 6: Specify that the answer should be about PMNDs in the speech-language pathologist's own caseload. | Question 6: Which of these AAC methods do you recommend to persons with MND whom you see in your caseload? |

| Objectives | Procedures | Results | Recommendations |
|--|---|--|---|
| <p>3. To evaluate the clarity and ease of understanding of the materials used in the study.</p> <ul style="list-style-type: none"> a. Message banking presentation b. Message banking pamphlet | <p>Following data collection of the pilot study, participants were engaged in a group discussion about the terms used in the message banking presentation and message banking pamphlet.</p> | <p>The participants were satisfied with all terminology used in the message banking pamphlet and presentation.</p> | <p>No changes were recommended by the participants.</p> |

3.4.1.2.3 *Summary of pilot study*

The pilot study highlighted some of the areas that would require some modification in the procedures and the materials used for data collection in the main study. For instance, participants wished to complete the questionnaire in writing, as they were fatiguing when they spoke. Changes to the wording of individual questions in the measuring instrument would also make these questions easier to understand.

The results of the pilot study were discussed with the same expert panel that had been consulted previously. The main change dealt with the selection criteria for PMNDs in order to limit possible variables that could influence the study. The panel agreed that the changes suggested for the main study would be appropriate and would enhance the selection criteria for participants. Hence these recommendations were incorporated into the main study.

3.4.1.3 *Participant selection and description*

The selection criteria and descriptive criteria for participants are provided in this section.

3.4.1.3.1 *Participant selection*

In this study, three participant groups were recruited. Non-probability, purposive sampling was used to recruit PMNDs (group 1). The PMNDs were recruited from the database of the MNDA of South Africa in Cape Town, because it constitutes the largest local database of people living with MND. Seeing that the nature of MND progression poses a threat to participant attrition, the researcher aimed to identify and include as many suitable participants as possible to ensure that the collected data would yield significant results. Table 3.4 includes the selection criteria for PMND.

Table 3.4: Selection Criteria for Persons with MND (PMNDs)

| <i>SELECTION CRITERIA: PMNDs</i> | <i>JUSTIFICATION</i> | <i>MEASURE</i> |
|--|---|--|
| 1. Diagnosed with MND by a neurologist. | Diagnosis of MND is a prerequisite as determined by the topic of this study. Message banking is a treatment option for persons with MND (Bongioanni, 2012). | Participants provided the name of the neurologist who confirmed the diagnosis of MND. |
| 2. Diagnosed with MND by a neurologist not longer than 15 years ago. | Survival rates longer than 15 years could indicate a possible misdiagnosis. Median survival rate with ALS is 50% at 3 years, however there is substantial variation between individuals, with 20% of people surviving for 5 years and 10% surviving for 10 years or longer (Pupillo et al., 2014). | Date of diagnosis provided in participant's biographical information. |
| 3. Live in the Western Cape. | Participants have to attend data collection in the Western Cape. Catchment area of MNDASA in the Western Cape (MNDASA, 2014). | Database of MNDASA. |
| 4. Literate in English. | Participants will be required to answer questions in English. Afrikaans (34.9%), isiXhosa (29.2%) and English (27.8%) are among the three languages most spoken in the Western Cape (STATS SA, 2011). All measures will be in English. | Biographical information supplied by participants. |
| 5. Able to independently and legibly complete questionnaire in writing. | Participants will be required to complete the questionnaire in writing. MND affects written and verbal communication (Murphy, 2004). | Biographical information questionnaire will be used as a task to evaluate if person can write legibly. |
| 6. Severity: mild (state 1), moderate (state 2) or severe (state 3). | PMND's severity should not impact writing. Patients whose severity is state 4 (terminal) have no functional use of at least two regions that affect speech, mobility and use of upper limbs (Riviere, Meininger, Zeisser & Munsat, 1998). This implies that neither speech nor writing can be used as a reliable means to collect data. | State of MND is classified according to Riviere et al. (1998). The classification ranges across the functional modalities of speech, mobility and ability to use upper limbs for activities of daily living. |
| 7. Must be able to identify at least one SO (spouse, partner, family member, child or friend) who spends a minimum of three hours per week with the PMND and consents to taking part in the study. | In order to take part in the study PMND should have a SO who will also take part in the study. PMND are typically cared for by informal caregivers like SO (Fried-Oken et al., 2006). | Biographical information supplied by participants. |

The SOs of the recruited PMNDs who met the selection criteria (Table 3.4) were subsequently approached to participate in the study. Table 3.5 includes the selection criteria for SO.

Table 3.5: Selection criteria for significant others (SOs)

| <i>SELECTION CRITERIA: SO</i> | <i>JUSTIFICATION</i> | <i>MEASURE</i> |
|--|--|--|
| 1. Should be identified as a SO by the PMND. | PMNDs are typically cared for by informal caregivers like SO (Fried-Oken et al., 2006). | Biographical information supplied by participants. |
| 2. Should be one of the following: <ul style="list-style-type: none"> • Spouse • Partner • Friend • Child • Family member | PMND are typically cared for by informal caregivers like SO (Fried-Oken et al., 2006). | Biographical information supplied by participants. |
| 3. Should spend a minimum of three hours a week with the PMND. | PMNDs are typically cared for by informal caregivers like SOs (Fried-Oken et al., 2006). | Biographical information supplied by participants. |
| 4. Live in the Western Cape. | Catchment area of MNDASA in the Western Cape (MNDASA, 2014). | Database of MNDASA. |
| 5. Literate in English. | Afrikaans (34.9%), isiXhosa (29.2%) and English (27.8%) are among the three languages most spoken in the Western Cape (STATS SA, 2011). All measures will be in English. | Biographical information supplied by participants. |

SLPs (group 3) were recruited by means of purposive sampling – a non-probability sampling method according to which participants were selected because they were interested in working with PMNDs at the time of the study. In addition, they expressed interest in attending a workshop on the management of PMND. The SLPs in Cape Town were recruited from the SASLHA database because they enrolled to attend a workshop about the multidisciplinary management of PMNDs. Selection criteria for SLPs are presented in Table 3.6.

Table 3.6: Selection criteria for speech-language pathologists (SLPs)

| <i>SELECTION CRITERIA: SLP</i> | <i>JUSTIFICATION</i> | <i>MEASURE</i> |
|--|---|--|
| 1. Registered with the Health Professionals Council of South Africa (HPCSA). | Speech-language pathology is crucial in the management of MND (Murphy, 2004). | Participants have to indicate if they are registered with the HPCSA on the biographical information questionnaire. |
| 3. Practising in the Western Cape. | Catchment area of SASLHA (Zone 3) (SASLHA, 2012). | SASLHA (Zone 3) database. Biographical information. |
| 4. Proficient and literate in English. | Afrikaans (34.9%), Xhosa (29.2%) and English (27.8%) are among the three languages most spoken in the Western Cape (STATS SA, 2011). All measures will be in English. | Biographical information. |
| 5. Interested in speech pathology services for PMNDs. | All SLPs are qualified to treat adult neurodegenerative disorders. | Enrolled to attend the SASLHA (Zone 3) workshop about multidisciplinary management of MND. |

3.4.2 Main study

3.4.2.1 Participants

A total of 38 participants were involved in the study – 10 PMNDs, 11 SOs and 17 SLPs. A detailed description of participants is provided in Tables 3.7 to 3.9.

3.4.2.1.1 Group 1: Persons with Motor Neuron Disease (PMNDs)

A total of 10 PMNDs participated in this study as illustrated in Table 3.7.

Table 3.7: Descriptive information for participant group 1: PMNDs (n = 10)

| No. | Gender | Age | Highest qualification | Date of diagnosis | Occupation / previous occupation | First language | Marital status | Living with | Consulted with an SLP | Nature of diagnosis | Severity of speech difficulties 1= Mild 2= Moderate 3= Severe | State of classification of MND (Reviere et al., 1998) 1= No detectable speech disorder 2= Obvious speech disorder with intelligible speech 3= Reductions in speech intelligibility |
|------|--------|-------|-----------------------|-------------------|----------------------------------|----------------|----------------|-----------------|-----------------------|---------------------|--|--|
| 1.1 | F | 56;8 | Diploma | 2015 | Teacher | English | Widowed | Alone | No | Bulbar | 2 | 3 |
| 1.2 | M | 58;10 | Grade 12 | 2013 | Mine Worker | English | Married | Wife | Yes | Other | 1 | 3 |
| 1.3 | M | 52;7 | Below Grade 12 | 2014 | Not specified | English | Unmarried | Ex-wife | No | Other | 1 | 1 |
| 1.4 | M | 34;10 | Grade 12 | 2015 | General worker | Afrikaans | Married | Wife & Child | Yes | Other | 1 | 1 |
| 1.5 | M | 52;10 | Diploma | 2015 | Foreman | Afrikaans | Married | Wife | No | Mixed | 3 | 2 |
| 1.6 | F | 74;5 | Grade 12 | 2000 | Not specified | English | Unmarried | Retirement home | No | Spinal | 2 | 3 |
| 1.7 | F | 53;8 | Diploma | 2015 | Market Manager | Afrikaans | Unmarried | Alone | No | Bulbar | 3 | 2 |
| 1.8 | M | 72;0 | Grade 12 | 2001 | Retired | Afrikaans | Married | Wife | No | Mixed | 1 | 2 |
| 1.9 | M | 41;10 | Below Grade 12 | 2015 | Supervisor | Afrikaans | Unmarried | Partner | No | Mixed | 3 | 2 |
| 1.10 | M | 77;11 | Not specified | 2015 | Minister of religion | English | Married | Wife | Yes | Not specified | 1 | 1 |

Table 3.7 illustrates that there were 7 male (70%) and 3 female (30%) participants. This sample is representative of the broader population of persons 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). The participants' ages ranged from 34.10 years to 77.10 years, with a mean age of 57.23 years. As MND peaks in the fifth and sixth decade of a person's life (Chiò et al., 2004), the average age of the present sample was consistent with the literature on the subject. The average time since diagnosis was 4 years 11 months, and the nature of diagnosis had been varied.

Participants' highest level of qualification ranged from below Grade 12 to a diploma. Two PMNDs' (20%) had a highest level of qualification of below Grade 12, four PMNDs (40%) completed Grade 12 and three PMNDs (30%) completed a diploma. One PMND (10%) did not specify his/her highest level of qualification.

Home language was equally split with five participants each speaking Afrikaans and English. Five PMNDs (50%) were married, four (40%) were unmarried or divorced and one (10%) had been widowed. Seven PMNDs (70%) were living with his/her spouse, partner or former spouse. Two PMNDs (20%) were living alone, while one (10%) lived in a retirement home. Three PMNDs (30%) had consulted with an SLP previously while the rest had never done so.

The severity of speech difficulties experienced by the participants and determined according to the *Staging of Dysarthria System* (Mathy et al., 2000) varied and ranged as follows: Five PMNDs (50%) had no detectable speech difficulties; two (20%) had obvious changes in their speech although they still had intelligible speech. Three PMNDs (30%) had reductions in speech intelligibility. For the classification of MND (Riviere et al., 1998), three PMNDs (30%) were classified as mild, three (30%) as moderate, and four (40) as severe. All participants (n=10) were able to write legibly, given the fact that this was part of the selection criteria.

3.4.2.1.2 Group 2: Significant Other (SO)

The sample of SOs was identified by the PMNDs and consisted of 11 individuals (n=11) as illustrated in Table 3.8. Eight SOs (73%) were female and three (27%) were male participants. A detailed description of the participants is included in Table 3.8. The ages of SOs ranged from 18.1 to 71.6 years old with an average age of 49.9 years. All were

proficient in English. The sample consisted of six spouses (55%), two former spouses (18%), two children (18%) and one friend (10%). Most PMNDs who participated in the study selected only one SO to participate in the study, but participant number 4 could not choose between his spouse and daughter and therefore selected them both to take part in the study.

Table 3.8: Descriptive information for participant group 2: SOs of PMNDs (n = 11)

| No. | Gender | Age | Relationship to PMND | Highest level of education | Occupation | First Language | Amount of time spent with PMND |
|------|--------|-------|----------------------|----------------------------|---------------|----------------|--------------------------------|
| 2.1 | F | 49;2 | Spouse | Diploma | Housewife | Afrikaans | 24 hours a day |
| 2.2 | M | 44;2 | Ex-husband | Grade 12 | Senior Clerk | English | All except working hours |
| 2.3 | F | 38;5 | Spouse | Diploma | Book Keeper | English | All except working hours |
| 2.4 | F | 51;3 | Spouse | Diploma | Teacher | Afrikaans | 5 hours per day |
| 2.5 | F | 18;1 | Child | Grade 12 | Not Specified | Afrikaans | 10 hours per day |
| 2.6 | F | 60;11 | Friend | Honours | Social Worker | Afrikaans | 2 days per week |
| 2.7 | F | 38;7 | Spouse | Grade 12 | Unemployed | Afrikaans | 24 hours a day |
| 2.8 | F | 68;8 | Spouse | Below Grade 12 | Housewife | English | 24 hours a day |
| 2.9 | M | 55;6 | Ex-husband | Diploma | Own Business | Afrikaans | 3-5 hours per week |
| 2.10 | M | 53;5 | Child | Grade 12 | Consultant | English | 4-5 hours per week |
| 2.11 | F | 71;6 | Spouse | Diploma | Retired | English | 24 hours a day |

3.4.2.1.3 Group 3: Speech-language pathologists (SLPs)

The sample of SLPs consisted of 17 individuals as illustrated in Table 3.9. Table 3.9 also illustrates that all participants in group 3 were female. This is not uncommon in the South African context, as SLPs in South Africa are mostly female (Pillay, Kathard, Samuel, 1997). Ten SLPs (59%) had experience with PMNDs while 7 (41%) had not yet seen any PMNDs. As SLPs are all qualified to work with adult neurogenic disorders, it was decided that all 17 participants could potentially see patients with MND and would provide valuable data. A detailed description of the participants is included in Table 3.9. The ages of the SLPs ranged from 23.0 to 65.7 with a mean age of 32.8. As with the PMNDs, SLPs spoke either Afrikaans or English as a first language, with a slightly larger number speaking English (n=10) than Afrikaans (n=7).

Table 3.9: Descriptive information for participant group 3: SLPs (n = 17)

| No. | Gender | Age | First language | Highest qualification | Additional AAC training | Number of years as a qualified SLP | Experience with PMNDs |
|------|--------|-------|----------------|-----------------------|-------------------------|------------------------------------|-----------------------|
| 3.1 | F | 26;1 | Afrikaans | Honours | No | 4 years | Yes |
| 3.2 | F | 53;0 | Afrikaans | Honours | No | 29 years | Yes |
| 3.3 | F | 65;7 | English | Master's | No | 42 years | Yes |
| 3.4 | F | 24;11 | English | Honours | No | 2 years | No |
| 3.5 | F | 33;1 | English | Master's | Yes | 13 years | Yes |
| 3.6 | F | 28;0 | English | Honours | Yes | 5 years | Yes |
| 3.7 | F | 37;9 | Afrikaans | Master's | Yes | 15 years | No |
| 3.8 | F | 26;6 | Afrikaans | Honours | No | 3 years | Yes |
| 3.9 | F | 25;9 | Afrikaans | Honours | No | 9 months | No |
| 3.10 | F | 30;1 | Afrikaans | Honours | No | 9 years | Yes |
| 3.11 | F | 44;6 | English | Master's | No | 22 years | Yes |
| 3.12 | F | 26;3 | English | Honours | No | 3 years | No |
| 3.13 | F | 30;6 | English | Honours | No | 7 years | No |
| 3.14 | F | 25;1 | English | Honours | No | 3 years | No |
| 3.15 | F | 23;0 | English | Honours | No | 9 months | Yes |
| 3.16 | F | 31;0 | Afrikaans | Master's | No | 8 years | No |
| 3.17 | F | 28;1 | English | Honours | No | 5 years | Yes |

3.4.2.2 *Equipment and instruments*

The equipment and the content of measuring instruments used in the research are discussed in this section and include the following: (i) the equipment; (ii) consent letters; (iii) biographical questionnaires; (iv) classification of MND; (v) message banking presentation; (vi) message banking pamphlet and (vii) message banking questionnaire.

3.4.2.2.1 *Equipment*

3.4.2.2.1.1 *Ipad™*

The equipment used for data collection and analysis included an Apple iPad™ version 7.1.2, model number MC984SO/A with operating system iOS 9.0.2 that was used to record all three data collection sessions.

3.4.2.2.1.2 *Adobe Voice App*

The “Adobe Voice” is a free app available on the Apple iStore. It allows one to add narration to a slideshow of pictures, with the option to add animations or music to the slideshow or presentation. The slideshow is then available online and can be downloaded on any device with an Internet connection.

3.4.2.2.1.3 *Computer*

A Samsung all-inclusive computer with 32-inch touch screen, Intel Core i3 with 8GB internal memory and 1TB hard drive, with Windows 10 was used to show the message banking presentation.

3.4.2.2.1.4 *Sound System*

A Logitech 400-watt mobile sound system with subwoofer and two speakers was used to amplify the sound of the message banking presentation played on the 32-inch Samsung computer.

3.4.2.2.2 *Instruments*

In order to meet the research aims, six different instruments were used to collect the data for this study.

3.4.2.2.2.1 *Permission and informed consent letters*

A letter to request permission from MNDASA was sent to the Association to recruit participants and conduct the study (see Appendix K).

An invitation and consent letter was developed and used to invite PMNDs and their SOs to attend a support group meeting in Cape Town where the research was conducted. (See Appendices L-M.) The consent letters provided information on the nature and aims of the study, procedures involved in the study, what participation in the study entailed, as well as the right of participants to withdraw from the study at any time, without any negative consequences. The researcher stated that the results would be made available to interested participants via email. In addition, participants were informed that the data would be stored at the Centre for AAC at the University of Pretoria for 15 years.

A similar invitation and consent letter was developed for SLPs that were identified as candidates to participate in this study. The invitation letter invited them to attend a data collection and information session in Cape Town. (See Appendix N.)

3.4.2.2.2.2 *Biographical information questionnaire*

A biographical information questionnaire was developed with nuanced differences for each of the three participant groups. The questions were selected to gather descriptive information about participants' biographical information in terms of their gender, age,

highest level of qualification and first language. Further descriptive criteria for PMNDs included date of diagnosis; previous occupation; marital status; living with; nature of diagnosis; and whether they had consulted with an SLP. Further descriptive criteria for SOs were: relationship to the PMND and amount of time spent with him/her. Additional descriptive criteria for SLPs were: additional training in AAC; number of years working as an SLP; experience in working with PMNDs; and how often they saw PMNDs. The biographical information questionnaire for PMNDs contained a total of 24 questions for PMNDs, 13 closed questions and 11 open-ended questions (see Appendix D). The SOs' questionnaire contained 11 questions in total, seven closed questions and four open-ended questions (see Appendix E). The SLPs' questionnaire contained 14 questions of which all 14 were closed (see Appendix F).

3.4.2.2.2.3 *Classification of MND*

Riviere et al. (1998) developed this classification system to describe the health state of PMNDs according to the severity and progression within the functional modalities of speech, mobility and ability to use upper limbs for activities of daily living (Mathy et al., 2000; Riviere et al., 1998). Their classification provides for four states: State 1 (mild), State 2 (moderate), State 3 (severe) and State 4 (terminal). Despite the fact that reliability and validity data has 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) (See Appendix O.)

3.4.2.2.2.4 *Message banking presentation*

A scripted message banking presentation (see Appendix B) was pre-recorded using the app Adobe Voice on the Apple iPad™. The message banking presentation was 6 minute and 52 seconds long and adhered to a script developed by the researcher. The purpose of the presentation was to provide information and explain the concept of message banking. This presentation covered the following material: (i) introduction to AAC; (ii) information about synthesised speech; (iii) information about digitised speech; (iv) the definition of message banking and (v) how message banking is done. The presentation is available at <https://voice.adobe.com/a/PNpRA>.

3.4.2.2.2.5 *Message banking pamphlet*

A pamphlet about message banking was developed to accompany the message banking presentation. The purpose of this pamphlet was purely to be informative and to explain the unfamiliar concept of message banking. The pamphlet covered the same content as the message banking presentation, in other words (i) introduction to AAC; (ii) information about synthesised speech; (iii) information about digitised speech; (iv) the definition of message banking and (v) how message banking is done (see Appendix C).

3.4.2.2.2.6 *Message banking questionnaire*

A questionnaire was custom developed for the purpose of the current study with minor modifications for each of the three participant groups. The development of this questionnaire was discussed earlier in Section 3.4.1.1.

The questionnaire focused on:

- Perceptions about AAC, which included awareness about AAC (three closed questions) and current AAC strategies used to communicate (one closed question);
- Perceptions about and awareness of message banking (two closed questions), relevance of message banking (four closed questions with additional prompts to provide a reason for the participant's answer) and interest in message banking (one closed question);
- Communication purposes of message banking (Fried-Oken et al., 2006), including messages that participants would like to bank (one open-ended question for PMNDs and SOs only);
- Categories of communication where a person's own voice is crucial (one closed question).

The message banking questionnaire for PMNDs and SOs comprised 13 questions for the PMNDs and SOs (see Appendices G and H) of which 12 were closed questions and one an open-ended question. The SLPs' message banking questionnaire contained a total of 14 questions. All 14 were closed questions with three questions prompting participants to provide a reason for their answer (see Appendix I).

The *Communication Device Use Checklist* developed by Fried-Oken et al. (2006) formed the last part of the message banking questionnaire. This checklist included 17 message categories and was adapted in two ways as an outcome of the pilot study–

firstly an additional five communication categories were added and secondly the 4-point Likert scale was replaced with two possible options in which participants could select either the “Computer Voice” or their “Own Voice” as essential for each category of messages.

3.4.2.3 Procedures

The ethical considerations, general procedures and data collection procedures are outlined in this section.

3.4.2.3.1 General procedures

The researcher obtained ethical approval for this study from the Faculty of Humanities’ Research Ethics Committee at the University of Pretoria (see Appendix P). Written permission was obtained from MNDASA (see Appendix Q) to use its database to recruit participants. Consent to participate in the study was obtained from PMNDs, their SOs and SLPs who participated in this study. All participants in the study were fully informed of the nature of the study and were assured of voluntary participation and confidentiality (see Appendices K-M).

Informed consent for the research was also obtained from MNDASA in the following order. The researcher contacted the national chairperson via e-mail and a meeting was scheduled. During this meeting the aim and procedures of the research were discussed and the consent form was provided in a hard copy. Written permission to conduct the research was subsequently obtained.

3.4.2.3.2 Data collection procedures

The main study phase commenced with the researcher confirming a data collection appointment with the identified participant groups telephonically or via e-mail. Two separate meetings were scheduled for data collection for PMNDs and their SOs. A third meeting was scheduled for SLPs.

3.4.2.3.3 Meeting 1: PMNDs and SOs

The researcher emailed the participant selection criteria for PMNDs to the three MNDASA caseworkers and the chairperson (a practising neurologist) of MNDASA. A list of names was then returned to the researcher reflecting candidates who would possibly meet the selection criteria. This list contained 28 names in total. The researcher phoned all 28

possible candidates to verbally inform and invite them to attend the data collection and also to determine whether participants met the selection criteria. Ten participants were not interested in taking part in the study. These participants were thanked and not contacted again. A further 18 possible participants met the selection criteria and were interested in attending data collection. These possible participants supplied the researcher with an email address and the formal invitation letter as well as additional data was sent to all 18 participants. Three participants responded that they were unable to attend due to difficulties with arranging transport on the days of data collection. Fifteen participants were again contacted telephonically a week before to confirm their attendance on the day of data collection. The researcher was then informed that two participants could not attend for unknown reasons, one participant could not attend due to hospitalisation and two participants had unfortunately passed away. A total of 10 participants were scheduled to attend data collection on the relevant days.

The ten PMNDs, together with 11 SOs (one PMND had two SOs attending the data collection) who expressed an interest to participate in the study were met by the researcher at one of two MNDASA support group meetings held in Cape Town. One meeting was held at a tertiary hospital, as many patients from the southern suburbs were able to attend this meeting. Five pairs of PMNDs and SOs attended the first meeting. A second meeting was held in Bellville where patients from the northern suburbs, West Coast and Cape Wineland areas were able to attend. Five pairs of PMNDs with their SOs also attended this meeting. Both venues were well ventilated and equipped with chairs and desks for participants to use during data collection. On arrival, participants were welcomed and the researcher and research assistant (a speech-language pathologist with five years' experience working with PMNDs) introduced themselves.

Scripts were used to enhance procedural reliability for data completion (Appendix R). The scripts covered aspects of (i) biographical information; (ii) the message banking questionnaire; and (iii) the message banking presentation and pamphlet. These scripts allowed the researcher and research assistant to follow the exact same procedure for data collection across all participant groups.

The researcher explained the procedures in the study for (i) obtaining informed consent; (ii) completing biographical information; (iii) the message banking

presentation; (iv) completing the message banking questionnaire and (v) questions and support group discussions.

Consent forms were distributed to participants and all participants provided written informed consent to take part in the study. The consent forms were collected from participants.

Biographical questionnaires were distributed to all participants and they were requested to complete the questionnaire in writing. The researcher and research assistant screened each participant's writing during the completion of the biographical information questionnaire to determine whether the participant's writing was legible enough to be included in the study.

The researchers also clinically observed participants during this time to further determine inclusion in the study. No participants were excluded at this point and the biographical questionnaires were collected.

Next the researcher and research assistant completed each participant's severity of MND as determined by Riviere et al. (1998). The researcher determined each participant's severity of MND by reviewing the participants' answers submitted as part of the biographical information in respect of difficulties they were currently experiencing (upper extremity, lower extremity and speech difficulties).

The participants' severity of MND as determined by Riviere et al. (1998) was classified into four states: State 1 (mild), State 2 (moderate), State 3 (severe) and State 4 (terminal). PMNDs who were classified as terminal (due to inability to use upper extremities for writing) were excluded from the study. There were, however, no participants who were in state 4, and hence data collection commenced.

PMNDs and SOs watched the 6 min 52 second video presentation about message banking on the Samsung all-inclusive computer. After the presentation, data collection commenced. PMNDs and SOs were presented with the measuring instrument (questionnaire), which they completed independently at their desk. Participants were not able to view one another's responses.

After data collection was completed, the message banking pamphlet was distributed to the participants for their personal use (see Appendix C). Participants were thanked for their participation. A question-and-answer session and support group meeting followed.

3.4.2.3.4 Meeting 2: SLPs

SLPs who attended the SASLHA workshop about the management of patients with MND were invited to attend the data collection on the day of the workshop in Cape Town. All SLPs were informed via email that the data collection would take place during the workshop and that participation was voluntary. All SLP's indicated an interest to participate in the study. Once informed consent had been obtained, SLPs were given the biographical questionnaire to complete. The same 6 minute 52 second presentation about message banking was shown. Immediately after the presentation, data collection commenced. SLPs were required to complete the questionnaire to determine their perceptions about message banking.

After data collection for all participants had finished, the message banking pamphlet was distributed. Participants were able to keep the information pamphlets. A question and answer session followed. Thereafter a 2-hour presentation of SLP management strategies followed as part of the SASLHA workshop.

3.4.3 Data analysis and interpretation

Biographical information was transferred to Excel spreadsheets and descriptive statistics was calculated. Data collected via questionnaires were transferred to Excel for all three participant groups. Scores were assigned to each response in the questionnaire.

The perceptions about message banking were described and compared for each participant group. Similarities and differences between groups were highlighted and described. Descriptive statistics were computed to determine the importance of message banking for each communication purpose for each participant group. Comparisons were made between the participant groups using inferential statistics. Ordinal data was analysed using the Mann Whitney U test and Kruskal-Wallis H tests. Categorical information was analysed with the Chi-Square and one-tailed Fisher's Exact test. The list of tests used is reflected in Table 3.10.

Table 3.10: Summary of statistical tests used

| Description of data | Statistical procedures used |
|---|----------------------------------|
| Ordinal information (where only two participant groups were compared) | Mann-Whitney U test |
| Ordinal information (where three participant groups were compared) | Kruskal-Wallis H test |
| Categorical variables | Chi-square test |
| Two-by-two variables | Fisher's Exact test (one-tailed) |

3.5 SUMMARY

This chapter described the methodology used in this study. It included the aim of the research, description of the research design and phases. A description of the aims, objectives and recommendations of the pilot study was also presented. The main study was discussed with respect to participant selection criteria and description, data collection procedures, as well as equipment and measuring instruments. Finally, data analysis was discussed.

CHAPTER 4: RESULTS AND DISCUSSION

4.1 INTRODUCTION

The results of the study are described and discussed in this chapter. The discussion is guided by the main aim of the study, namely to determine and compare the perceptions of PMNDs, SOs and SLPs of message banking. Chapter 4 commences with a presentation dealing with the reliability of the data. Thereafter the results of the study are shown. First, a description and comparison of perceptions of PMNDs, SOs and SLPs regarding AAC is given, followed by a description and comparison about message banking. Finally the communication purposes (categories of messages) that PMNDs, SOs and SLPs consider as important for message banking in the voice of the PMND are presented and discussed. The nature of this discussion is illustrated in Figure 4.1

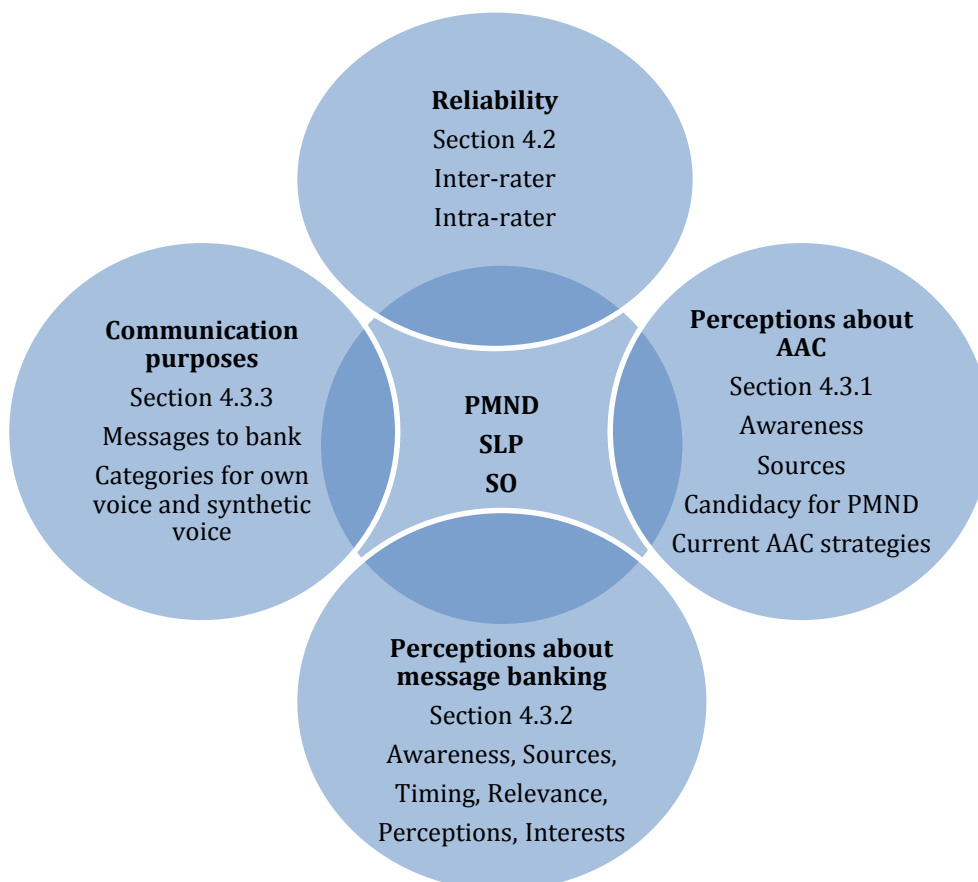


Figure 4.1: Schematic outline of Chapter 4

4.2 RELIABILITY

4.2.1 Reliability of the classification of MND severity

Inter-rater reliability for the classification of the state of MND was conducted. An SLP with five years' experience working with PMNDs acted as the inter-rater and attended all the data collection meetings. To determine the severity of MND, each PMND provided answers to questions about aspects of daily living, which included difficulties with upper extremities, lower extremities and speech. Both the researcher and inter-rater independently coded the participant's written responses according to the MND severity scale (Riviere et al., 1998) to establish reliability for the accuracy of the severity rating. The inter-rater agreement for the severity of the participants' MND was 100%. Although this was high, it was expected because of the clinical observation and direct questions that were asked to the participants to gain an indication of their level of severity.

4.2.2 Data reliability

In terms of the capturing of the data on to Excel sheets, the inter-rater (SLP) reviewed 40% of the data entries. This was done to determine percentage agreement as stipulated by McMillan and Schumacher (2014). Inter-rater agreement was calculated with the following formula (House et al., 1981; Maxwell & Satake, 2006).

$$\frac{\text{Total number of scores} - \text{extent of disagreement}}{\text{Total scores}} \times 100$$

$$\frac{1378 - 5}{1378} \times 100 = 99,63\%$$

The reliability of the data was 99.63%, which is considered excellent (McMillan & Schumacher, 2014).

4.2.3 Coding reliability

Participants provided messages that they would like to bank in their own voice when they answered an open-ended question. The researcher coded each participant's

sentences according to the four communication purposes proposed by Light (1988), namely communication of needs and wants; information transfer; social closeness; and social interaction. One month later the researcher re-coded the messages again. Intra-rater reliability was 100%.

4.3 RESULTS

4.3.1 Perceptions about AAC

Perceptions that participants had regarding AAC were reported and discussed. This included (i) awareness of AAC (Section 4.3.1.1); (ii) sources from where participants gained awareness (Section 4.3.1.1.1); (iii) candidacy for PMND (Section 4.3.1.1.2) and (iv) current AAC strategies used (Section 4.3.1.1.3). Figure 4.2 shows the results of participants' overall awareness of AAC.

4.3.1.1 Awareness of AAC

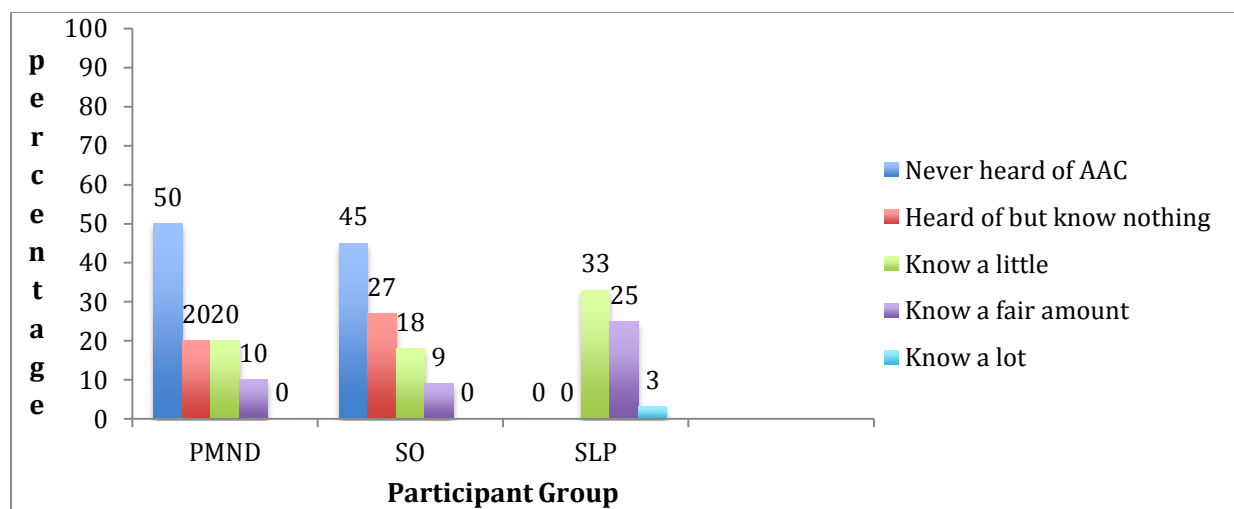


Figure 4.2: Awareness about AAC across participant groups

Figure 4.2 shows that awareness of AAC was limited. Five PMNDs (50%) and five SOs (45%) had never heard about AAC before, while two PMNDs (20%) had heard of AAC, but knew nothing about it, or knew a little. Three SOs (27%) had heard of AAC, but knew nothing about it, and only two SOs (18%) knew a little about AAC. One PMND (10%) and one SO (9%) felt they knew a fair amount about AAC, but no PMNDs or SOs stated that they knew a lot about AAC. Participants might have responded about their awareness about AAC before the day of data collection.

SLPs were not given the option of “never heard of AAC” or “heard of, but know nothing about AAC”, as it was believed that SLP graduates received training in AAC during their degree programme. For this reason, their results were not compared to those of the PMND and SO participant groups. This assumption was however incorrect as it was later found that not all SLPs had received AAC training in their degree programmes. Nine SLPs (33%) felt they only knew a little about AAC. Seven SLPs (25%) felt they knew a fair amount about AAC and only one (6%) indicated she knew a lot about AAC.

Although literature discusses the acceptance of, as well as preferences and attitudes towards AAC, there is limited information about awareness of AAC for PMNDs and their SOs. From the current results it is evident that the majority of PMNDs and SOs participants had either never heard of AAC, or heard of it but felt that they knew nothing about AAC. This could likely be due to delayed referral to an SLP. Of the ten PMNDs who participated in the study, only three (30%) had consulted with an SLP before. This is quite concerning in view of the fact that research shows that 95% of those diagnosed with MND will lose the ability to meet their daily communication needs with their natural speech (Mckelvey et al., 2012). Doyle and Phillips (2001) state that timely referral to an SLP is important for AAC acceptance. Furthermore, screening, referral, assessment, acquisition of technology and training on how to use this technology must also occur timeously (Bongioanni, 2012). Often PMNDs, SOs and SLPs wait to implement AAC until after speech has deteriorated, but unfortunately once this starts happening, MND progresses so rapidly that effective training and use are not possible (Beukelman et al., 2011).

Awareness of AAC was quite limited for the group of SLPs. The majority of SLPs in this study felt they only knew a little about AAC. Of the 17 SLPs who participated, only three (18%) reported that they had received additional training in AAC. This is supported in international literature as Murphy (2004) expresses concern about the knowledge and skills of those who are responsible for providing AAC devices. Murphy (2004) further states that many SLPs have a lack of knowledge about the potential of AAC devices, due to the pressure of a large general case load and lack of training.

4.3.1.1.1 Sources of information about AAC

Table 4.1 reports where PMNDs and SOs who knew about AAC strategies had gained

their information about AAC strategies.

Table 4.1 Sources of information for PMNDs and SOs about AAC

| Participant Group | Number of participants | Received information about AAC from an SLP | Received information about AAC from the MNDASA |
|-------------------|------------------------|--|--|
| PMND | 3 | 1 (25%) | 2 (55%) |
| SO | 3 | 1 (33%) | 2 (67%) |

Table 4.1 indicates that the three PMNDs and three SOs who were aware of AAC, had been informed by either an SLP (one PMND (10%) as well as one SO (9%)) or by the Motor Neuron Disease Association of South Africa (MNDASA) (two PMNDs (20%) and two SOs (18%)).

Even though only three PMNDs and SOs had knowledge of AAC, their information came from the same sources, namely an SLP or MNDASA. The American Speech-Language-Hearing Association (ASHA) includes the management of PMNDs in the scope of practice of the SLP. The SLP's role includes maintaining functional communication and swallowing throughout the progression of the disease. The SLP provides strategies to improve speech intelligibility and prevent exhaustion during communication. The SLP may also help the individual to use AAC strategies to successfully communicate when speech production becomes effortful (ASHA, 1991). Therefore, it is surprising that although three PMNDs had seen an SLP since diagnosis, only one had been informed about AAC. It is likely that the person who informed the PMND and SO about AAC at the MNDASA was in fact also an SLP, as SLP volunteers often attend the MNDASA support group meetings.

SLPs, in turn, reported that they mostly gained their knowledge about AAC from colleagues (59% or n=16), graduate studies (56% or n=15), the Internet (37% or n=10) and Continuing Professional Development (CPD) courses (33% or n=8) as illustrated in Figure 4.3.

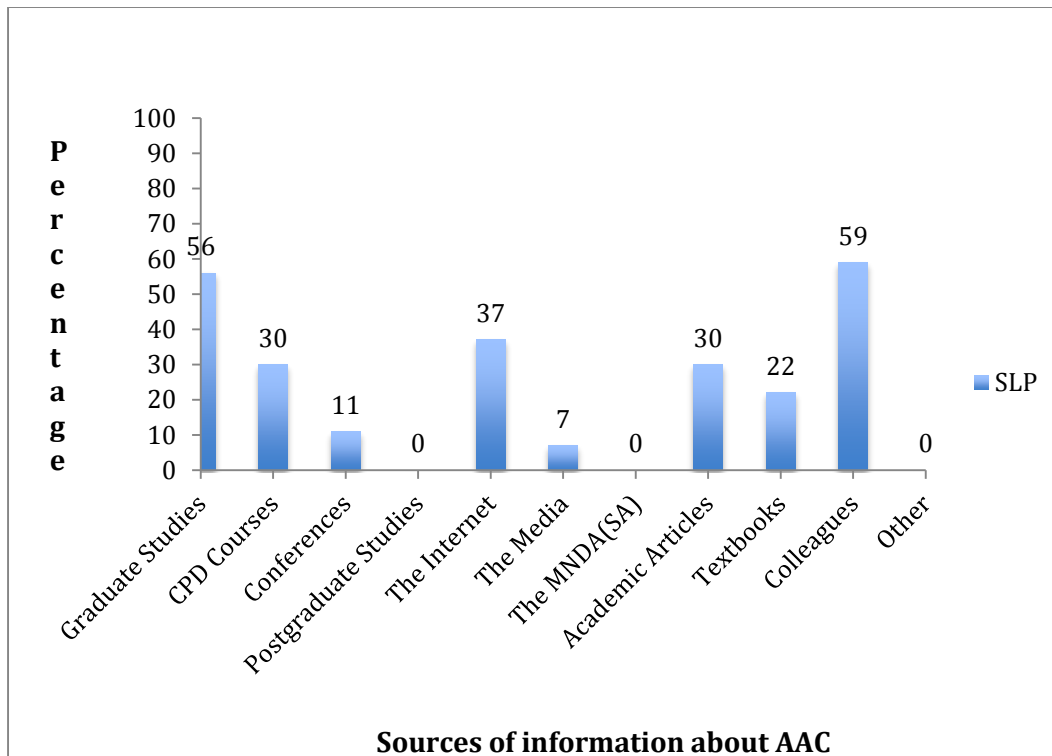


Figure 4.3: SLPs’ sources of information about AAC

It was interesting to note that more SLPs received information about AAC from colleagues than from their graduate studies. This may indicate that the inclusion of AAC modules in graduate training programmes may not be a given across the various universities. This finding highlights the need for adequate training and funding of professionals if they are to be expected to provide the input, time and backup that is required for PMNDs and SOs to use AAC technology successfully (Wendt, 2002). Baxter et al. (2012) and Beukelman et al. (2011) also found that while the training of SLP staff members is a great facilitator, a lack of AAC training is an equally significant barrier.

4.3.1.1.2 AAC candidacy for PMNDs

Table 4.2 reflects participants’ awareness about PMNDs as potential candidates for AAC. The results were compared across groups.

Table 4.2: Awareness of AAC candidacy for PMNDs

| Description | Results | | | | | | | | |
|---|---|----------|------------|-----|------|--------------|-----|--------|-----|
| <p>PMNDs' own awareness of AAC strategies for PMNDs.</p> <p>Seven PMNDs were aware that AAC strategies could be used once speech becomes difficult.</p> | <p>■ Yes ■ No ■ Unsure</p> <table border="1"> <caption>Awareness of AAC strategies for PMNDs</caption> <thead> <tr> <th>Response</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>Yes</td> <td>70%</td> </tr> <tr> <td>No</td> <td>20%</td> </tr> <tr> <td>Unsure</td> <td>10%</td> </tr> </tbody> </table> | Response | Percentage | Yes | 70% | No | 20% | Unsure | 10% |
| Response | Percentage | | | | | | | | |
| Yes | 70% | | | | | | | | |
| No | 20% | | | | | | | | |
| Unsure | 10% | | | | | | | | |
| <p>SOs' awareness of AAC strategies for PMNDs</p> <p>All SOs were aware that AAC strategies could be used by PMNDs once speech becomes difficult.</p> | <p>■ Yes ■ No ■ Unsure</p> <table border="1"> <caption>Awareness of AAC strategies for PMNDs</caption> <thead> <tr> <th>Response</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>Yes</td> <td>100%</td> </tr> <tr> <td>No</td> <td>0%</td> </tr> <tr> <td>Unsure</td> <td>0%</td> </tr> </tbody> </table> | Response | Percentage | Yes | 100% | No | 0% | Unsure | 0% |
| Response | Percentage | | | | | | | | |
| Yes | 100% | | | | | | | | |
| No | 0% | | | | | | | | |
| Unsure | 0% | | | | | | | | |
| <p>SLPs' awareness of AAC strategies for PMNDs</p> <p>In the SLP group, 16 of the 17 participants were aware that AAC strategies could be used for PMNDs. The remaining participant did not select an option for this question, resulting in missing data.</p> | <p>■ Yes ■ Missing Data</p> <table border="1"> <caption>Awareness of AAC strategies for PMNDs</caption> <thead> <tr> <th>Response</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>Yes</td> <td>94%</td> </tr> <tr> <td>Missing Data</td> <td>6%</td> </tr> </tbody> </table> | Response | Percentage | Yes | 94% | Missing Data | 6% | | |
| Response | Percentage | | | | | | | | |
| Yes | 94% | | | | | | | | |
| Missing Data | 6% | | | | | | | | |

A high number, 16 out of 17 (94%), of SLPs were aware that AAC strategies could be used for PMNDs. This could be due to the fact that all SLPs were interested in working with MND and that the majority, 10 out of 17 (59%), had experience of working with PMNDs. The findings of this study are consistent with literature that suggests that AAC strategies are increasingly becoming more successful with PMNDs and that SLPs are increasingly aware of this (Ball et al., 2004). The same authors found that a total of 96% of PMNDs accepted AAC – a total of 90% accepted technology immediately, while only 6% needed a little time to get used to the idea. Only two participants in their study of 50 PMNDs rejected AAC.

4.3.1.1.3 Current AAC strategies used

SLPs were subsequently also asked if they recommended AAC strategies to PMNDs, and if so, what these strategies were. The results of this question are presented in Figure 4.4.

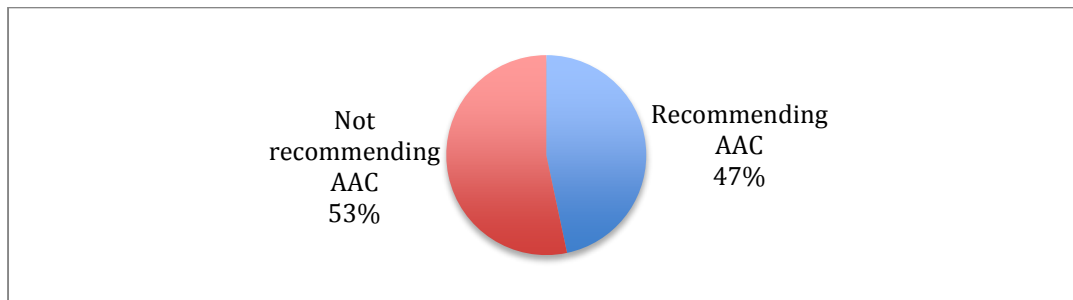


Figure 4.4: SLPs recommending AAC strategies to PMNDs

It is noteworthy that only 47% (n=7) of SLPs actually recommended AAC strategies when working with PMNDs, even though 94% of SLPs were aware that AAC strategies could be used for PMNDs once speech becomes compromised (Table 4.2). The management strategies that SLPs used for PMNDs are reflected in Figure 4.5 below.

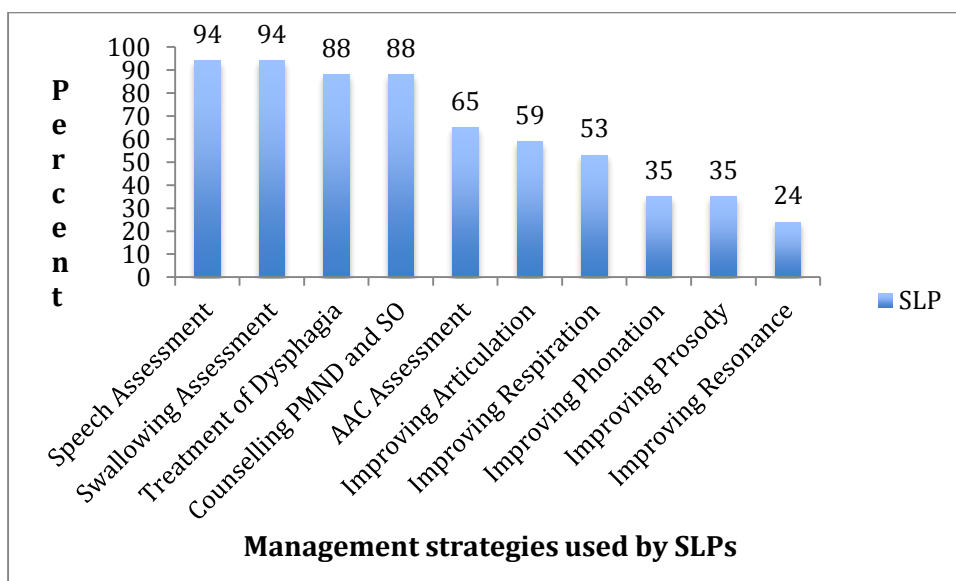


Figure 4.5: Current management strategies reported by SLPs

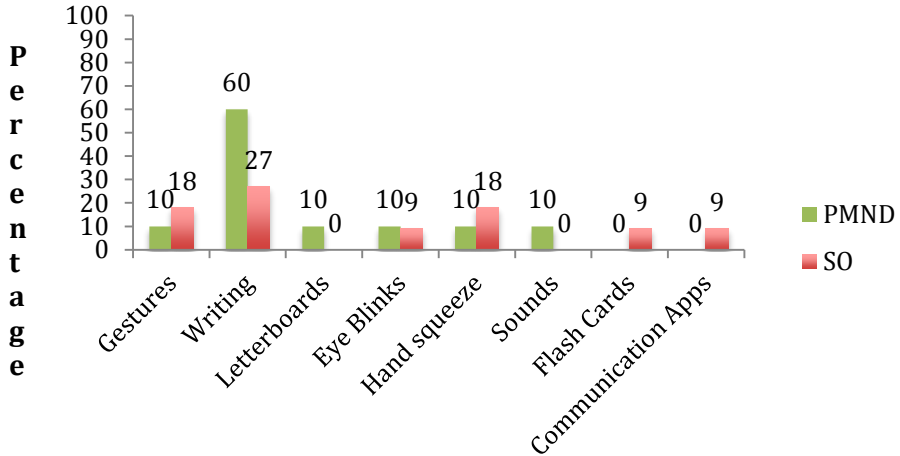
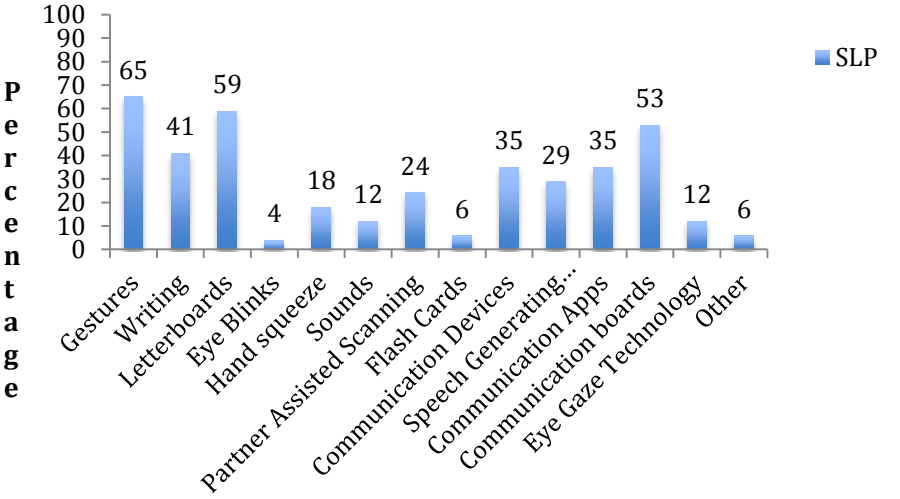
SLPs reported that their management of PMNDs mostly included speech assessment (94% or n=16); swallowing assessment (94% or n=16); treatment of dysphagia (88% or n=15); counselling the patient and family (88% or n=15); AAC assessment and implementing no/low-technology AAC (65% or n=11); improving articulation (59% or n=10); improving respiration (53% or n=9); improving phonation and prosody (35% or n=6); improving resonance (24% or n=4). The limited recommendations regarding AAC

may be due to the negative attitudes that some communication partners might associate with AAC fearing that implementing AAC implies giving up on speech (Brown, 2011).

The emphasis that SLPs place on management of speech strengthening and improvement is contrary to the current evidence in literature. In a review examining AAC patterns and use for PMNDs, Hanson (2011) states that there is a lack of evidence to support speech-strengthening or speech improvement exercises such as improving articulation, respiration, phonation, prosody and resonance for PMNDs. Furthermore, in their scope of practice for the SLP, ASHA (2001) indicates that strategies to improve speech intelligibility and prevent exhaustion during communication should be emphasised by assisting the PMND to use AAC to successfully communicate when speech production becomes effortful (ASHA, 2001). Beukelman et al. (2011) acknowledge the challenging task that SLPs have in terms of screening, referral, assessment and implementation of AAC systems and technology for PMNDs and they highlight the need for training in AAC strategies. SLPs therefore need to be adequately trained in AAC strategies and should attend a variety of CPD activities so as to feel confident enough to suggest and implement AAC strategies with PMNDs.

The AAC strategies that were used by PMNDs or that were reported as being used by the SOs are presented in Table 4.3.

Table 4.3: AAC strategies used by PMNDs: Comparing participant groups

| Description | Results | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
|--|--|----------|----------|----------|----------|---------|----|--------------|----|------------|--------------|--------------|----|------------|----|---------------------------|--------------|-------------|----|-----------------------|----|----------------------|-------------|--------------------|----|----------------------|----|---------------------|----|-------|---|
| <p>AAC strategies currently used by PMNDs as reported by themselves</p> <p>The use of AAC strategies across the group was limited. AAC strategies were mostly used supportively and included 60% writing (n=6), 10% (n=1) gestures, 10% (n=1) letter boards, 10% (n=1) eye blinks, 10% hand squeeze (n=1) and 10% sounds (n=1). No other AAC strategies were used by the PMNDs who participated in the study.</p> |  <table border="1"> <caption>AAC strategies currently used by PMNDs as reported by themselves</caption> <thead> <tr> <th>Strategy</th> <th>PMND (%)</th> <th>SO (%)</th> </tr> </thead> <tbody> <tr> <td>Gestures</td> <td>10</td> <td>18</td> </tr> <tr> <td>Writing</td> <td>60</td> <td>27</td> </tr> <tr> <td>Letterboards</td> <td>10</td> <td>0</td> </tr> <tr> <td>Eye Blinks</td> <td>10</td> <td>9</td> </tr> <tr> <td>Hand squeeze</td> <td>10</td> <td>18</td> </tr> <tr> <td>Sounds</td> <td>10</td> <td>0</td> </tr> <tr> <td>Flash Cards</td> <td>0</td> <td>9</td> </tr> <tr> <td>Communication Apps</td> <td>0</td> <td>9</td> </tr> </tbody> </table> | Strategy | PMND (%) | SO (%) | Gestures | 10 | 18 | Writing | 60 | 27 | Letterboards | 10 | 0 | Eye Blinks | 10 | 9 | Hand squeeze | 10 | 18 | Sounds | 10 | 0 | Flash Cards | 0 | 9 | Communication Apps | 0 | 9 | | | |
| Strategy | PMND (%) | SO (%) | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Gestures | 10 | 18 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Writing | 60 | 27 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Letterboards | 10 | 0 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Eye Blinks | 10 | 9 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Hand squeeze | 10 | 18 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Sounds | 10 | 0 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Flash Cards | 0 | 9 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Communication Apps | 0 | 9 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| <p>AAC strategies recommended by SLPs</p> <p>The strategies that were mostly recommended were gestures 65% (n= 11); letter boards 59% (n=10); communication boards 53% (n=9); and writing 41% (n=7). The strategy that was least selected included eye blinks (4%), despite the fact that voluntary eye control remains intact throughout MND progression.</p> |  <table border="1"> <caption>AAC strategies currently used by PMNDs as recommended by SLPs</caption> <thead> <tr> <th>Strategy</th> <th>SLP (%)</th> </tr> </thead> <tbody> <tr> <td>Gestures</td> <td>65</td> </tr> <tr> <td>Writing</td> <td>41</td> </tr> <tr> <td>Letterboards</td> <td>59</td> </tr> <tr> <td>Eye Blinks</td> <td>4</td> </tr> <tr> <td>Hand squeeze</td> <td>18</td> </tr> <tr> <td>Sounds</td> <td>12</td> </tr> <tr> <td>Partner Assisted Scanning</td> <td>24</td> </tr> <tr> <td>Flash Cards</td> <td>6</td> </tr> <tr> <td>Communication Devices</td> <td>35</td> </tr> <tr> <td>Speech Generating...</td> <td>29</td> </tr> <tr> <td>Communication Apps</td> <td>35</td> </tr> <tr> <td>Communication boards</td> <td>53</td> </tr> <tr> <td>Eye Gaze Technology</td> <td>12</td> </tr> <tr> <td>Other</td> <td>6</td> </tr> </tbody> </table> | Strategy | SLP (%) | Gestures | 65 | Writing | 41 | Letterboards | 59 | Eye Blinks | 4 | Hand squeeze | 18 | Sounds | 12 | Partner Assisted Scanning | 24 | Flash Cards | 6 | Communication Devices | 35 | Speech Generating... | 29 | Communication Apps | 35 | Communication boards | 53 | Eye Gaze Technology | 12 | Other | 6 |
| Strategy | SLP (%) | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Gestures | 65 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Writing | 41 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Letterboards | 59 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Eye Blinks | 4 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Hand squeeze | 18 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Sounds | 12 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Partner Assisted Scanning | 24 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Flash Cards | 6 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Communication Devices | 35 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Speech Generating... | 29 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Communication Apps | 35 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Communication boards | 53 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Eye Gaze Technology | 12 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Other | 6 | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |

As depicted in Table 4.3, limited use of AAC strategies was found. Possible reasons for this may be that the mild-moderate selection criteria for inclusion may have resulted in the participants having not yet required AAC strategies for communication and therefore they did not use them. Nine PMNDs who participated in the study (90%) were still able to communicate with a degree of intelligible speech, despite the fact that their MND severity ranged from moderate to severe. This finding is consistent with that of Ray (2015) who also found that a combination of speech and gestures was used 60% of the time when a person with MND was attempting to communicate. Similarly, Doyle and Phillips (2001) found that unaided strategies are valuable for persons when speech was only slightly compromised and that limbs could be engaged to enhance communication with gestures and signs. They further discovered that participants relied more heavily on unaided or low-technology approaches in the initial stages of the disease. As seen in the current research study, using natural speech remained a preference, which is consistent with the findings of Brownlee and Bruenning (2012) that speech remained a preference above AAC when the person could still talk.

A wide range of AAC strategies were reported as being recommended by SLPs to PMNDs. This was despite the fact that only 47% of SLPs stated that they actually recommended AAC strategies to PMNDs. It is possible that SLPs selected many options because they were given a closed set of answers and were allowed to select all the AAC strategies that they were currently using with PMNDs.

It must be noted that the SLPs in this study did not directly provide AAC services to the PMNDs who participated in this study. It is however interesting to note that in general, SLPs mostly suggested gestures (65%), letter boards (59%) and communication boards (53%) as AAC strategies for assisting the PMNDs whom they saw at their practice. PMNDs however used AAC strategies that had not originally been suggested by SLPs, such as eye blinks (10%), hand squeeze (10%) and sounds (10%).

4.3.2 Perceptions about message banking

In this section the perceptions about message banking are discussed across the three participant groups. This includes (i) awareness about message banking

(Section 4.3.2.1); (ii) sources of information about message banking (Section 4.3.2.1.1); (iii) timing of message banking (Section 4.3.2.1.2); (iv) relevance of message banking (Section 4.3.2.1.3); (v) positive and negative perceptions about message banking (Section 4.3.2.1.4); and (vi) interest in message banking (Section 4.3.2.2).

4.3.2.1 Awareness about message banking

Table 4.4 presents a summary of all participants' awareness of message banking.

Table 4.4: Awareness about message banking

| Description | Results | | | | | | | | | | | | | | | | | | | | | | | | |
|--|---|--------------------------------|--------------------------------|---------------------------|--------------------|----------------------|------------|------|------|--------------|---|----|------|-----------|----|---|------|--------------|----|-----|------|---------------|----|----|---|
| <p>Awareness of message banking for PMNDs Seven PMNDs (70%) had never heard of message banking prior to this study, while two PMNDs (20%) had heard of message banking, but knew nothing about it. One PMND (10%) felt he/she knew a fair amount about message banking.</p> | <table border="1"> <caption>Awareness Levels by Group</caption> <thead> <tr> <th>Group</th> <th>Never heard of Message Banking</th> <th>Heard of but know nothing</th> <th>Know a little</th> <th>Know a fair amount</th> <th>Know a lot</th> </tr> </thead> <tbody> <tr> <td>PMND</td> <td>70</td> <td>20</td> <td>0</td> <td>10</td> <td>0</td> </tr> <tr> <td>SO</td> <td>55</td> <td>9</td> <td>22</td> <td>2</td> <td>2</td> </tr> <tr> <td>SLP</td> <td>35</td> <td>24</td> <td>24</td> <td>11</td> <td>0</td> </tr> </tbody> </table> | Group | Never heard of Message Banking | Heard of but know nothing | Know a little | Know a fair amount | Know a lot | PMND | 70 | 20 | 0 | 10 | 0 | SO | 55 | 9 | 22 | 2 | 2 | SLP | 35 | 24 | 24 | 11 | 0 |
| Group | | Never heard of Message Banking | Heard of but know nothing | Know a little | Know a fair amount | Know a lot | | | | | | | | | | | | | | | | | | | |
| PMND | | 70 | 20 | 0 | 10 | 0 | | | | | | | | | | | | | | | | | | | |
| SO | | 55 | 9 | 22 | 2 | 2 | | | | | | | | | | | | | | | | | | | |
| SLP | | 35 | 24 | 24 | 11 | 0 | | | | | | | | | | | | | | | | | | | |
| <p>Awareness of message banking for SOs Six SOs (55%) had never heard of message banking. Only one SO (9%) had heard of message banking but knew nothing about it, while two SOs (22%) knew a little or a fair amount about message banking.</p> | | | | | | | | | | | | | | | | | | | | | | | | | |
| <p>Awareness of message banking for SLPs Six SLPs (35%) had never heard of message banking. Only four SLPs (24%) had heard of message banking but knew nothing about it, or knew only a little about message banking. Two SLPs (11%) felt they knew a fair amount about message banking.</p> | | | | | | | | | | | | | | | | | | | | | | | | | |
| <p>PMNDs' sources of information about message banking Of the three PMND who knew about message banking, two (80%) had been informed by an SLP, while one (20%) participant had been informed via the MNDASA and the media.</p> | | | | | | | | | | | | | | | | | | | | | | | | | |
| <p>SOs' sources of information about message banking Of the three SOs who knew about message banking prior to the study, only one (25%) had been informed by an SLP. A further two (50%) had been informed by MNDASA.</p> | | | | | | | | | | | | | | | | | | | | | | | | | |
| <p>SLPs' sources of information about message banking Of the 10 SLPs who knew about message banking prior to the study, six (85,7%) had been informed about message banking by a fellow SLP. Four SLPs (57%) had been informed via the Internet, three (43%) by the media and one SLP via MNDASA.</p> | <table border="1"> <caption>Sources of Information by Group</caption> <thead> <tr> <th>Source</th> <th>PMND (%)</th> <th>SO (%)</th> <th>SLP (%)</th> </tr> </thead> <tbody> <tr> <td>A Speech Language...</td> <td>80</td> <td>25</td> <td>85.7</td> </tr> <tr> <td>The Internet</td> <td>0</td> <td>0</td> <td>57.1</td> </tr> <tr> <td>The Media</td> <td>20</td> <td>0</td> <td>42.9</td> </tr> <tr> <td>The MNDA(SA)</td> <td>20</td> <td>50</td> <td>14.3</td> </tr> <tr> <td>J9 Foundation</td> <td>0</td> <td>0</td> <td>0</td> </tr> </tbody> </table> | Source | PMND (%) | SO (%) | SLP (%) | A Speech Language... | 80 | 25 | 85.7 | The Internet | 0 | 0 | 57.1 | The Media | 20 | 0 | 42.9 | The MNDA(SA) | 20 | 50 | 14.3 | J9 Foundation | 0 | 0 | 0 |
| Source | PMND (%) | SO (%) | SLP (%) | | | | | | | | | | | | | | | | | | | | | | |
| A Speech Language... | 80 | 25 | 85.7 | | | | | | | | | | | | | | | | | | | | | | |
| The Internet | 0 | 0 | 57.1 | | | | | | | | | | | | | | | | | | | | | | |
| The Media | 20 | 0 | 42.9 | | | | | | | | | | | | | | | | | | | | | | |
| The MNDA(SA) | 20 | 50 | 14.3 | | | | | | | | | | | | | | | | | | | | | | |
| J9 Foundation | 0 | 0 | 0 | | | | | | | | | | | | | | | | | | | | | | |

Message banking is an early intervention option for PMNDs with intact speech skills (Bongioanni, 2012). The majority of PMNDs who participated in this study (90%) still had intelligible speech. On this basis, these nine PMNDs were all potential candidates for early intervention message banking. Despite this, the study indicates that participants across all participant groups had limited knowledge about message banking. There is a paucity of research about message banking currently, which might explain the low awareness levels of message banking for PMNDs. The importance of early intervention for PMND is, however, highlighted in literature. Yorkston et al. (1993) found that early intervention in the beginning stage of MND is advantageous in a number of ways, for example to develop a relationship with the PMND and his/her family; to offer information regarding the disorder at a pace with which the family and PMND can cope; and also to help educate the PMND and his/her family to become informed consumers of medical and technological services. If the SLP is not adequately trained to meet the collaborative needs of the PMND in the initial stages of MND, then adequate services cannot be provided throughout the later stages of the disease progression.

Awareness about message banking was low for PMNDs and SOs. Seven PMNDs (70%) and six SOs (55%) indicated that they had never heard of message banking. This is not surprising, given that awareness about AAC overall was also low. Most SLPs (33%) indicated that they knew only a little about AAC, therefore it is not surprising that many SLPs (35%) had never heard about message banking. Baxter et al. (2012) and Murphy (2004) found that the training of SLPs can be a great facilitator of or barrier to AAC implementation.

4.3.2.1.1 Sources of information about message banking

As reflected in Table 4.4, two of the three PMNDs (80%) who were aware of message banking had been informed by an SLP. Only one (25%) of the three SOs who were aware of message banking had been informed of it by an SLP. If a third of the SLPs in the present study had never heard of message banking before (35%), and most PMNDs had heard about AAC strategies from an SLP, it is inevitable that the PMNDs and SOs in the study will also have low levels of awareness about message banking. This points to the importance of training

SLPs (e.g. through CPD activities or as part of their graduate degree training) about message banking to enable them to keep abreast of early intervention strategies for this population.

4.3.2.1.2 Timing of message banking

Participants in this study had conflicting views regarding the best time to start with message banking. They were asked about the best time to start doing message banking and had to select an answer from a 6-point closed question with the following options: (i) As soon as possible after being diagnosed with MND; (ii) Once you realise that your speech starts changing; (iii) Once other people realise that your speech starts changing; (iv) Once an SLP recommends it; (v) I'm not sure; (vi) Other. The results of this question are summarised in Figure 4.6. No participants in any of the participant groups selected the "Other" option.

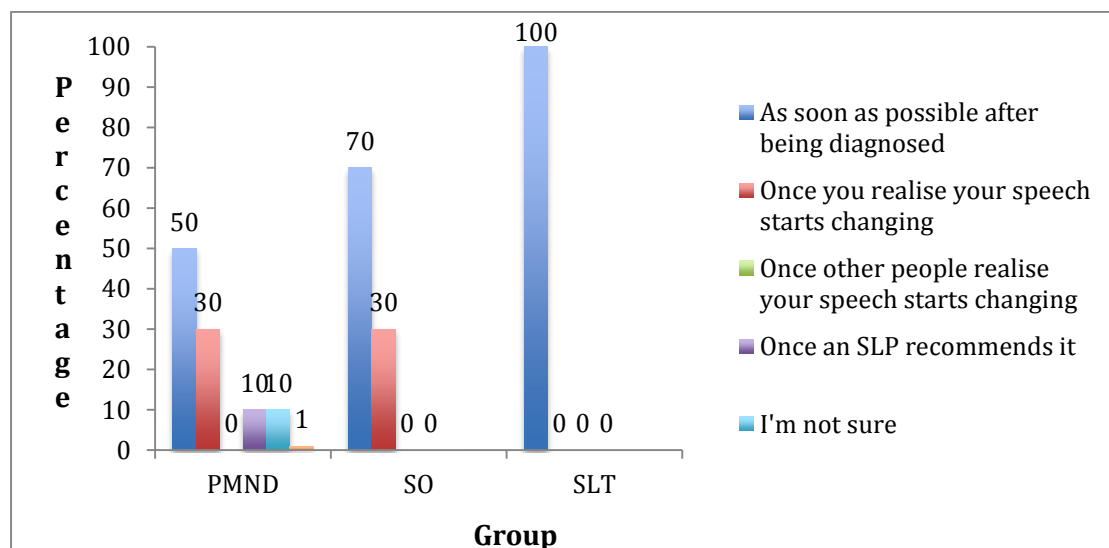


Figure 4.6: Timing of message banking

As shown in Figure 4.6, five PMNDs (50%) said the best time to start doing message banking was as soon as possible after having been diagnosed with MND, while three PMNDs (30%) said that it should be once you realise your speech starts changing. Slightly more SOs than PMNDs said that message banking should start as soon as possible after being diagnosed with MND (seven SOs compared to five PMNDs), while three SOs (30%) agreed with the PMNDs and said message banking should only occur once you realise your speech starts changing. All the

SLPs said that message banking should start as soon as possible after being diagnosed with MND.

Literature currently offers no published evidence regarding the best possible timing for message banking. Due to the degenerative nature of the disease, one could safely assume that message banking should commence as soon as possible after diagnosis. As stated earlier, message banking is an early intervention option for PMNDs with intact speech skills (Bongioanni, 2012). Murphy (2004) suggests that PMNDs and their communication partners may benefit from SLP intervention during various different stages after diagnosis. At or soon after diagnosis, SLP intervention is beneficial to emphasise that help and support will be available if and when needed. At the stage when speech deterioration becomes evident, SLP intervention is helpful as it focuses on explaining the speech mechanism and suggesting ways for both partners to maintain/preserve interaction. When speech is more effortful and less intelligible, SLP intervention supports communication as it suggests possible strategies to assist interaction and resolve misunderstandings. In the final stages, when speech is largely unintelligible, the PMND and SOs may benefit from SLP services that would suggest alternative methods of interaction and communication (Murphy, 2004).

Starting with message banking when a PMND does not yet experience any speech difficulties can be an extremely difficult process as the possibility of losing one's ability to communicate is daunting. Communication is associated with humanity and personal identity (Shadden et al., 2009). The loss or anticipated loss of speech and communication can be perceived as the loss of humanity, and having to face this loss when confronted with a terminal illness is even more challenging (Brownlee & Bruenning, 2012). It may often seem unrealistic to prepare for speech changes when no symptoms are evident. There is however a need for both the PMND and SOs to adapt to the changing situation brought on by this progressive disease by acquiring new communication strategies as early after diagnosis as possible, in order to move with the growing speech disability of the PMND (Fried-Oken et al., 2006; Murphy, 2004). It is therefore an easier task for SLPs to recommend that message banking should start as soon as possible, although many PMNDs and SOs might not appear to be

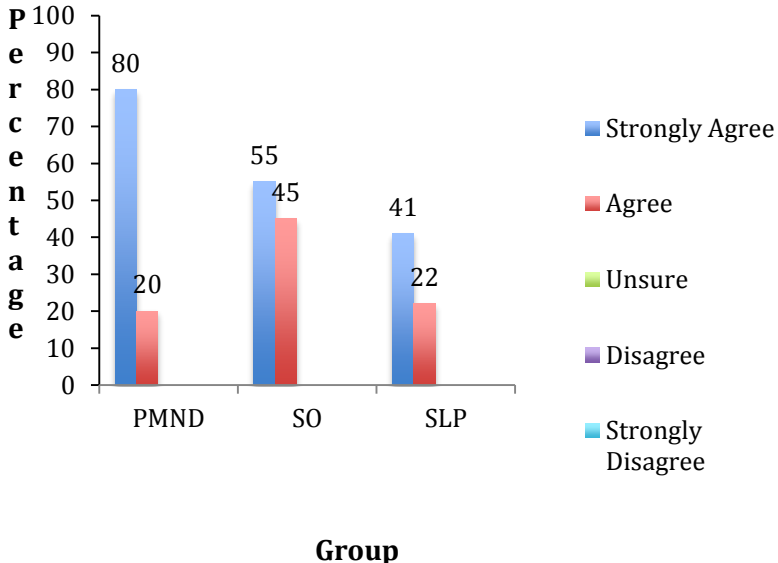
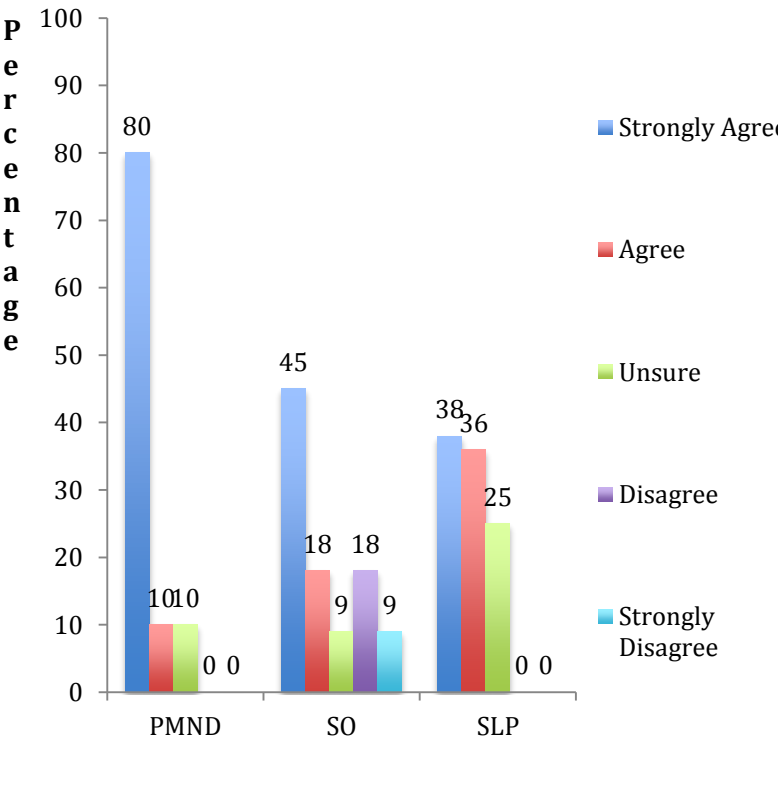
ready for this step and might need more time and support to adjust to the thought of message banking in the initial stages of the diagnosis (Murphy, 2004).

Moss et al. (1996) consider the importance of early acknowledgment of communication difficulties so as to enable the PMND to make decisions before the disease becomes life threatening or debilitating. Depending on the individual person, it may be valuable for SLPs to suggest AAC strategies and systems early so that the PMND may receive adequate training before fatigue makes new learning too strenuous.

4.3.2.1.3 Relevance of message banking for PMNDs in general

All participants were asked to think of all PMNDs in general and consider if they thought that message banking would be a relevant option for them. They were also asked to think of message banking for themselves and consider if it would be a relevant option for them. Results for both questions to all three participant groups are reflected in Table 4.5.

Table 4.5: Relevance of message banking for PMNDs

| Description | Results | | | | | | | | | | | | | | | | | | | | | | | | |
|--|---|-------|----------------|----------|-------------------|----------|-------------------|------|----|----|----|---|---|----|----|----|---|----|---|-----|----|----|----|---|---|
| <p>Relevance for PMNDs in general as reported by PMNDs All PMNDs agreed that message banking was a good idea for PMNDs in general, with eight PMNDs (80%) strongly agreeing and two PMNDs (20%) agreeing.</p> |  <table border="1"> <caption>Data for Relevance for PMNDs in general</caption> <thead> <tr> <th>Group</th> <th>Strongly Agree</th> <th>Agree</th> <th>Unsure</th> <th>Disagree</th> <th>Strongly Disagree</th> </tr> </thead> <tbody> <tr> <td>PMND</td> <td>80</td> <td>20</td> <td>0</td> <td>0</td> <td>0</td> </tr> <tr> <td>SO</td> <td>55</td> <td>45</td> <td>0</td> <td>0</td> <td>0</td> </tr> <tr> <td>SLP</td> <td>41</td> <td>22</td> <td>0</td> <td>0</td> <td>0</td> </tr> </tbody> </table> | Group | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | PMND | 80 | 20 | 0 | 0 | 0 | SO | 55 | 45 | 0 | 0 | 0 | SLP | 41 | 22 | 0 | 0 | 0 |
| Group | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | | | | | | | | | | | | | | | | | | | | |
| PMND | 80 | 20 | 0 | 0 | 0 | | | | | | | | | | | | | | | | | | | | |
| SO | 55 | 45 | 0 | 0 | 0 | | | | | | | | | | | | | | | | | | | | |
| SLP | 41 | 22 | 0 | 0 | 0 | | | | | | | | | | | | | | | | | | | | |
| <p>Relevance for PMNDs in general as reported by SOs All SOs agreed that message banking was a good idea for PMNDs in general, with six SOs (55%) strongly agreeing and five (45%) agreeing.</p> | | | | | | | | | | | | | | | | | | | | | | | | | |
| <p>Relevance for PMNDs in general as reported by SLPs All SLPs agreed that message banking was a good idea for PMNDs in general, with eleven (41%) SLPs strongly agreeing and six (22%) agreeing.</p> | | | | | | | | | | | | | | | | | | | | | | | | | |
| <p>Relevance for specific PMNDs as reported by PMNDs themselves Eight PMNDs (80%) again strongly agreed that message banking was a good idea for themselves, while one PMND (10%) simply agreed. One PMND (10%) was unsure if message banking was relevant for him.</p> |  <table border="1"> <caption>Data for Relevance for specific PMNDs</caption> <thead> <tr> <th>Group</th> <th>Strongly Agree</th> <th>Agree</th> <th>Unsure</th> <th>Disagree</th> <th>Strongly Disagree</th> </tr> </thead> <tbody> <tr> <td>PMND</td> <td>80</td> <td>10</td> <td>10</td> <td>0</td> <td>0</td> </tr> <tr> <td>SO</td> <td>45</td> <td>18</td> <td>9</td> <td>18</td> <td>9</td> </tr> <tr> <td>SLP</td> <td>38</td> <td>36</td> <td>25</td> <td>0</td> <td>0</td> </tr> </tbody> </table> | Group | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | PMND | 80 | 10 | 10 | 0 | 0 | SO | 45 | 18 | 9 | 18 | 9 | SLP | 38 | 36 | 25 | 0 | 0 |
| Group | Strongly Agree | Agree | Unsure | Disagree | Strongly Disagree | | | | | | | | | | | | | | | | | | | | |
| PMND | 80 | 10 | 10 | 0 | 0 | | | | | | | | | | | | | | | | | | | | |
| SO | 45 | 18 | 9 | 18 | 9 | | | | | | | | | | | | | | | | | | | | |
| SLP | 38 | 36 | 25 | 0 | 0 | | | | | | | | | | | | | | | | | | | | |
| <p>Relevance for a specific PMND as reported by SOs The SO group had varied answers when they had to reflect on a specific PMND. Five SOs (45%) strongly agreed, two (18%) agreed and one SO was unsure. SOs were the only group who indicated that they disagreed (2 SO, 18%) or strongly disagreed (1 SO, 9%) that message banking was a good idea for their significant other with MND. Interestingly, there was a significant difference ($p \leq 0.037$) between responses of PMND and SO groups.</p> | | | | | | | | | | | | | | | | | | | | | | | | | |
| <p>Relevance for a specific PMND as reported by SLPs Seven SLPs (38%) strongly agreed, six (36%) agreed and four SLPs (25%) were unsure if message banking would be a relevant option for the PMNDs whom they saw at their practice.</p> | | | | | | | | | | | | | | | | | | | | | | | | | |

Participants were furthermore asked to rate their agreement with the following statement: “I believe message banking is a good idea for me.” Participants could select any of the following statements and a numerical value was allocated to each statement: strongly agree = 1, agree = 2, unsure = 3, disagree = 4, strongly disagree = 5. Significant differences were found amongst participant groups. Table 4.6 reflects these differences.

Table 4.6: Significant differences in perceived relevance of message banking

| Participant Group | Number of participants | Mean | Standard deviation | p-Value |
|-------------------|------------------------|------|--------------------|------------------|
| Total | 37 | 1.83 | 1.06 | |
| PMNDs | 10 | 1.30 | 0.67 | $p \leq 0.037^*$ |
| SOs | 11 | 2.27 | 1.48 | $p \leq 0.037^*$ |
| SLPs | 17 | 1.87 | 0.25 | |

* Indicates statistical significance on the 5% level of confidence ($p \leq 0.05$)

Table 4.6 indicates that there was a significant difference ($p \leq 0.037$) in the mean rating of perceived relevance of message banking between PMNDs and SOs. Eight PMNDs (80%) felt that message banking would be a good idea for themselves, while only five of their SOs (45%) felt that message banking would be a good idea for their significant other with MND. Two SOs (18%) disagreed, and one SO (9%) strongly disagreed that message banking was a good idea for his/her significant other with MND.

In the results reported in Tables 4.5 and 4.6 it is noteworthy that PMNDs perceived message banking as equally relevant for themselves (80%) and for other people with MND in general (80%). SOs however perceived the relevance of message banking much lower for both people with MND in general (55%) and for their own significant other with MND (45%). Significant differences occurred between PMND and SO groups ($p \leq 0.037$). Research findings document that family perceptions and attitudes toward technology could be a barrier to implementation and highlight the importance of a collaborative effort between a person with communication difficulties and his/her SO, resulting in shared responsibility between them for communication (Calculator 1998, Murphy et al., 1996). Successful use of AAC often depends on the partners' concerns, skills and preferences about AAC (Murphy, 2004). Communication is a collective effort and therapy and goal setting needs to be provided as such. Therapy should not concentrate solely on the PMND, but must always involve the person's communication partner or partners (Murphy, 2004).

4.3.2.1.4 Positive and negative perceptions about message banking

Participants were given a list of positive and negative statements about message banking. PMNDs were requested to select statements that they agree with, while SOs were requested to think of their significant other with MND and select statements that would apply to them. SLPs were requested to think of the PMNDs whom they saw at their practices and select statements that apply to them. Participants could select any number of statements they agree with. Figure 4.7 illustrates all three participant groups' positive perceptions about message banking.

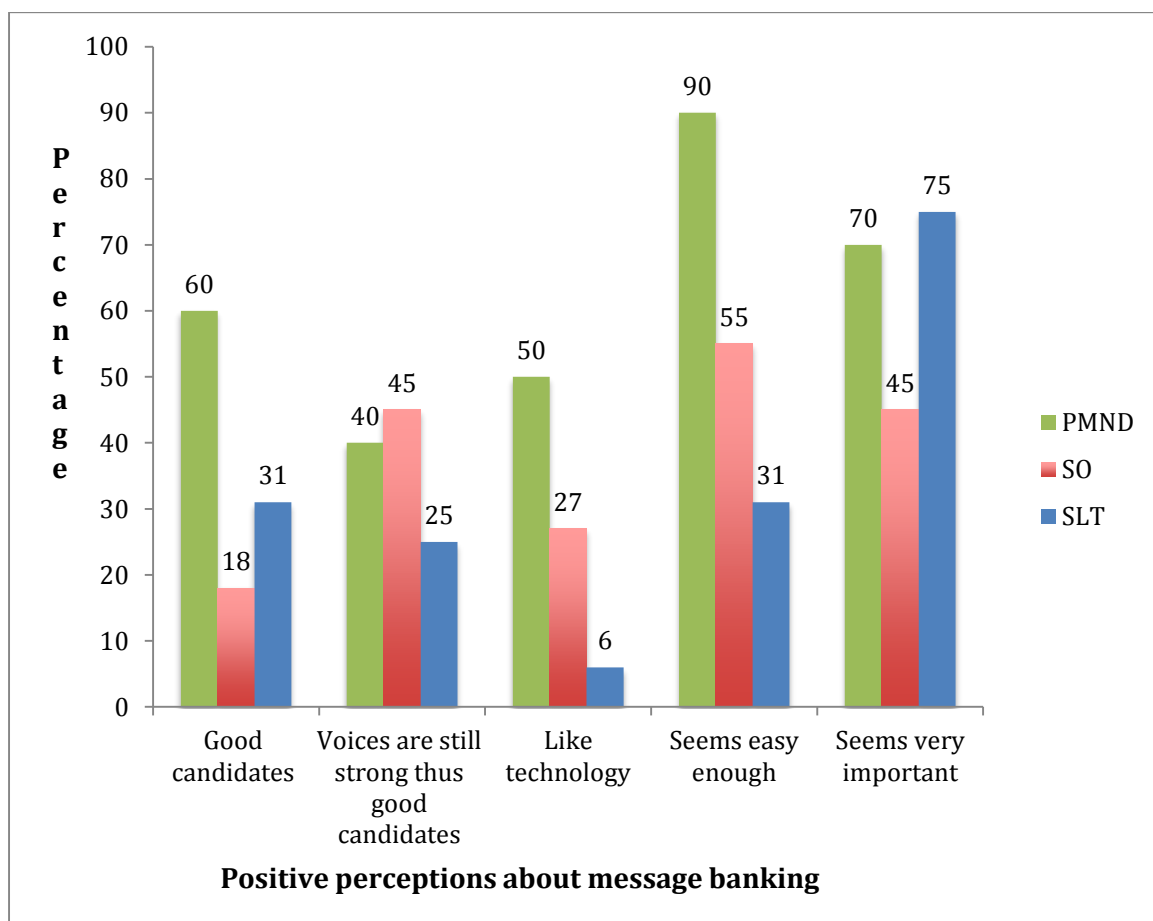


Figure 4.7: Positive perceptions about message banking

Figure 4.7 illustrates a variety of positive statements regarding message banking. Nine PMNDs (90%) indicated that message banking seems easy enough, but significant differences ($p \leq 0.009$) occurred across groups for this statement as only six SOs (55%) agreed and only five SLPs (31%) agreed. Seven PMNDs (70%) felt that message banking seems very important and there were no significant differences across groups ($p \leq 0.27$)

as five SOs (45%) and twelve SLPs (75%) agreed with this statement. Furthermore, six PMNDs (60%) felt they would be good candidates for message banking. There were no statistically significant differences across the three groups ($p \leq 0.12$), although only two SOs (18%) felt that their significant other with MND would be a good candidate and only five SLPs (31%) agreed with this statement regarding the PMNDs they saw at their practices.

Interestingly enough, four PMNDs (40%) and five SOs (45%) felt that the PMNDs would be good candidates for message banking because their voices were strong enough. Four SLPs (25%) felt that the voices of the PMNDs they saw at their practices were strong enough to make them good candidates for message banking.

Some participants however had negative perceptions and attitudes towards message banking. These perceptions are illustrated in Figure 4.8.

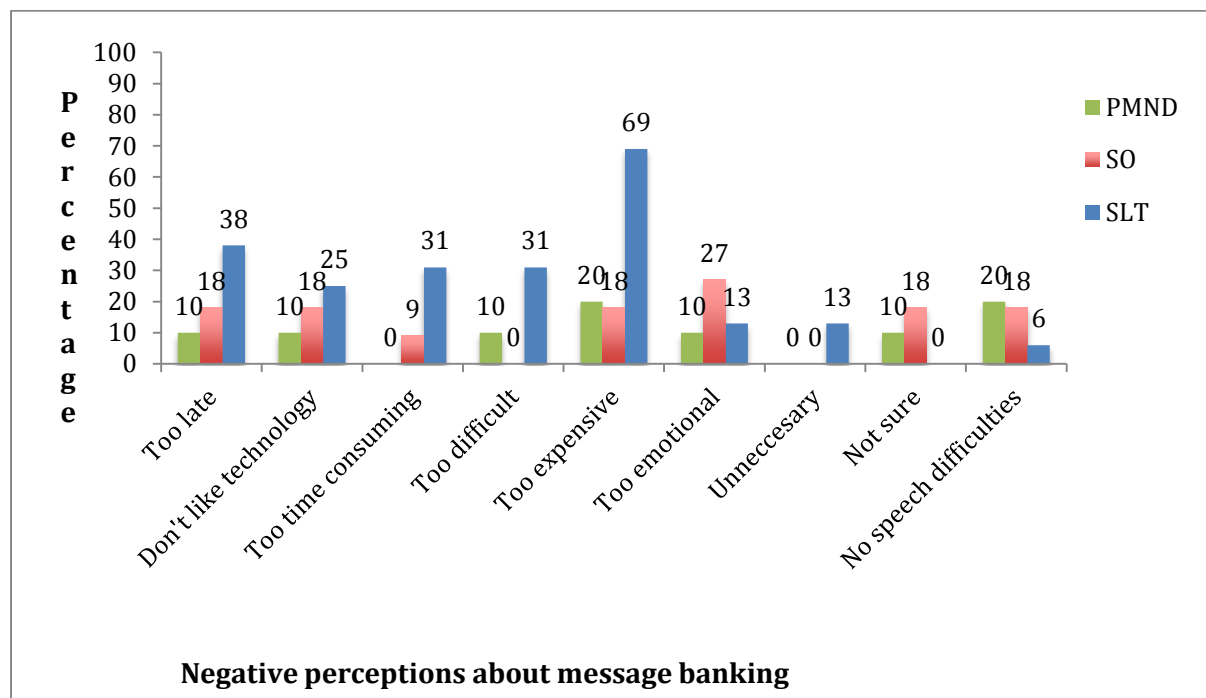


Figure 4.8: Negative perceptions about message banking

Figure 4.8 illustrates that two PMNDs (20%) and two SOs (18%) saw the PMND's strong voice as an indicator that he/she would not be a good candidate for message banking, as they were not experiencing any speech difficulties yet. Only one SLP (6%) indicated that at the stage when she saw patients, they were not experiencing any speech difficulties

yet.

On the other hand, one PMND (10%) and two SOs (18%) felt that the PMND's speech had deteriorated too much and that it was too late for message banking to be an option for them. Six SLPs (38%) indicated that the speech of PMNDs whom they saw at their practice would soon have deteriorated too much for message banking to be an option for them.

Less PMNDs had negative perceptions than positive perceptions about message banking. However, this was not the case for all participant groups. Only two PMNDs (20%) felt that message banking would be too expensive. Statistically significant differences ($p \leq 0.008$) were found between SLPs and SOs using the Chi-square test. As two SOs (18%) and 11 SLPs (69%) felt that message banking would be too expensive. The negative perceptions of SLPs about message banking could potentially be a barrier to the implementation of message banking as PMNDs and SOs are likely to seek the guidance of an SLP when deciding to do message banking.

No PMND felt that message banking would be too time consuming, however statistically significant differences occurred between SOs and SLPs ($p \leq 0.04$) as one SO (9%) and five SLPs (31%) felt that message banking would be too time consuming. Only one PMND (10%) felt that message banking seemed too difficult, whereas none of the SOs and five SLPs (31%) felt it seemed too difficult. Statistically significant differences ($p \leq 0.04$) therefore occurred between PMNDs and SLPs in terms of the difficulty of the task. Again the negative perceptions of SLPs could be threatening to the successful implementation of message banking.

Only one PMND (10%) felt that message banking would be too emotional, while three SOs (27%) and two SLPs (13%) thought that it would be too emotional. No PMND or SO felt that message banking would be unnecessary, but two SLPs (13%) thought so. One PMND (10%) indicated that he/she did not like technology, while two SOs (18%) indicated that their significant others with MND did not like technology. Four SLPs (25%) indicated that they thought their patients did not like technology.

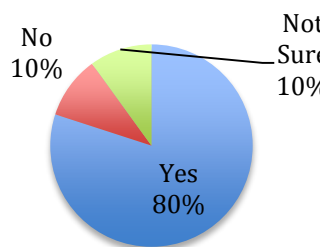
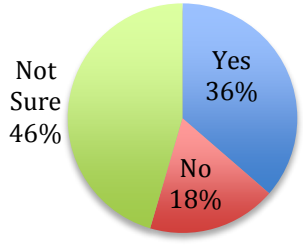
The negative perceptions towards message banking were not surprising as the literature indicates that no matter how advanced technology is, it can never replace the voice, fingers or legs of the PMND (Beukelman et al., 1985). Given the steady decline in their physical functioning, PMNDs often have little tolerance for any technology that requires extensive new learning (Beukelman et al., 1985; Doyle & Phillips, 2001). The

increased number of negative perceptions for the SO and SLP groups could be an indicator of barriers to successful implementation of message banking and highlights the need for training SLPs in particular on aspects such as costs involved, difficulty and the process of message banking. SOs also require accurate information, as family perceptions and support have been identified to constitute one of the three major barriers to successful AAC implementation (Baxter et al., 2012).

4.3.2.2 Interest in message banking

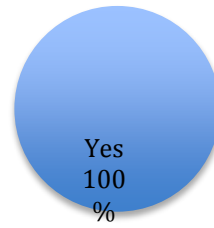
Participants across all participant groups were asked about their interest in message banking. PMNDs were asked if they themselves would be interested in message banking, while SOs were asked whether they thought their significant other with MND would be interested in message banking. SLPs were asked if they would be interested in doing message banking with the PMNDs they saw at their practice. The results of these questions are given in Table 4.7.

Table 4.7: Interest in message banking

| Description | Results |
|--|--|
| <p>PMNDs' interest in message banking</p> <p>Eight PMNDs (80%) indicated that they would be interested in message banking. Only one PMND (10%) each indicated that he/she was unsure or that he/she would not be interested in message banking.</p> |  <p>A pie chart with three segments: a large blue segment for 'Yes' (80%), a small red segment for 'No' (10%), and a small light green segment for 'Not Sure' (10%).</p> |
| <p>SOs' interest in message banking</p> <p>Four SOs (36%) felt that their significant others with MND would be interested in message banking. Slightly more (5 SOs) (45%) were unsure about the interest of their significant other with MND in message banking. Lastly, two SOs (18%) felt that their significant other with MND would not be interested in message banking,</p> |  <p>A pie chart with three segments: a blue segment for 'Yes' (36%), a large light green segment for 'Not Sure' (46%), and a red segment for 'No' (18%).</p> |

SLPs' interest in message banking

All SLPs were interested in doing message banking with the PMNDs whom they saw at their practice.



4.3.3 Communication purposes of message banking

Message banking is of great importance for continued communication. In this section the communication purposes of message banking are discussed across the three participant groups. These include the specific messages to bank (Section 4.3.3.1), as well as the categories of messages to bank in the voice of the person with MND (Section 4.3.3.2).

4.3.3.1 Messages to bank

PMND and SO participant groups were asked to provide the researcher with a list of messages in their own words that they thought would be important to record during message banking. Participants' sentences were then grouped according to the four purposes of communication as defined by Light (1988), namely (i) communication of needs and wants; (ii) information transfer; (iii) social closeness; and (iv) social interaction. This was done to determine what the communication purposes were that PMNDs and SOs viewed as most important for message banking. Results are presented in Figure 4.9.

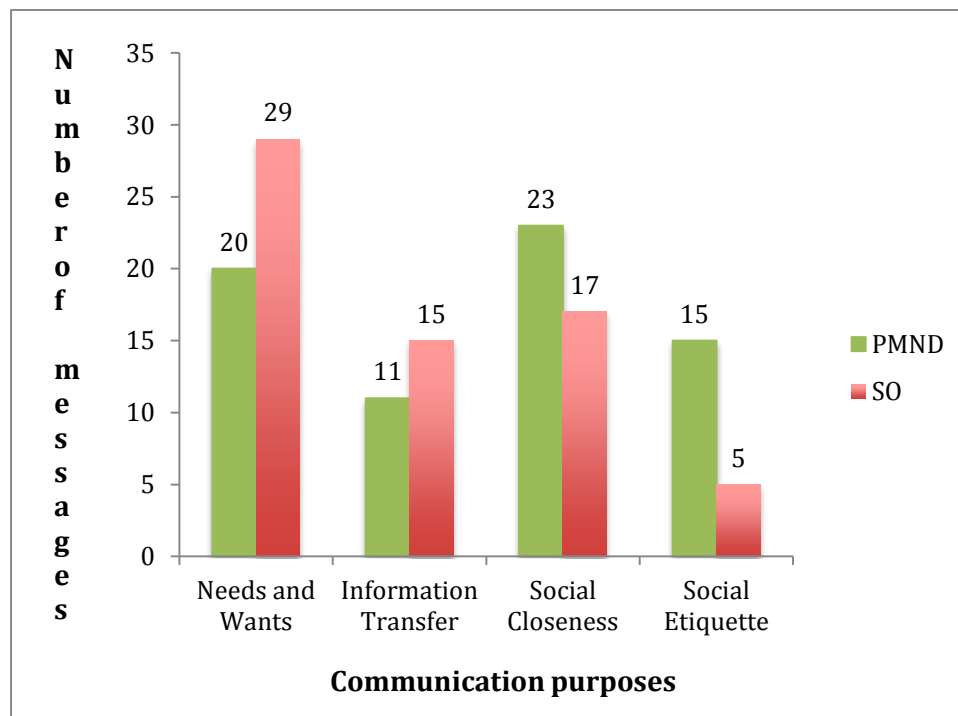


Figure 4.9: Communication purposes of messages to bank

The communication of needs and wants focuses less on the individual and more on the end goal (Light, 1988). Messages relating to needs and wants could, to some extent, be predictable perhaps making them easier to predict for message banking. For the purpose of information transfer the focus is placed more on the message. This is a more challenging communication purpose, as it is less predictable than the communication of needs and wants. Information transfer depends on the ability to construct novel messages in response to conversation (Light, 1988). The pre-recording of messages to transfer information could be more challenging, as such messages are often composed on the spot. The third purpose of communication, to maintain social closeness, is even more challenging, as such messages are usually not predictable and the interaction with another is the most important aspect (Light, 1988). Specific messages of social closeness (e.g. "I love you") can, however, be predicted and pre-recorded to use during message banking. The last purpose of communication, to conform to social conventions, revolves around fulfilling designated turns in an acceptable manner, with less focus on developing interaction (Light, 1988). These messages would also be easier to predict for message banking.

PMNDs provided the largest number of messages in the category of social closeness (23), while they provided only 20 messages relating to their own needs and wants. This is less than the number of messages (29) suggested by SOs for this category. PMNDs provided 15 messages of social etiquette and 11 messages relating to information transfer. For SOs, messages of social closeness were less important during message banking than messages relating to needs and wants, and they provided 17 messages related to social closeness and 29 messages related to needs and wants. They also provided 15 messages relating to information transfer, thus ranking this category as more important than messages of social etiquette (5 messages). Reverse patterns were seen for the two most important purposes (social closeness and needs and wants) for PMNDs and SOs, as well as for the two least important purposes (social etiquette and information transfer).

It was noteworthy that statistically significant differences ($p \leq 0.039$) were found based on the Chi-square test between PMNDs and SOs for the messages that participants regarded as important to bank. PMNDs provided 69 sentences in the following order: Most PMNDs wanted to bank sentences about social closeness (36%); followed by messages about needs and wants (30%); followed by social etiquette

(19%); and least messages were provided about information transfer (15%). In contrast, when SOs were asked what they would like their partner to bank, they provided 66 messages: Most wanted their significant other with MND to bank messages about needs and wants (43%), followed by messages about social closeness (26%) and messages about information transfer (23%), and least wanted them to bank messages about social etiquette (8%).

The findings regarding SOs are consistent with those of Fried-Oken et al. (2006) who also found that caregivers reported that PMNDs used AAC to get their needs met, to achieve social closeness and to transfer information.

Results for the group of PMNDs are also supported in literature. Costello (2014) states that message banking allows for social closeness as it enables the PMND to record legacy messages. Furthermore The SOs in the Fried-Oken et al. (2006) study reported that PMNDs regard the ability to maintain social closeness with another person as the most important purpose of communication, above their desire to indicate wants and needs or to pass on information (Fried-Oken et al., 2006). Similarly, the focus on social closeness is supported by Stuart et al. (2000) who suggested that that at all stages of the disease, the PMND might need vocabulary to conserve 'small talk' – in other words to help maintain and nurture personal relationships, to gossip, to reduce conflict and to tell and respond to jokes.

4.3.3.2 Categories of messages to bank in the voice of the person with MND

The use of a synthesised or digital voice on an SGD is often both a barrier and a facilitator for AAC implementation (Baxter et al., 2012). Message banking, however, will allow the SGD to speak certain pre-recorded messages in the voice of the PMND. Creating novel messages in the voice of the PMND would nonetheless not be possible and the demands in terms of memory space on the device are some of the disadvantages (Brownlee, 2014). It is furthermore unrealistic to expect every PMND to record every possible message in his/her own voice. Therefore participants who rely on speech-generating devices will have messages banked in their own voice (these could be legacy messages), whilst also relying on an SGD to create novel messages.

Participants in the study were for instance asked which categories of messages would be acceptable in a computer voice (digital/synthetic voice) and for which

categories they thought their own voice would be crucial. Participants indicated this in each category of the *Communication Device Use Checklist* developed by Fried-Oken et al. (2006). Not all participants provided answers in each category causing the group size to vary for each category. The results for the messages that participants wanted in their own voice are summarised in Figure 4.10.

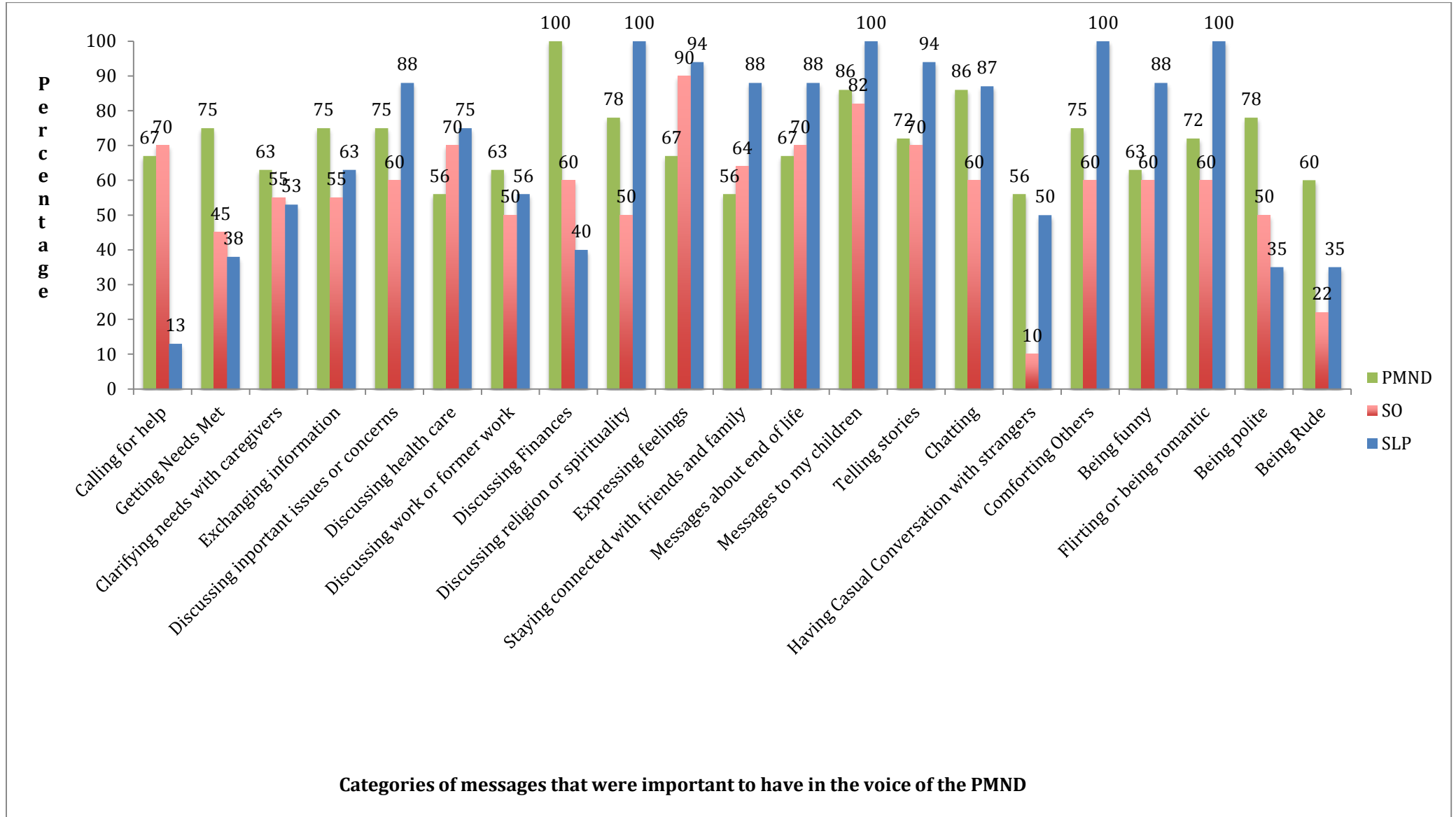


Figure 4.10: Messages to bank in the voice of the PMND

Figure 4.10 illustrates that there was great variety in the messages that participants from the three participant groups considered as important to bank in their own voice (PMNDs), in the voice of their significant other with MND (SOs), or the voice of the patients with MND whom they saw at their practice (SLPs).

PMNDs indicated that discussing their finances was one of the most important areas that they wanted to bank in their own voice. All PMNDs, six SOs (60%) and only seven SLPs (40%) felt it was important to bank messages related to finances in the voice of the PMND. Statistically significant differences ($p \leq 0.008$) using the chi-square test were found between PMNDs and SLPs.

Seven PMNDs (88%) furthermore felt that messages for chatting were important to record in their own voice. Six SOs (60%) and 13 SLPs (87%) agreed that messages to allow the person to chat were important to record for message banking. No significant differences occurred for SOs or SLPs ($p \leq 0.242$).

All three participant groups agreed that messages to children were very important to record in the voice of the person with MND (seven PMNDs (88%); nine SOs (82%); all SLPs (100%)), which resulted in no significant differences ($p \leq 0.122$) across groups.

Messages to convey being polite were also important to all three participant groups (PMNDs 7 (88%); SOs 5 (50%); SLPs 6 (35%)), with no significant differences occurring across groups ($p \leq 0.109$). Equally important were discussing messages related to religion or spirituality in the voice of the PMND (PMNDs 7 (88%); SOs 5 (50%); SLPs 17 (100%)). Despite the fact that all participants felt religion or spirituality was important, the chi-square test revealed statistically significant differences ($p \leq 0.002$) between all three participant groups.

All participant groups (PMNDs 6 (75%); SOs 6 (55%); SLPs 10 (63%)) considered messages used to exchange information as important to be recorded in the voice of the PMND. No significant differences were noted across groups ($p \leq 0.652$).

Discussing important issues or concerns were also important and all participant groups wished to have them banked in the own voice of the PMND

(PMNDs 6 (75%); SOs 6 (60%); SLPs 15 (88%)). No significant differences occurred across the three groups ($p \leq 0.239$).

Messages to comfort others were also important to bank in the voice of the person with MND. Six PMNDs (75%), 6 SOs (60%) and 27 SLPs (100%) indicated that this was important to them. The chi-square test revealed statistically significant differences between SO and SLP groups ($p \leq 0.008$).

Messages to enable the person with MND to continue flirting or be romantic were important across all groups, with 5 PMNDs (72%), 6 SOs (60%) and 17 SLPs (100%) selecting this option. The chi-square test revealed that significant differences occurred between the SO and SLP groups ($p \leq 0.007$).

It was lastly important across all groups to record stories in the voice of the PMND (PMNDs 5 (72%); SOs 7 (70%); SLPs 25 (94%)). No significant differences were found ($p \leq 0.200$).

4.3.3.3 Categories of messages where a digital voice would be sufficient as reflected by PMNDs

Messages that PMNDs were less interested to bank in their own voice and where a synthetic voice would therefore suffice are also reflected in Figure 4.10. These were messages about discussing healthcare (PMNDs (44%); SOs (30%); SLPs (25%));, messages to stay connected with friends and family (PMNDs (44%); SOs (36%); SLPs (12%)) and messages to be used in casual conversation with strangers (five PMNDs (44%); SO (90%); SLPs (45%)).

Current research shows that SOs who care for PMNDs have expressed concern about the quality of speech synthesis (Mckelvey et al., 2012), because speech synthesis options on assistive communication devices do not reflect the user's vocal quality or personality. Thus it can be understood why differences occurred between PMNDs and SOs in categories related to discussing healthcare, feelings, staying connected with friends and family, and messages about end-of-life issues. In these cases SOs preferred the voice of the PMND above a synthetic or digital voice. Categories where PMNDs would be satisfied with a synthetic voice have important clinical implications and these should be established for each PMND when embarking on the process of message banking.

Lund and Light (2007) highlighted cultural issues and commented on the

fact that SGDs using synthetic voices do not have two languages available at a time – making it difficult for multilingual families. In the multilingual South African setting, this could be problematic. If a person’s SGD uses a language that is different from the language in which message banking was done, it could be disruptive to listen to a conversation in multiple languages. In the current research study, only 50% of PMNDs were English speaking, indicating that the other 50% would likely use different languages for message banking and computer-generated speech.

Murphy (2004) states that because PMNDs have used normal speech throughout their lives, they find it hard to accept an alternative voice for any communication purpose. Participants also commented that no device could ever replace the human voice (Murphy, 2004). This could perhaps clarify why PMNDs rated messages about discussing finances (information transfer) as the highest category for which they wanted messages in their own voice. The next important categories that PMNDs wanted in their own voice (messages to children and chatting) were related to social closeness and support previous results reported in Section 4.3.3.2 where PMNDs provided the longest list of messages in the category of social closeness. Brownlee and Bruening (2012) found that least popular topics for conversation for PMNDs were those related to spirituality, as well as to death and dying.

Recent research about changes in communication needs and strategies during MND progression suggests that newer technologies may make it possible for people with late stage MND to communicate effectively further into the disease progression (Ball et al., 2010; Beukelman et al., 2011). Doyle and Phillips (2001) added that spontaneous and novel communication appeared to become restricted and difficult in the late stages of MND. Perhaps message banking could be one such strategy that will allow for PMNDs to maintain and achieve social closeness through communication during the late stages of the disease.

The categories of messages that SLPs selected as important to bank in the voice of the PMND differed from those of the PMNDs themselves. The categories that SLPs selected as most important were discussing religion and spirituality (exchanging information); messages to children (social closeness); comforting others (social closeness); and flirting or being romantic (social closeness).

Although the specific categories differed from those of PMNDs, social closeness was seen as the most important purpose of communication in which the voice of the PMND was of importance.

PMNDs and SOs will rely on SLPs for guidance about message banking. However, before any form of AAC is initiated, it is imperative that the PMND should be allowed to reflect on and discuss his/her own goals for intervention. Professionals probably set goals without truly understanding the opinions and aspects in a person's life that might affect his/her ability to accept and effectively use AAC devices in future (Murphy, 2004). Murphy (2004) states that the advice given to PMNDs in terms of the possible vocabulary they could store in the device is crucial in introducing an AAC device. For the process of message banking, guidance about possible vocabulary and messages to bank for future use is of fundamental importance. Enough time must be taken to talk through the kind of messages the PMND might want. This will depend on many factors, not least of which will be the stage of the disease. Stuart et al. (2000) describe four stages of MND illness, namely vigilance, relinquishing care to others, enduring self and new sense of self. They also claim that different types of vocabulary are needed at each stage, as was mentioned earlier. Murphy (2004) recommends that in the process to understand how PMNDs use AAC systems, it may be helpful to reflect on the purpose of communication. SLPs should be sensitive about these purposes of communication when they advise PMNDs and their SOs about AAC strategies. In order for message banking to be successful, PMNDs would need guidance to think about the different messages that could be necessary during different stages, as mentioned by Stuart et al. (2000). Through each stage of the disease there might be stronger focus on certain communication purposes such as needs and wants or social closeness. Careful guidance throughout the process of message banking is important.

It is crucial for the SLP to consider the abilities and expectations of the PMND and his/her SOs in suggesting AAC devices. Research findings confirm the importance of collaborative effort among the service providers – i.e. the SLP, the person with communication difficulties and his/her significant others – resulting in shared responsibility between them all for communication and early intervention (Calculator, 1998; Murphy et al., 1996). The SLP, family members

and SOs should be encouraged to take part in the PMND's early rehabilitation. The role of the family will increase as the disease progresses, the patient becomes weaker and requirements for assistive devices change (Bongioanni, 2012).

None of the people involved in Murphy's (2004) study had been given any guidance about specific vocabulary that they might need or want to use in the future. From previous literature it appears that contemporary speech and language pathology is not meeting the collaborative needs of the PMNDs or their SOs. Furthermore, despite the obvious potential, AAC is not working well for many PMNDs and a much more concerted look needs to be taken at what systems and strategies are available, how different devices work, and what training can be provided for PMNDs (Murphy, 2004). Message banking is another AAC strategy that will be difficult to implement without adequate training and guidance from a trained SLP.

4.4 SUMMARY

Chapter 4 was devoted to a discussion of the results of this study after comparisons had been made across the three participant groups. The results were discussed in terms of awareness of and perceptions about AAC, as well as in terms of awareness, perception, relevance and interest in message banking. The chapter concluded with the categories of messages that were found to be important during message banking and where it would be crucial to have messages banked in the voice of the person with MND.

CHAPTER 5: CONCLUSION

5.1 INTRODUCTION

This chapter concludes the study. A summary of the most important findings is presented, followed by the clinical implications of the study. The study is then evaluated in terms of its strengths and limitations, after which the recommendations for future research are explored.

5.2 SUMMARY OF THE FINDINGS

In an attempt to identify the current perceptions of PMNDs, their SOs and SLPs, the study compared (i) awareness and perceptions about AAC; (ii) awareness and perceptions about message banking; (iii) interest in message banking; and (iv) communication purposes (categories of messages) that PMNDs, SOs and SLPs considered as important for message banking in the voice of the PMND.

Firstly, awareness about AAC was found to be similar for PMNDs and SOs as the majority of these participants had either never heard of AAC (PMNDs 50%; SOs 45%), or heard of it but knew nothing about AAC (PMNDs 20%; SOs 27%). A third of SLPs in this study (33%) felt they only knew a little about AAC. PMNDs and SOs who were aware of AAC had in most case been informed by an SLP (PMNDs 10%; SOs 10%) or MNDASA (PMNDs 20%; SOs 20%). SLPs gathered most of their information about AAC from their colleagues (59%), their undergraduate training programme (56%) or the Internet (37%). Most of the participants (PMNDs 70%, SOs 100% and SLPs 94%) in the study were aware of the fact that AAC strategies could be used for PMNDs when speech became difficult. Nevertheless, AAC strategies were not widely used by PMNDs in this study, as 90% of them still had intelligible speech. Even though most SLPs were aware of AAC strategies for PMNDs (94%), less than half of the SLPs (47%) were actually recommending AAC strategies to PMNDs. The AAC strategies that were most recommended were gestures (65%), letter boards (59%) and communication boards (53%).

Secondly, awareness about message banking was similar across all groups. The majority of participants in all groups had never heard of message

banking (PMNDs 75%; SOs 55%; SLPs 35%). The few PMNDs, SOs and SLPs who knew about message banking had been informed by an SLP (PMNDs 80%; SOs 25%; SLPs 85%) or MNDASA (PMNDs 20%; SOs 50%; SLPs 14%). The majority of participants in all groups felt that the best time to start doing message banking was as soon as possible after having been diagnosed (PMNDs 50%; SOs 70%; SLPs 100%). The majority of participants across all groups felt that message banking was a good idea for PMNDs in general (PMNDs 80%; SOs 55%; SLPs 41%). It was interesting to note that the majority of PMNDs also felt message banking would be a good idea for themselves (80%), while slightly fewer SOs (45%) and SLPs (38%) felt that message banking would be a good idea for their specific partner with MND or for the PMNDs whom they saw at their practices. Both positive and negative perceptions about message banking were encountered for all three participant groups. PMNDs had more positive perceptions toward message banking than did SOs or SLPs. SLPs had the most negative perceptions towards message banking, including that it would be too expensive (69%), too time consuming (31%) and too emotional (13%) for PMNDs whom they saw at their practice.

Thirdly, the majority of PMND and SLP participants felt they themselves or their patients would be interested in message banking (PMNDs 80%; SLPs 100%). The majority of SOs (46%) were not sure if their significant other with MND would be interested in message banking.

Finally, differences occurred between messages that PMNDs felt were important to bank, versus messages their SOs felt were important to bank. PMNDs felt it was important to bank messages in the following order: social closeness (33%); personal needs and wants (29%); social etiquette (22%); information transfer (16%). SOs on the other hand felt it was important to bank messages in a different order, namely needs and wants (44%); social closeness (26%); information transfer (23%); social etiquette (8%). PMNDs rated messages about discussing finances (information transfer) as the most important category (100%) for which they wanted messages in their own voice. The subsequent categories that PMNDs wanted in their own voice (messages to children and chatting – both 86%) were related to social closeness. Differences occurred between PMNDs and SOs in categories related to discussing healthcare,

expressing feelings, staying connected with friends and family, and messages about end of life, for which SOs preferred the voice of the PMND above a synthetic or digital voice. PMNDs felt that a synthetic or digital voice would be sufficient for these categories.

The categories of messages that SLPs selected as important to bank in the voice of the PMND differed somewhat from those of the PMNDs. The categories that SLPs selected as most important were discussing religion and spirituality (100%) (i.e. exchanging information); messages to children (100%) (i.e. social closeness); comforting others (100%) (i.e. social closeness); and flirting or being romantic (100%) (i.e. social closeness). Although the specific categories differed from those indicated by PMNDs, social closeness was seen as the most important purpose for all participant groups to bank messages in the voice of the PMND.

5.3 CLINICAL IMPLICATIONS

Training opportunities for SLPs regarding AAC strategies should be increased, as the results from this study has shown that SLPs are a valuable source of information about message banking. SLPs should stay abreast of developments in AAC and hence CPD activities should be developed to address this need. Graduate training should also equip SLP students with knowledge about new developments in the field of AAC. PMNDs furthermore require information about communication strategies via MNDASA. Awareness should be created of the importance of communication and the role of the SLP in progressive diseases such as MND so that referral pathways are clear for neurologists and MNDASA caseworkers. With inadequate information and a limited education, SLPs, family members and caregivers are unable to keep up with the expectations and AAC needs of the PMND (Ray, 2015).

SLPs furthermore have a responsibility to create awareness about AAC strategies such as message banking. Careful guidance throughout the process of message banking is important. Early intervention for PMNDs is vital in order to provide the support and guidance that both PMNDs and SOs need throughout the progression of the disease. Research findings confirm the importance of collaborative effort between the SLP, the PMND and his/her SOs, resulting in

their shared responsibility for communication (Calculator, 1998; Murphy et al., 1996).

The most prominent clinical implication of this study is that it proved that SLPs and SOs could potentially have different perceptions about message banking than the PMNDs themselves. SLPs should take care not to assume that their perceptions are necessarily those of the PMND or SOs. In addition, clinical implications for message banking include that communication purposes seen as most important for message banking are social closeness as well as needs and wants. These categories should be explored when advising PMNDs to do message banking.

5.4 EVALUATION OF THE STUDY

5.4.1 Strengths

One of the major strengths of this study is that it is the first study that focused on perceptions about message banking from the perspective of three participant groups. The specific design that was used allowed for comparisons to be made between three participant groups regarding their perceptions about message banking. Furthermore, this study made it necessary for a message banking presentation and pamphlet to be developed with guidance from an AAC expert panel, and both of these documents have had significant clinical appeal beyond the research period.

The measuring instrument was quick to administer and provided relevant information. Every attempt was made to minimise the Hawthorne effect. Participants were informed prior to data collection that there were no correct or incorrect answers to the questions. Each participant completed the measuring instrument individually. The use of scripts throughout the study ensured that data collection was the same for each participant group, which heightened procedural integrity.

5.4.2 Limitations

The limitations of the study included the relatively small sample size, since only 10 PMNDs and their 11 SOs and 17 SLPs participated in the study. The study

targeted a very specific population and due to the degenerative nature of MND it was difficult to include more PMNDs. Despite efforts by the researcher, the unpredictable nature of MND and the unique circumstances of the individuals impinged on the numbers of participants who could be included in the study. The findings of the study therefore have limited generalisability.

Furthermore, comparisons could unfortunately not be made between triads of PMNDs, SOs and SLPs as only two PMNDs had consulted an SLP. Groups in general were compared with each other. The relationship between SOs and PMNDs varied as one SO was a friend, two were children, and eight were spouses or previous spouses. The type of relationship between the SO and the PMND could potentially have influenced the perceptions that the SO had regarding message banking for the PMND. The variation found in the types of relationships may have influenced the results of the study and therefore they cannot be generalised to the larger population.

The use of the *Staging of Dysarthria System* could have been omitted, as the PMND's level of intelligibility did not have an impact on their inclusion in the study. Handwriting was selected as a better indicator of PMNDs' ability to participate in the study, as the measuring instrument was completed in writing.

5.5 RECOMMENDATIONS FOR FURTHER RESEARCH

A number of recommendations for future research stem from this study:

- To explore the perceptions of people with neurological disorders who are no longer able to speak or write, as the retrospective perceptions will be valuable guidance for those participants who are in the early stages of such a degenerative disorder.
- To investigate the messages that PMNDs and SOs would like to bank in more depth, e.g. by using open-ended questions in semi-structured interviews over a longer period of time. This would provide participants with actual time to reflect on the messages that they deem important for message banking.
- To investigate the effect of guidance and support by an SLP during the process of message banking in order to determine if participants find it easier to do message banking with or without the guidance of a trained SLP.

- To determine the attitudes of familiar listeners when message banking is used in conjunction with a synthetic voice on the SGD. This study should be comparative in nature and compare the messages that are spoken in the synthetic voice with messages spoken from the directory of banked messages, e.g. by emphasising a cross-over design.

5.6 SUMMARY

This final chapter presented conclusions based on the results of the study. The most important contributions of the study were highlighted, and the clinical implications of the results were discussed. The strengths and limitations of the study were also presented. Lastly, recommendations were made as to how future studies could further expand the body of knowledge on and perceptions of the communicative needs of people with degenerative diseases. The study laid the groundwork for future more in-depth research to replicate, refine and expand the current study in various ways that could be generalised beyond the specific population.

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| Appendix A: List of studies included in the literature review | | | | | | | | |
|---|------|--|---|---|---|--|--|--|
| Authors | Year | Title | Aim | Participants | Design | Procedure | Results | Implications for study |
| 1. Ball, Beukelman & Pattee | 2004 | Acceptance of augmentative and alternative communication technology by persons with amyotrophic lateral sclerosis (ALS) | A review of the use of AAC was completed over the course of four years. | A total of 50 persons with ALS, comprising 28 males and 22 females. Age ranged from 36 to 78 years (mean=60.16 years). Primarily bulbar (n=17); primarily spinal (n=22); primarily mixed (n=11). | Descriptive study | Data was obtained through direct assessment and intervention. | <ul style="list-style-type: none"> • 96% accepted AAC. • 90% accepted technology immediately. • 6% needed a little while to get used to the idea. • 2 participants rejected AAC. | Acceptance of AAC technology was high among people with ALS. |
| 2. Richter, Ball, Beukelman, Lasker & Ullman | 2003 | Attitudes toward communication modes and message formulation techniques used for storytelling by people with amyotrophic lateral sclerosis | <p>To determine attitudes toward components of AAC used to tell stories by people with ALS.</p> <p>The attitudes of three groups of listeners (PMNDs, caregivers, and unfamiliar listeners) toward three communication modes (unintelligible natural speech, communication notebook, and synthesised speech) were examined.</p> | <p>Three groups of listeners:</p> <p>PMND group (n=10) ranged in age from 32 to 74 years and comprised 6 males and 4 females.</p> <p>Caregivers group (n=8) included spouses and home health aides with daily contact with the PMND. They ranged in age from 22 to 75 years and comprised 1 male and 7 females.</p> <p>Unfamiliar listeners group (n=27) ranged in age from 33 to 84 years and comprised 14 males and 13 females.</p> | <p>A 3x3 group mode with repeated measures experimental design was employed.</p> <p>All groups participated in all three conditions, i.e. severely unintelligible natural speech, communication notebook, and synthesised speech.</p> | <p>Nine videotapes were constructed, containing three different narratives conveyed in three different communication modes by a male speaker with ALS.</p> <p>The modes of communication were natural speech, a communication notebook, and synthesised speech.</p> <p>After viewing each of the videotapes, the listeners responded to a questionnaire.</p> | <p>The results demonstrated a clear preference for AAC strategies (i.e., communication notebook, synthesised speech) over unintelligible natural speech.</p> | <p>Listeners preferred AAC strategies or synthesised to unintelligible natural speech.</p> |

| Authors | Year | Title | Aim | Participants | Design | Procedure | Results | Implications for study |
|---|------|--|---|---|----------------------------------|---|--|---|
| 3. Brown | 2011 | Critical review: for patients with ALS. What are the outcomes associated with AAC devices? | To determine perceptions of listeners, patterns of AAC use for PMNDs and acceptance or rejection of AAC. | Results of the literature revealed four articles that matched the aforementioned selection criteria: counterbalanced repeated measures design, survey, qualitative and retrospective cohort design studies. | Critical review | Computerised databases, including PubMed, CINAHL, Proquest, SCOPUS, and Google scholar, were searched using the following search strategy: Amyotrophic lateral sclerosis OR ALS AND augmentative and alternative communication OR AAC. | <ul style="list-style-type: none"> • Communication modes and message formulation alter the attitudes of listeners who are speaking to PMNDs. • Further research is needed to determine the underlying reasons for these perceptions. • Caregivers reported that 'getting needs met' and 'giving instructions or directions to others' were the most important reason for using an AAC device. • Acceptance and rejection of AAC: due to poor cognitive ability, lack of financial resources and rejection of technology as a means of communication contribute to AAC rejection. | Getting needs met and giving instructions are potentially among the most important messages for PMNDs who use AAC. |
| 4. Ball, Nordess, Fager, Kersch, Mohr, Pattee & Beukelman | 2010 | Eye gaze access to AAC technology for persons with amyotrophic lateral sclerosis (ALS) | To describe a group of individuals with ALS' training and use of the Eye-gaze Response Interface Computer Aid (ERICA) with Type & Talk or Life Mate 1.1 communication software. | Fifteen adults (5 female, 10 male) with a mean age of 52.9 years. | Quantitative, descriptive survey | Each participant completed a questionnaire during one visit. A care provider was present during each session to assist in verifying the information provided by the person with ALS and expand responses to questions, as requested by the person with ALS. | <ul style="list-style-type: none"> • All but one successfully used ERICA as the primary communication device. • The participant who discontinued use experienced impaired eyelid control during training. • A total of 100% used the ERICA for face-to-face interaction. • A total of 43% used ERICA for group interaction, 71% for phone calls, 79% for emails and 86% for Internet access. | The ERICA technology offers a practical system of access to communication systems, and is among the only existing functional options for a person with ALS to gain access to a communication system when all other motor skills have degraded and other access options have been exhausted. |

| Authors | Year | Title | Aim | Participants | Design | Procedure | Results | Implications for study |
|------------------------------------|------|--|---|---|-------------------------|---|---|--|
| 5. Beukelman, Fager, Ball & Dietz | 2007 | AAC for adults with acquired neurological conditions: A review | To describe the state of AAC for adults with acquired neurogenic communication disorders. | Six groups of people with degenerative neurologic conditions | Systematic review | Not documented | <ul style="list-style-type: none"> • AAC strategies and technology are often combined for the best effect. • AAC acceptance and use had increased for PMNDs in the past decade. • Not many studies investigating specific AAC strategies were suggested, preferred or utilised during disease progression for PMNDs. | <p>A combination of strategies is often best for PMNDs throughout disease progression.</p> <p>There is a void in the literature regarding the specific AAC strategies preferred or utilised for disease progression.</p> |
| 6. Bloch, Steven, Clarke & Michael | 2013 | Handwriting-in-interaction between people with ALS/MND and their conversation partners | To investigate how handwriting is used as a communicative strategy. | Two couples, which included one person with ALS and a significant other (for example, spouse or son or daughter). | Conversational analysis | The couples were loaned video-camera recording equipment, and were asked to record themselves for approximately 30 min within an agreed one-week sampling period. | <ul style="list-style-type: none"> • Handwriting was an effective tool for PMNDs with efficient motor control for writing. • It was hypothesised that handwriting was less problematic than other forms of AAC because it was a more familiar modality with clearer transition boundaries like physically handing over a writing pad to convey the message. | <p>Research article examining the use of handwriting by people with ALS/MND.</p> <p>The ability to write will probably be affected as the disease advances to the spinal nerves. Thus handwriting is a strategy to be used during the earlier stages of MND.</p> <p>The literature for MND tends to focus more on electronic AAC approaches despite the high demand for non-electronic aids.</p> |

| Authors | Year | Title | Aim | Participants | Design | Procedure | Results | Implications for study |
|---|------|---|--|--|---------------------------|---|---|--|
| 7. Brownlee & Bruening | 2012 | Methods of communication at end of life for the person with amyotrophic lateral sclerosis | This article reviews the communication needs of PMNDs and the range of communication strategies used, including most forms of AAC. | 625 family members or caregivers. | Descriptive survey design | Surveys about communication strategies used for the person with ALS were emailed to participants. | <ul style="list-style-type: none"> PMNDs used 11 AAC strategies including: talking, writing, gestures, letter boards, communication devices, eye-blinks, hand squeeze, sounds, partner-assisted scanning, and flash cards. Some caregivers also described that the patient had no means of communication. The most popular topics for communication were physical needs, caregiving issues, and family issues. The least discussed topics were spiritual, death and dying issues. | <p>Limited use of AAC technology and perhaps not enough use of simpler, unaided, or low-tech communication systems.</p> <p>Speech remained a preference when the person could still talk.</p> <p>Gestures and eye-blinks were not used effectively.</p> |
| 8. Fried-Oken, Fox, Rau, Tullman, Baker, Hindal, Wile & Lou | 2006 | Purposes of AAC device use for persons with ALS as reported by caregivers | To discover patterns of importance and patterns of use of AAC technology for various communication purposes. | 34 informal caregivers who support 26 PMNDs. | Survey | Each caregiver completed the <i>Communication Device Use Checklist</i> . | <p>Reported that the PMNDs in their care used AAC to</p> <ul style="list-style-type: none"> get their needs met; achieve social closeness; communicate information. | <p>From the caregivers' perspective, AAC was used firstly for the communication purpose of fulfilling needs and wants; secondly to achieve social closeness; and thirdly to share information. Social etiquette was the communication purpose that AAC was least used for.</p> |

| Authors | Year | Title | Aim | Participants | Design | Procedure | Results | Implications for study |
|-----------|------|--|---|--------------|-----------------------|--|---|--|
| 9. Hanson | 2011 | Dysarthria in ALS: A systematic review of characteristics in speech treatment, and AAC options | This evidence-based review examines speech strategies and AAC patterns for PMNDs. | 713 papers | Evidence-based review | Three electronic databases (PsychInfo, Medline and CINAHL) and hand searches of relevant books delivered 713 articles related to dysarthria and ALS. | <ul style="list-style-type: none"> Well-documented characteristics of the progressive mixed dysarthria. Consensus of expert opinion of the benefits of communication strategies, including: speech supplementation, partner training. Lack of evidence to support speech-strengthening exercises for improving speech. Usefulness of monitoring speech rates for timely AAC intervention. Emerging evidence of long-term benefits of AAC strategies Influence of other factors such as cognitive decline on successful use of AAC strategies. | <p>Patterns of AAC use for PMNDs include:</p> <p>Alphabet supplementation (pointing to the first letter of each word):</p> <ul style="list-style-type: none"> Extends the time that natural speech can be used Makes the transition from speech to AAC a more gradual one <p>Low-technology such as writing</p> <p>High-technology such as SGD</p> <p>Alternative access options such as eye-gaze to operate SGD</p> <p>Strategies are often combined for the best effect</p> <p>Future directions:</p> <ul style="list-style-type: none"> Better voices Brain Computer Interface (BCI) Voice banking |

| Authors | Year | Title | Aim | Participants | Design | Procedure | Results | Implications for study |
|--|------|---|--|--|----------------------------|--|--|---|
| 10. Ray | 2015 | Real-life challenges in using AAC by persons with ALS | To summarise the communication needs and AAC intervention strategies used for people with MND. | Mr. Seabaugh, a 55-year-old male, with ALS. He was also diagnosed with moderate to severe dysarthria, characterised by limited speech intelligibility. | Single subject case report | The subject was monitored throughout the assessment and intervention phases. | <ul style="list-style-type: none"> The subject wished to improve his communication by using a variety of no-technology, low technology and high-technology strategies ranging from gestures, verbal speech, and AAC devices. He used typing for 10% of his communication purposes; Pre-stored messages for 20% of the time. A combination of gestures and natural speech was used 60% of the time. | PMNDs wish to attempt multiple modalities when using AAC strategies to supplement their communication. |
| 11. Spataro, Ciriaco, Manno & La Bella | 2014 | The eye-tracking computer device for communication in amyotrophic lateral sclerosis | To determine the effectiveness of communication and the variables affecting the eye-tracking computer system (ETCS) utilisation in patients with late-stage amyotrophic lateral sclerosis (ALS). | 30 patients with advanced MND who were using ETCS devices to communicate. | Structured interviews | Caregivers were contacted and completed a telephone survey. | <p>All participants used the ETCS to access communication software.</p> <ul style="list-style-type: none"> 73% for browsing the Internet and e-mailing. 42.3% for social networking. 23% of patients did not use the ETCS regularly due to reported fatigue when using eye-gaze. <p>ETCS is a valuable tool for AAC patients with ALS as it can be operated with good performance.</p> <p>Oculomotor impairment may limit its functional use.</p> | <p>Eye-gaze strategies can be used to communicate as only the eyes are used when all other mobility is lost.</p> <p>Options include transparent panels with alphabet letters and numbers, high-tech systems, electronic vocal synthesis, and ETCS. ETCS is one of the most advanced devices for PMNDs. Besides vocal synthesis, ETCS also allows for internet connection, webmail, and access to social networks.</p> |

| Authors | Year | Title | Aim | Participants | Design | Procedure | Results | Implications for study |
|----------------------|------|--|--|---|------------------|---|--|---|
| 12. Doyle & Phillips | 2001 | Trends in augmentative and alternative communication use by individuals with amyotrophic lateral sclerosis | <p>To describe speech production and the need for AAC in ALS.</p> <p>To review psychosocial and cognitive issues that may influence AAC use.</p> <p>To discuss trends in AAC systems and their use.</p> <p>To describe the stages of AAC intervention.</p> | Four PMNDs in different stages of AAC intervention. | Case studies | Four patients' AAC evaluation, recommendation and intervention (initial stages, middle stages and final stages of ALS) are described to illustrate types of approaches in different stages. | <ul style="list-style-type: none"> All four relied more on unaided or low technology approaches in the initial stages of the disease. Participants became increasingly dependent on high-technology options during the middle stage of the disease. Participants who used high-technology strategies in the middle phase of MND returned to low-technology approaches during the late stage of the disease. | <p>Low-technology strategies used in the initial stages.</p> <p>High-technology used in the middle stages.</p> <p>Low-technology again used in the final stages.</p> |
| 13. Mathy | 1996 | Use of electronic communication by adult AAC users | To determine the use of electronic AAC strategies used by PMNDs. | 24 individuals with ALS. | Research article | Not applicable | <ul style="list-style-type: none"> All 12 persons with spinal ALS chose to use a high-technology approach to tell stories. Only 6 of 12 persons with bulbar ALS chose to use a high-technology approach to tell stories. | <p>PMNDs chose high-technology to tell stories.</p> <p>The results of the study must be interpreted cautiously, given that equipment was provided based on availability in the programme's loan pool.</p> |

| Authors | Year | Title | Aim | Participants | Design | Procedure | Results | Implications for study |
|---|------|--|--|--------------|---------------|----------------|--|---|
| 14. Mathy, Yorkston & Gutmann | 2000 | AAC for adults with ALS | To determine the AAC strategies used by PMNDs. | 36 PMNDs | Book chapter | Not applicable | <ul style="list-style-type: none"> Initial MND symptoms influenced the use of AAC techniques. Participants with initial spinal symptoms were more likely to use high technology. Participants with bulbar symptoms were more likely to depend on handwritten messages as well as the frequent use of low technology AAC approaches. | Quick needs are frequently communicated via low-technology AAC, while high-technology AAC is used for in-depth conversations. They also determined that unaided and low-technology strategies were used across environments and positions (e.g. in a wheelchair or in bed), whereas high-technology systems were primarily used in one environment, often the home. |
| 15. Yorkston, Strand, Miller, Hillel, & Smith | 1993 | Speech deterioration in ALS: Implications for the timing of intervention | Not specified | PMNDs | Not specified | Not specified | Summarised in implications for the study | Individuals with bulbar ALS may use low-technology AAC such as writing, alphabet boards or SGDs. Individuals with spinal ALS may use a range of low-technology AAC and switches to access high-technology options such as dedicated or communication devices. All PMNDs may use unaided AAC such as gestures, facial expressions, and yes or no responses. |

| Authors | Year | Title | Aim | Participants | Design | Procedure | Results | Implications for study |
|--|------|---|---|---|--|--|---|--|
| 16. McKelvey, Evans, Kawai & Beukelman | 2012 | Communication styles of persons with ALS as recounted by surviving partners | Investigated communication styles, AAC use, decision making, and lifestyle changes for PMNDs. | One daughter and six surviving spouses of individuals diagnosed with ALS. | Research article | Semi-structured interviews with each of the participants, using an 18-question interview protocol. | Four themes emerged: <ul style="list-style-type: none"> • Communication styles • AAC use • Decision making • Lifestyle changes | <p>AAC use included:</p> <ul style="list-style-type: none"> • A combination of high and low-tech options. <p>Disadvantages included:</p> <ul style="list-style-type: none"> • The quality of the voice being used on the SGD <p>Receiving support about how to operate the AAC device provided.</p> |
| 17. Murphy | 2004 | "I prefer contact this close": Perceptions of AAC by people with Motor Neurone Disease and their communication partners | To investigate the communication of people with MND and their partners. | 15 people with MND and their closest communication partners over a 3 year period. | Qualitative case study methodology. Involving <ul style="list-style-type: none"> • using video recordings of dyads in open conversation; • semi-structured interviews in order to gain rich and detailed narrative information from a number of sources; • field notes. | <p>Seven individual meetings were set up at patients' homes.</p> <p>Participants were free to talk about any topic they wished.</p> <p>Video recordings captured the use and interplay of different modes of communication, including speech, non-verbal methods, and AAC.</p> | <ul style="list-style-type: none"> • AAC strategies were less successful than expected. • Barriers included difficulties with regard to learning to use high-technology devices. • A need for social closeness that may be a challenge when communicating via an AAC device • A lack of training. | <p>A critical issue in this study is that participants had received very little input about how to use their devices. A lack of training to ensure that the PMNDs and their SOs understand the device and its functions e.g. storing phrases, changing the voice and using prediction is disastrous for implementation of AAC.</p> |

| Authors | Year | Title | Aim | Participants | Design | Procedure | Results | Implications for study |
|---------------------------------|------|--|--|----------------|------------------------------------|----------------|--|--|
| 18. Ball & Lasker | 2013 | Teaching partners to support communication for adults with acquired communication impairment | Article offers specific guidance about AAC techniques and message selection for people with degenerative conditions. | Not applicable | Special interest group publication | Not applicable | <ul style="list-style-type: none"> Adults with communication difficulties may benefit from partner-supported techniques. Training to support the effective use of specific strategies is essential. It is imperative that all members of the AAC team agree on the value of these tools and that these relatively simple partner-supported strategies are taught explicitly to partners and clients with complex communication needs. | Strategies that can be used include: <ul style="list-style-type: none"> Augmented input Written choice conversation strategy Tagged Yes No Eye linking / Pointing Partner dependent scanning Yes/ No hierarchy Facial movement / Gestures Alphabet supplementation Teaching strategies to partners of AAC communicators |
| 19. Beukelman, Fager & Nordness | 2011 | Communication support for people with ALS | A review article with a section on AAC use. | Not applicable | Review article | Not documented | <ul style="list-style-type: none"> Clinical decision making is complex. Screening, referral, assessment, acquisition of technology and training must occur in a timely manner. AAC acceptance increased throughout the last decade. Many PMNDs use AAC until a few weeks before death. | SLPs must be trained in the timing, screening, referral, assessment and training of AAC technology. |

Appendix B: Message Banking Presentation Script.

Introduction:

What is in a voice? The voice is more than a means to transmit language. The moment speak, even if it is only to read from a book, your voice reveals much about you, perhaps your age, mood, and possibly your health and education. Your voice is unique to you and provides insight into who you are as a person.

Loosing your voice would provoke many feelings, including sadness and despair. It is estimated that over 3000 people are living with Motor Neuron Disease in South Africa today. That means that over 3000 people could, potentially, loose the ability to communicate using their own unique voice.

Many people with MND use Augmentative and Alternative or AAC strategies to communicate if they loose their ability to speak. One of the high-technology AAC strategies that people could use is called a speech generating device. When you use this system you will type a message and the device will speak it on your behalf. These systems mostly use a computerized or digital voice that sounds a little like this:

Synthetic speech option included too

Insert sound clip of digitized speech

Message banking provides an alternative option for people to use their own voice instead of using a computerized voice. I will now explain what message banking is and how it is done:

What is Message Banking?

Message banking is an early communication intervention option for people with degenerative neurological disorders. John Costello, a speech language pathologist at the

Boston Children's Hospital founded the concept of message banking. It involves recording and storing your own words, phrases, meaningful sounds, as well as stories using your own, unique, voice.

This will allow you to use the pre-recorded phrases or words in your own, unique voice when you operate the speech generating device. Message Banking could sound like this:

Insert a sound clip of what message banking would sound like in the person's own voice

- Hallo, Goeie More, Molo, Hi, Howzit, Hey!
- How are you? Hoe gaan dit? Unjani? Hoe lyk dit? All good?
- Ouch! Sheesh! Eish! Ne? Wow! Eina! xhosa

This means that if and when a person with MND loses the ability to speak they can use these recorded messages to say certain important things in their own voice. Because it is your own voice in these messages, people will hear your natural inflection and intonation.

How is message banking done?

1. Decide that you are ready to start doing message banking.
2. Start thinking about the messages you want to record.
3. Get guidance from an AAC specialist or speech therapist to assist you with message banking.
4. Think about what electronic device you will use to record these messages, and the electronic device that will be used to play the messages on. Will it be:
 - a. A Cell Phone or Smartphone?
 - b. A tablet?
 - c. A laptop computer?
 - d. A dedicated communication device?
 - e. Or a computer that you will operate using your eyes?
5. Together with your speech therapist or AAC specialist:

- Choose a voice recorder that will be enable you to record your messages in .wav files.
- You can do this using laptop computer with a microphone.
- Transfer your messages to your communication AAC device.
- Organize these messages in categories
- Finally, practice different ways of selecting these messages in actual conversations with different communication partners.

Conclusion

Now that you know a little bit about message banking, I am curious to know:

- Is this the first time you've heard about message banking?
- What do you think about message banking?
- Would you be interested in doing message banking?
- What are the messages that you think are important to record during message banking?

Your participation in this study will help answer some of these important questions whether you are a patient, a caregiver, a loved one or a speech therapist.

Thank you very much for taking the time to provide me with some answers to these questions. Together you will help to make Motor Neuron Disease history.

This means that if and when you lose the ability to speak you can use these recorded messages to say certain important things in their own voice. Because it is your voice in these messages, people will hear your natural inflection and intonation.

How is message banking done?

1. Decide that you are ready to start doing message banking.
2. Start thinking about the messages you want to record.
3. Get guidance from an AAC specialist or speech therapist to assist you with message banking.
4. Think about what device you will use to record these messages, and the device that will be used to play the messages on. Will it be:
 - a. A Cell Phone or Smartphone?
 - b. A tablet?
 - c. A laptop computer?
 - d. A dedicated AAC device?
 - e. Or a communication device

Together with your speech therapist or AAC specialist:

- Choose a voice recorder that will be able to record your messages in .wav files.
- You can do this using laptop computer with a microphone.
- Transfer your messages to your communication AAC device.
- Organize these messages in categories
- Finally, practice different ways of selecting these messages in actual conversations with different communication partners.

Thank you very much for taking the time to provide me with some answers to these questions.

Together we can attempt to improve the quality of life of those living with the diagnosis of Motor Neuron Disease.

Inke Oosthuizen

Speech and Language Therapist
Stellenbosch

Message Banking

For people with degenerative communication disorders



Introduction:

What is in a voice? The voice is more than a means to transmit language. The moment you speak, even if it is only to read from a book, your voice reveals much about you, perhaps your age, mood, and possibly your health and education. Your voice is unique to you and provides insight into who you are as a person.



Losing your voice would provoke many feelings, including sadness and despair.

It is estimated that over 3000 people are living with Motor Neuron Disease in South Africa today. That means that over 3000 people could, potentially, lose the ability to communicate using their own unique voice. Many people with MND use Augmentative and Alternative Communication or AAC strategies to communicate if they lose their ability to speak. AAC Strategies can involve no technology such as using gestures or pointing to words. AAC can also involve technology. One of the high-technology AAC strategies that could be used is called a speech generating device. When you use this system you will type a message and the device will speak it on your behalf. These systems mostly use a computerized voice called a synthetic voice. As technology evolved, so did the quality of voices being used by these speech generating devices. Now a days, real

human voices are being used to combine sound clips for actual words and sentences.

Message banking provides an alternative option for people to use their own voice instead of using a computerized voice. I will now explain what message banking is and how it is done:

Message banking is an early communication intervention option for people with degenerative neurological disorders. John Costello, a speech language pathologist at the Boston Children's Hospital founded the concept of message banking. It involves recording and storing by your own words, phrases, meaningful sounds, as well as stories using your own, unique, voice. This will allow you to use the pre-recorded phrases or words in your own, unique voice when you operate the speech generating device.

| |
|------------------|
| Participant No.: |
|------------------|

Biographical Interview for Persons with Motor Neuron Disease

1. What is your gender? F M
2. What is your date of birth? _____/_____/19____
3. When were you diagnosed with MND? _____
4. From whom did you receive the diagnosis? _____
5. What was the nature of your diagnosis?

| Bulbar | Spinal | Mixed | Other |
|--------|--------|-------|-------|
| | | | |

6. Are you able to write? Yes _____/No _____

7. Do you require assistance with the following?

Activities of daily living

| | Never | Rarely | Sometimes | Often | Always |
|-------------------------|-------|--------|-----------|-------|--------|
| Dressing | | | | | |
| Undressing | | | | | |
| Preparing your meals | | | | | |
| Eating | | | | | |
| Drinking | | | | | |
| Bathing / Showering | | | | | |
| Going to the bathroom | | | | | |
| Walking | | | | | |
| Accessing your computer | | | | | |

| | Never | Rarely | Sometimes | Often | Always |
|--|-------|--------|-----------|-------|--------|
| Using your cell phone for calls | | | | | |
| Using your cell phone for sending messages | | | | | |

8. Who are the significant others who are here with you today? Please specify your relationship with each of them.

9. What is your highest educational qualification?

| Below Matric | Matric | Diploma | Bachelor's degree | Honours degree | Master's degree | PhD |
|--------------|--------|---------|-------------------|----------------|-----------------|-----|
| | | | | | | |

10. Are you still working? Yes _____/No _____

11. What is/was your occupation? _____

12. What is your first language? _____

13. In what other languages are you proficient?

| Language | Speak | Read | Write | Understand |
|----------|-------|------|-------|------------|
| 1. | | | | |
| 2. | | | | |
| 3. | | | | |
| 4. | | | | |

14. Are you married? _____

15. Who do you live with? _____

16. Where do you live? _____

17. Who is your primary caregiver? _____

18. Please select if you are currently receiving any of the following:

| Speech therapy | Occupational therapy | Physiotherapy | Other |
|----------------|----------------------|---------------|-------|
| | | | |

19. Have you consulted a speech language therapist after your diagnosis of MND? Yes _____/No _____

20. Have you experienced any changes in your speech? Please explain.

21. When was this? _____

22. Who was the speech language therapist? _____

23. Where did you consult a speech language therapist?

| Private practice | Rehabilitation unit / centre | Private hospital | State hospital | MNDA support group | Clinic | Other |
|------------------|------------------------------|------------------|----------------|--------------------|--------|-------|
| | | | | | | |

24. Did your speech therapy management include any of the following techniques? Please select all that apply:

| <u>Goals</u> | | <i>Please Select</i> |
|--------------------------------|-------------------------|----------------------|
| Assessment | Speech assessment | |
| | Swallowing assessment | |
| | AAC assessment | |
| Compensatory strategies | Improving breathing | |
| | Improving voice quality | |
| | Improving pronunciation | |

| | | |
|-------------------------------|--------------------------------------|--|
| | Improving resonance | |
| | Improving prosody | |
| Dysphagia / Swallowing | Treatment of dysphagia | |
| AAC | Implementing no-technology systems | |
| | Implementing high-technology systems | |
| Counselling | Counselling the patient | |
| | Counselling the family | |
| | Group training | |

For researcher / research assistant to complete:

- **Severity of speech difficulties (see separate document for detailed classification):**

Stage 1 _____ No Detectable Speech Disorder

Stage 2 _____ Obvious Speech Disorder with Intelligible Speech

Stage 3 _____ Reductions in Speech Intelligibility

Stage 4 _____ Natural Speech Supplemented with Augmentative Communication

Stage 5 _____ No Useful Speech

- **Classification on MND (see separate document for detailed classification):**

State 1 _____ (mild)

State 2 _____ (moderate)

State 3 _____ (severe)

State 4 _____ (terminal)

Biographical Questionnaire for Significant Others of Persons with Motor Neuron Disease

1. What is your relationship to the person with MND? *Please select*

| Spouse | Child | Friend | Family member | Other (<i>Specify</i>) |
|--------|-------|--------|---------------|--------------------------|
| | | | | |

2. Do you live with the person with MND? _____

3. How many hours per day do you spend with this person with MND?

4. What is your gender? F M

5. What is your date of birth? _____/_____/19_____

6. What is your highest educational qualification?

| Below Matric | Matric | Diploma | Bachelor's degree | Honours degree | Master's degree | PhD |
|--------------|--------|---------|-------------------|----------------|-----------------|-----|
| | | | | | | |

7. What is your occupation? _____

8. If you are no longer working, what was your previous occupation?

9. What is your first language? _____

10. In what other languages are you proficient? *Please complete.*

| Language | Speak | Read | Write | Understand |
|----------|-------|------|-------|------------|
| 1. | | | | |
| 2. | | | | |
| 3. | | | | |
| 4. | | | | |

11. Do you assist the person with MND with any of the following aspects of daily living?

Please select.

| | Never | Rarely | Sometimes | Often | Always |
|-------------------------------------|-------|--------|-----------|-------|--------|
| Dressing | | | | | |
| Undressing | | | | | |
| Preparing their meals | | | | | |
| Eating | | | | | |
| Drinking | | | | | |
| Bathing / Showering | | | | | |
| Going to the bathroom | | | | | |
| Walking | | | | | |
| Accessing their computer | | | | | |
| Using their cell phone for calls | | | | | |
| Using their cell phone for messages | | | | | |

Biographical Questionnaire for Speech Language Therapist / Pathologist

Please complete the following questions to provide biographical information:

1. What is your gender?

F

M

2. What is your date of birth?

____/____/19____

3. In what languages are you proficient?

| Language | Speak | Read | Write | Can you provide Speech Therapy in this language? |
|----------|-------|------|-------|--|
| 1. | | | | |
| 2. | | | | |
| 3. | | | | |
| 4. | | | | |
| 5. | | | | |

4. Please select your highest level of qualification:

| Bachelor's Degree | Honours Degree | Master's Degree | PhD | Other (<i>Specify</i>) |
|-------------------|----------------|-----------------|-----|--------------------------|
| | | | | |

5. Please indicate from which universities you obtained these degrees:

| | Bachelor's Degree | Honours Degree | Master's Degree | PhD | Other (Specify) |
|------------------------------|--------------------------|-----------------------|------------------------|------------|------------------------|
| Name of University | | | | | |
| Name of qualification | | | | | |
| Year completed | | | | | |
| Year enrolled | | | | | |

6. Number of years practicing as a Speech Language Therapist (including community service) _____

7. Are you registered with the HPCSA? Yes _____/No _____

8. In what sector are you currently working?

| | Private Sector | Public sector | Tertiary institution | Tertiary institution | Other (Specify) |
|----------------------------|-----------------------|----------------------|-----------------------------|-----------------------------|------------------------|
| Hospital | | | | | |
| Rehabilitation unit | | | | | |
| Outpatient clinic | | | | | |

9. Do you have any additional training in AAC?

Yes _____/No _____

10. Have you attended any CPD activities about any of the following topics?

| Course attended | Yes / No |
|--------------------------------------|-----------------|
| Adult Communication Disorders | |
| AAC | |
| AAC Devices | |
| Degenerative Communication Disorders | |

11. Do you have experience in working with people with Motor Neuron Disease?

Yes _____/No _____

12. How many years of experience do you have in working with people with Motor Neuron Disease?

| 0 – 2 years | 3 – 5 years | 6 – 8 years | 9 + years |
|--------------------|--------------------|--------------------|------------------|
| | | | |

13. Give an estimation of how many patients you have seen with MND within the timeframe selected.

| Fewer than 10 | Fewer than 50 | Fewer than 100 |
|----------------------|----------------------|-----------------------|
| | | |

Please turn to the next page.

14. Which of the following goals do **you** pursue in the management of the person with Motor Neuron Disease?

Please select the applicable goals for your therapy:

| <u>Goals</u> | | ✓ Select |
|--------------------------------|----------------------------------|----------|
| Assessment | Speech Assessment | |
| | Swallowing Assessment | |
| | AAC Assessment | |
| Compensatory strategies | Improving Respiration | |
| | Improving Phonation | |
| | Improving Articulation | |
| | Improving Resonance | |
| | Improving Prosody | |
| Dysphagia management | Treatment of Dysphagia | |
| AAC | Implementing No-Technology AAC | |
| | Implementing Low-Technology AAC | |
| | Implementing High-Technology AAC | |
| Counselling | Counselling the patient | |
| | Counselling the family | |
| | Group training | |
| Other (please specify) | | |
| Other (please specify) | | |
| Other (please specify) | | |
| Other (please specify) | | |

Research Questionnaire for Person with Motor Neuron Disease

**For
Researcher's
Use Only**

Participant
Number:

In this questionnaire, I will ask you a question and you will be given a few answers to choose from. Please select the most appropriate answer. Where asked to explain your answer, please do so in the lines provided.

1. Augmentative and Alternative Communication (AAC) refers to the use of less frequently used modes of communication, to either supplement or replace your speech. These AAC strategies include writing, gestures, signs, communication boards and electronic devices (including speech-generating devices) that can help you to communicate effectively if your speech deteriorates. Have you ever heard of AAC before today?

Question 1

1_____ Never heard of AAC.

1_____

2_____ Heard of AAC but do not know anything about it.

2_____

3_____ Know a little about AAC.

3_____

4_____ Know a fair amount about AAC.

4_____

5_____ Know a lot about AAC.

5_____

2. If you selected options 3, 4, or 5 in Question 1, where did you hear about AAC? *You can select more than one option.*

Question 2

A Speech Language Therapist

1_____

The Internet (social media)

2_____

The Media (newspapers, TV, radio, magazines)

3_____

The Motor Neuron Disease Association of South Africa

4_____

The J 9 Foundation

5_____

Other (*Please Specify*)

6_____

3. Are you aware that AAC strategies can be used to help people with MND to communicate once speech becomes difficult?

Question 3

Yes

1_____

No

2_____

Unsure

3_____

4. Which of these methods are you currently using to communicate? *You can select more than one option.*

- Speaking
- Social media
- Email
- Phone calls
- SMS
- WhatsApp
- Gestures (e.g. pointing)
- Writing
- Letter boards (e.g. boards with the alphabet on)
- Eye-blinks
- Hand squeeze
- Sounds
- Partner-assisted scanning
- Flash cards
- Communication devices
- Speech-generating devices
- Communication Apps
- Communication boards /books (e.g. boards or books with words or pictures)
- Eye-gaze technology
- Other (please specify)

5. **Before** today, have you ever heard of message banking?

- 1_____ Never heard of message banking.
- 2_____ Heard of message banking but do not know anything about it.
- 3_____ Know a little about message banking.
- 4_____ Know a fair amount about message banking.
- 5_____ Know a lot about message banking.

Code

Question 4

- 1_____
- 2_____
- 3_____
- 4_____
- 5_____
- 6_____
- 7_____
- 8_____
- 9_____
- 10_____
- 11_____
- 12_____
- 12_____
- 13_____
- 14_____
- 15_____
- 16_____
- 17_____
- 18_____
- 19_____
- 20_____

Question 5

- 1_____
- 2_____
- 3_____
- 4_____
- 5_____

6. If you selected options 3, 4, or 5 in Question 5, where did you hear about message banking? *You can select more than one option.*

- A Speech Language Therapist
 - The Internet (social media)
 - The media (newspapers, TV, radio, magazines)
 - The Motor Neuron Disease Association of South Africa
 - The J 9 Foundation
 - Other (*please specify*)
-

Question 6

- 1_____
- 2_____
- 3_____
- 4_____
- 5_____
- 6_____

7. Think about other people with MND. Please select to what extent you agree with the following statement and provide a reason for your answer.

| Statement | Strongly agree | Agree | Unsure | Disagree | Strongly disagree | Please explain your answer: |
|---|----------------|-------|--------|----------|-------------------|--|
| 1. I believe message banking is a good idea for <u>other people</u> with MND. | | | | | | |

Question 7

- 1_____
- 2_____
- 3_____
- 4_____
- 5_____

8. Think about yourself as a person living with MND. Please select to what extent you agree with the following statement and provide a reason for your answer.

| Statement | Strongly agree | Agree | Unsure | Disagree | Strongly disagree | Please explain your answer: |
|---|----------------|-------|--------|----------|-------------------|--|
| 2. I believe message banking is a good idea for <u>me</u> . | | | | | | |

Question 8

- 1_____
- 2_____
- 3_____
- 4_____
- 5_____

9. When do you think is the best time for a person with MND to start doing message banking?

- As soon as possible after being diagnosed with MND.
- Once you realise that your speech starts changing.
- Once other people realise that your speech starts changing.
- Once a speech language therapist recommends it.
- I'm not sure.
- Other (*please specify*)

10. Which of these perceptions do you agree with regarding message banking? *Mark as many as apply.*

- It's too late, my speech has deteriorated too much.
- I am not experiencing any speech difficulties.
- I do not like technology.
- It seems too time consuming.
- It is seems too difficult.
- It seems too expensive.
- It is too emotional.
- It is unnecessary.
- I'm not sure.
- I would be a good candidate for message banking.
- My voice is still strong therefore I am a good candidate for message banking.
- I like technology.
- Message banking seems easy enough.
- Message banking is very important.
- Other (*please specify*)

Question 9

- 1____
- 2____
- 3____
- 4____
- 5____
- 6____

Question 10

- 1____
- 2____
- 3____
- 4____
- 5____
- 6____
- 7____
- 8____
- 9____
- 10____
- 11____
- 12____
- 13____
- 14____
- 15____

11. Would you be interested in doing message banking? *Please explain your answer in the lines below.*

- Yes
- No
- Not sure

Please explain:

12. Think about messages, phrases, words or sounds that people will associate with you. What are some of these messages that you would like to bank during message banking? Please list 5 to 10 messages that you would like to bank. Please write these down in your own words

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____

Question 11

1_____

2_____

3_____

Question 12

Category_____

Category_____

Category_____

Category_____

Category_____

Category_____

Category_____

Category_____

Category_____

Category_____

Category_____

Category_____

13. We communicate for various reasons (see the list below). Given limited time, it is not always possible to record everything in one's own voice. Read the various types of messages in the table below. Please indicate if you would be satisfied with a computer voice saying these messages, or would it be important to have them in your own voice? Remember there are no right and wrong answers. I want to know what you would prefer.

| Communication purpose | Computer voice | Own voice |
|--|----------------|-----------|
| 1. Calling for help | | |
| 2. Getting my needs met | | |
| 3. Clarifying my needs with my caregivers | | |
| 4. Exchanging information | | |
| 5. Discussing my important issues or concerns | | |
| 6. Discussing my health care | | |
| 7. Discussing my work or former work | | |
| 8. Discussing my finances | | |
| 9. Discussing my religion or spirituality | | |
| 10. Expressing my feelings | | |
| 11. Staying connected with my family and friends | | |
| 12. Messages about end of life | | |
| 13. Messages to my children | | |
| 14. Telling stories | | |

| Communication purpose | Computer voice | Own voice |
|---|----------------|-----------|
| 15. Chatting | | |
| 16. Having a casual conversation with strangers | | |
| 17. Comforting others | | |
| 18. Being funny | | |
| 19. Flirting or being romantic | | |
| 20. Being polite | | |
| 21. Being rude | | |
| 22. Other <i>(you can write down your own)</i> | | |
| 23. Other <i>(you can write down your own)</i> | | |
| 24. Other <i>(you can write down your own)</i> | | |
| 25. Other <i>(you can write down your own)</i> | | |
| 26. Other <i>(you can write down your own)</i> | | |
| 27. Other <i>(you can write down your own)</i> | | |
| 28. Other <i>(you can write down your own)</i> | | |
| 29. Other <i>(you can write down your own)</i> | | |

Research Questionnaire for Significant Others of Persons with MND

In this questionnaire, I will ask you a question and you will be given a few answers to choose from. Please select the most appropriate answer. Where asked to explain your answer, please do so in the lines provided.

1. Augmentative and Alternative Communication (AAC) refers to the use of less frequently used modes of communication, to either supplement or replace your speech. These AAC strategies include writing, gestures, signs, communication boards and electronic devices including speech generating devices that can help you to communicate effectively if your speech deteriorates. Have you ever heard of AAC before today?

- 1_____ Never heard of AAC.
- 2_____ Heard of AAC but do not know anything about it.
- 3_____ Know a little about AAC.
- 4_____ Know a fair amount about AAC.
- 5_____ Know a lot about AAC.

2. If you selected options 3, 4, or 5 in Question 1, where did you hear about AAC? *You can select more than one option.*

- A Speech Language Therapist
- The Internet (Social Media)
- The Media (Newspapers, TV, Radio, Magazines)
- The Motor Neuron Disease Association of South Africa
- The J 9 Foundation
- Other *(Please Specify)*

3. Are you aware that AAC strategies can be used to help people with MND for communication once speech becomes difficult?

- Yes
- No

**For
Researcher's
Use Only**

Participant
Number:

Question 1

- 1_____
- 2_____
- 3_____
- 4_____
- 5_____

Question 2

- 1_____
- 2_____
- 3_____
- 4_____
- 5_____
- 6_____

Question 3

- 1_____
- 2_____
- 3_____

Unsure

4. Which of these methods does your significant other with MND, currently use to help with his or her communication? *You can select more than one option*

- Speaking
- Social Media
- Email
- Phone calls
- SMS
- WhatsApp
- Gestures (e.g. pointing)
- Writing
- Letter boards (e.g. boards with the alphabet on)
- Eye-blinks
- Hand squeeze
- Sounds
- Partner assisted scanning
- Flash cards
- Communication devices
- Speech generating devices
- Communication Apps
- Communication boards /books (e.g. boards or books with words or pictures)
- Eye Gaze Technology
- Other (Please Specify)

5. **Before** today, have you ever heard about message banking?

- 1_____ Never heard of message banking.
- 2_____ Heard of message banking but do not know anything about it.
- 3_____ Know a little about message banking.
- 4_____ Know a fair amount about message banking.
- 5_____ Know a lot about message banking.

Question 4

- 1_____
- 2_____
- 3_____
- 4_____
- 5_____
- 6_____
- 7_____
- 8_____
- 9_____
- 10_____
- 11_____
- 12_____
- 12_____
- 13_____
- 14_____
- 15_____
- 16_____
- 17_____
- 18_____
- 19_____
- 20_____

Question 5

- 1_____
- 2_____
- 3_____
- 4_____
- 5_____

6. If you selected options 3, 4, or 5 in Question 5, where did you hear about message banking? *You can select more than one option.*

- A Speech Language Therapist
- The Internet (Social Media)
- The Media (Newspapers, TV, Radio, Magazines)
- The Motor Neuron Disease Association of South Africa
- The J 9 Foundation
- Other (*Please Specify*)

Question 6

- 1_____
- 2_____
- 3_____
- 4_____
- 5_____
- 6_____

7. Think about people with MND in general (not just your significant other with MND). Please select to what extent you agree with the following statement and provide a reason for your answer.

| <i>Statement</i> | <i>Strongly Agree</i> | <i>Agree</i> | <i>Unsure</i> | <i>Disagree</i> | <i>Strongly Disagree</i> | <i>Please Explain your answer:</i> |
|---|-----------------------|--------------|---------------|-----------------|--------------------------|--|
| 1. I believe message banking is a good idea for <u>other people</u> with MND. | | | | | | |

Question 7

- 1_____
- 2_____
- 3_____
- 4_____
- 5_____

8. Think about your significant other who is living with MND. Please select to what extent you agree with the following statement for them and provide a reason for your answer.

| <i>Statement</i> | <i>Strongly Agree</i> | <i>Agree</i> | <i>Unsure</i> | <i>Disagree</i> | <i>Strongly Disagree</i> | <i>Please Explain your answer:</i> |
|--|-----------------------|--------------|---------------|-----------------|--------------------------|---|
| 2. I believe message banking is a good idea for <u>my significant other.</u> | | | | | | |

Question 8

- 1_____
- 2_____
- 3_____
- 4_____
- 5_____

| | | | | | | |
|--|--|--|--|--|--|--|
| | | | | | | |
|--|--|--|--|--|--|--|

9. When do you think is the best time for a person with MND to start doing message banking?

- As soon as possible after being diagnosed with MND.
- Once you start realizing that your speech starts changing.
- Once other people start realizing that your speech starts changing.
- Once a speech language therapist recommends it.
- I'm not sure.
- Other (*Please Specify*)

10. Which of these perceptions do you agree with regarding message banking for your significant other with MND? *Mark as many as apply*

- It's too late, his / her speech has deteriorated too much.
- He / she is not experiencing any speech difficulties.
- He / she does not like technology.
- It seems too time consuming.
- It is seems too difficult.
- It seems too expensive.
- It seems too emotional.
- It seems unnecessary.
- I'm not sure.
- He / She would be a good candidate for message banking
- His / Her voice is still strong therefore he / she is a good candidate for message banking
- He / She likes technology
- Message banking seems easy enough
- Message banking seems very important

Question 9

- 1____
- 2____
- 3____
- 4____
- 5____
- 6____

Question 10

- 1____
- 2____
- 3____
- 4____
- 5____
- 6____
- 7____
- 8____
- 9____
- 10____
- 11____
- 12____
- 13____
- 14____
- 15____

Other (Please Specify)

11. Would your significant other be interested in doing message banking? *Please explain your answer in the lines below.*

- Yes
- No
- Not Sure

Please Explain: _____

12. Think about messages, phrases, words or sounds that people will associate with your significant other. What are some of these messages that you would like him / her to bank during message banking? Please list 5 – 10 messages that you would like him / her to bank. Please write these down in your own words

- _____
- _____
- _____
- _____
- _____
- _____
- _____
- _____
- _____
- _____
- _____
- _____

Question 11

1_____

2_____

3_____

Question 12

Category_____

Category_____

Category_____

Category_____

Category_____

Category_____

Category_____

Category_____

Category_____

Category_____

Category_____

Category_____

13. We communicate for various reasons listed below. Given limited time it is not always possible to record everything in one's own voice. Read the various types of messages in the table below. Please indicate if you would be satisfied with a computer voice saying these messages or would it be important to have it in your partner's own voice. Remember there are no right and wrong answers. I want to know what you would prefer.

| Communication Purpose | Computer Voice | Own Voice |
|---|----------------|-----------|
| 1. Calling for help | | |
| 2. Getting his / her needs met | | |
| 3. Clarifying his / her needs with caregivers | | |
| 4. Exchanging information | | |
| 5. Discussing his / her important issues or concerns | | |
| 6. Discussing his / her health care | | |
| 7. Discussing his / her work or former work | | |
| 8. Discussing his / her finances | | |
| 9. Discussing his / her religion or spirituality | | |
| 10. Expressing his / her feelings | | |
| 11. Staying connected with his / her family and friends | | |
| 12. Messages about end of life | | |
| 13. Messages to his / her children | | |
| 14. Telling stories | | |
| 15. Chatting | | |

| Communication Purpose | Computer Voice | Own Voice |
|--|----------------|-----------|
| | | |
| 16. Having casual conversation with strangers | | |
| 17. Comforting others | | |
| 18. Being funny | | |
| 19. Flirting or being romantic | | |
| 20. Being polite | | |
| 21. Being rude | | |
| 22. Other <i>(you can write down your own)</i> | | |
| 23. Other <i>(you can write down your own)</i> | | |
| 24. Other <i>(you can write down your own)</i> | | |
| 25. Other <i>(you can write down your own)</i> | | |
| 26. Other <i>(you can write down your own)</i> | | |
| 27. Other <i>(you can write down your own)</i> | | |
| 28. Other <i>(you can write down your own)</i> | | |
| 29. Other <i>(you can write down your own)</i> | | |

Appendix I: Questionnaire for SLPs

Research Questionnaire for Speech Language Therapists

In this questionnaire, I will ask you a question and you will be given a few answers to choose from. Please select the most appropriate answer. Where asked to explain your answer, please do so in the lines provided.

1. Augmentative and Alternative Communication (AAC) refers to the use of less frequently used modes of communication, to either supplement or replace your speech. These AAC strategies include writing, gestures, signs, communication boards and electronic devices including speech generating devices that can help you to communicate effectively if your speech deteriorates. How much do you think you know about AAC?

- Know a little about AAC.
- Know a fair amount about AAC.
- Know a lot about AAC.

2. Please describe where you received your AAC training. *You can select more than one option*

- Undergraduate Studies
- CPD Courses
- Conferences
- Postgraduate Studies
- The Internet
- The Media
- MNDSA
- Academic Articles
- Text books
- Colleagues
- Other (Please Specify)

For Resercher's Use Only

Participant Number:

Question 1

- 3____
- 4____
- 5____

Question 2

- 1____
- 2____
- 3____
- 4____
- 5____
- 6____
- 7____
- 8____
- 9____
- 10____
- 11____

3. Are you aware that AAC strategies can be used to help persons with Motor Neuron Disease (MND) to communicate once speech becomes difficult?

- Yes
- No
- Unsure

3b. How often do you see PMND in your caseload?

- Rarely
- Occasionally
- Frequently

3c. Are you currently using any AAC strategies in your management of Persons with MND?

- Yes
- No

4. Which of these AAC methods do you recommend to persons with MND, who you see in your caseload, to help with his or her communication? *You can select more than one option*

- Gestures (e.g. pointing)
- Writing
- Letter boards (e.g. boards with the alphabet on)
- Eye-blinks
- Hand squeeze
- Sounds
- Partner assisted scanning
- Flash cards
- Communication devices
- Speech generating devices
- Communication Apps
- Communication boards/books (boards or books with words or pictures)
- Eye Gaze Technology
- Other (Please Specify)

Question 3

1____

2____

3____

Question 3b

1____

2____

3____

Question 3c

1____

2____

Question 4

1____

2____

3____

4____

5____

6____

7____

8____

9____

10____

11____

12____

13____

14____

5. **Before** today, have you ever heard about message banking?

- 1 _____ Never heard of message banking.
- 2 _____ Heard of message banking but do not know anything about it.
- 3 _____ Know a little about message banking.
- 4 _____ Know a fair amount about message banking.
- 5 _____ Know a lot about message banking.

6. If you selected options 3, 4, or 5 in Question 5, where did you hear about message banking? *You can select more than one option.*

- A Speech Language Therapist
- The Internet (Social Media)
- The Media (Newspapers, TV, Radio, Magazines)
- The Motor Neuron Disease Association of South Africa
- The J 9 Foundation
- Undergraduate Studies
- CPD Courses
- Conferences
- Postgraduate Studies
- The Internet
- The Media
- MNDSA
- Academic Articles
- Text books
- Other (Please Specify)

Question 5

- 1 _____
- 2 _____
- 3 _____
- 4 _____
- 5 _____

Question 6

- 1 _____
- 2 _____
- 3 _____
- 4 _____
- 5 _____
- 6 _____
- 7 _____
- 8 _____
- 9 _____
- 10 _____
- 11 _____
- 12 _____
- 13 _____
- 14 _____
- 15 _____

7. Think about other people with MND in general (not only those you see at your practice). Please select to what extent you agree with the following statement and provide a reason for your answer.

| <i>Statement</i> | <i>Strongly Agree</i> | <i>Agree</i> | <i>Unsure</i> | <i>Disagree</i> | <i>Strongly Disagree</i> | <i>Please Explain your answer:</i> |
|---|-----------------------|--------------|---------------|-----------------|--------------------------|--|
| 1. I believe message banking is a good idea for <u>people</u> with MND. | | | | | | |

8. Think about persons with MND who you see in your caseload as a speech language therapist. Please select to what extent you agree with the following statement and provide a reason for your answer.

| <i>Statement</i> | <i>Strongly Agree</i> | <i>Agree</i> | <i>Unsure</i> | <i>Disagree</i> | <i>Strongly Disagree</i> | <i>Please Explain your answer:</i> |
|--|-----------------------|--------------|---------------|-----------------|--------------------------|--|
| 2. I believe message banking is a good idea for <u>my patients</u> . | | | | | | |

9. When do you think is the best time for a person with MND to start doing message banking?

- As soon as possible after being diagnosed with MND.
- Once they realize that their speech starts changing.
- Once other people realize that their speech starts changing.
- Once a speech language therapist recommends it.
- I'm not sure.
- Other (*Please Specify*)

Question 7

- 1 _____
- 2 _____
- 3 _____
- 4 _____
- 5 _____

Question 8

- 1 _____
- 2 _____
- 3 _____
- 4 _____
- 5 _____

Question 9

- 1 _____
- 2 _____
- 3 _____
- 4 _____
- 5 _____
- 6 _____

Question 10

10. Which of these perceptions do you agree with regarding message banking for your patients? *Mark as many as apply*

- By the time they see me their speech has deteriorated too much.
- By the time they see me they are not yet experiencing any speech difficulties.
- Most of my patients do not like technology.
- It seems too time consuming for my patients.
- It is seems too difficult for my patients.
- It seems too expensive for my patients.
- It seems too emotional for my patients.
- It seems unnecessary for my patients.
- I'm not sure.
- Most of my patients would be good candidates for message banking
- Most of my patients' voices are still strong therefore they would be good candidates for message banking.
- Most of my patients like technology.
- Message banking seems easy enough.
- Message banking seems very important.
- Other *(Please Specify)*

- 1____
- 2____
- 3____
- 4____
- 5____
- 6____
- 7____
- 8____
- 9____
- 10____
- 11____
- 12____
- 13____
- 14____
- 15____

11. Would you be interested in doing message banking with your patients? *Please explain your answer in the lines below.*

- Yes
- No
- Not Sure

Question 11

- 1____
- 2____
- 3____

12. We communicate for various reasons listed below. Given limited time it is not always possible to record everything in one's own voice. Read the various types of messages in the table below. Please indicate if you think your patients would be satisfied with a computer voice saying these messages or would it be important to have it in his / her own voice. Remember there are no right and wrong answers. I want to know what you think they would prefer.

| Communication Purpose | Computer Voice | Personal Voice |
|--|----------------|----------------|
| 1. Calling for help | | |
| 2. Getting my needs met | | |
| 3. Clarifying my needs with my caregivers | | |
| 4. Exchanging information | | |
| 5. Discussing my important issues or concerns | | |
| 6. Discussing my health care | | |
| 7. Discussing my work or former work | | |
| 8. Discussing my finances | | |
| 9. Discussing my religion or spirituality | | |
| 10. Expressing my feelings | | |
| 11. Staying connected with my family and friends | | |
| 12. Messages about end of life | | |
| 13. Messages to my children | | |
| 14. Telling stories | | |
| 15. Chatting | | |

| Communication Purpose | Computer Voice | Personal Voice |
|--|----------------|----------------|
| | | |
| 16. Having casual conversation with strangers | | |
| 17. Comforting others | | |
| 18. Being funny | | |
| 19. Flirting or being romantic | | |
| 20. Being polite | | |
| 21. Being rude | | |
| 22. Other (<i>you can write down your own</i>) | | |

Appendix J: Summary of suggestions from expert panel

Appendix J: Summary of suggestions from expert panel.

| Measure / Material | Suggestions from panel | Changes |
|----------------------------------|--|--|
| 1. Message Banking Questionnaire | <p>Question 11: Which of these perceptions do you agree with regarding message banking? <i>Mark as many as apply.</i></p> <p>Panel suggested to use “forced choice” to gather participant’s answers. This prompts participants to provide a definite response by giving them statements that they can select if they agree with. This is used instead of a Likert scale to provide their perceptions.</p> <p>Question 12: Panel suggested that question 12 (for PMND and SO) be omitted from the SLP questionnaire, as the answers will be patient dependent.</p> <p>Question 13: Panel suggested changing the wording of the question to highlight the fact that with limited time, it is not always possible to record everything in your own voice.</p> <p>Question 13: Participants were given multiple purposes of communication. Panel suggested that participants decide if they preferred a “computer voice” or their “own voice” saying these messages.</p> <p>Format changes: Panel suggested multiple formatting changes.</p> | <p>14 Statements that were either positive or negative were included regarding message banking. Participants could mark as many as they agreed with.</p> <p>Question 12 omitted from SLP questionnaires.</p> <p>Wording changed to: “We communicate for various reasons listed below. <u>Given limited time it is not always possible to record everything in ones own voice.</u> Read the various types of messages in the table below. Which of these would you like to have in your own voice and which with a computer generated voice? Remember there are no right and wrong answers. I want to know what you would prefer.”</p> <p>Term: “Digital Voice” was changed to “Computer voice”. Own voice was provided as a second option.</p> <p>Format changes were made to the questionnaires were suggested.</p> |

| Measure / Material | Suggestions from panel | Changes |
|---------------------------------|--|---|
| 2. Message Banking Presentation | <p>Shorten the introduction.</p> <p>Provide an introduction about AAC</p> <p>Provide an example of synthetic and digital voices used by speech generating devices.</p> | <p>Introduction shortened to the following “What is in a voice? The voice is more than a means to transmit language. The moment you speak, even if it is only to read from a book, your voice reveals much about you, perhaps your age, mood, and possibly your health and education. Your voice is unique to you and provides insight into who you are as a person.</p> <p>AAC introduction included: Many people with MND use Augmentative and Alternative Communication or AAC strategies to communicate if they lose their ability to speak. AAC Strategies can involve no technology such as using gestures or pointing to words. AAC can also involve technology. One of the high-technology AAC strategies that people could use is called a speech generating device. When you use this system you will type a message and the device will speak it on your behalf.</p> <p>Audio clips were inserted to provide examples of synthetic and digital voices.</p> |
| 3. Message Banking Pamphlet | <p>Make the same changes to the message banking pamphlet as suggested for the presentation.</p> | <p>Changes were made to the message banking pamphlet.</p> |



Appendix K

Permission from the Motor Neuron Association of South Africa

Dear Sir/Madam

Re: Request for permission to assist with Masters Study

I am currently a Masters student at the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria. In order for me to comply with the requirements set to complete the degree, I have to do a research study.

The title of my study is: “Message banking: comparing perceptions of people with motor neuron disease, their significant others and speech language therapists”. The aim of the study is to determine and compare the perceptions about message banking for people with MND, significant others and speech language therapists.

Message banking is an early communication intervention option for people with MND pioneered by John Costello at the Boston Children’s Hospital (Costello, 2014). It involves digitally recording and storing words, phrases, sentences, personally meaningful sounds and stories using a person’s own voice, natural inflection and intonation before their intelligibility becomes significantly affected.

I would like to request your permission to recruit participants from the database of the Motor Neuron Association of South Africa for my study described below. I would therefore like to request permission to conduct my research study at a monthly support group meeting held in Bellville, Cape Town. I will require the help of coordinators at your Cape Town monthly meetings to identify patients with MND as well as their significant others. I would also require a timeslot during one of these meetings in order to conduct the study.

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The participants or persons with MND and significant others will be provided with a letter of informed consent. They will be informed that participation in this study is voluntary and that they may withdraw from this study at any time, that all information and data will be treated confidentially and stored for 15 years at the Centre for AAC. They will be required to complete two questionnaires (see attached) and listen to a brief 15 – 20 minute presentation about message banking.

The participants will not be harmed by participating in this study. The potential benefits of this study may be that the participants gain some information about message banking.

I would appreciate your consideration of my request. Should you like to grant permission, please sign the reply slip and email it back to imkeoosthuizen@gmail.com. For any further information, please contact me on the contact details supplied below.

Kind regards



Imke Oosthuizen
imkeoosthuizen@gmail.com
0721308739



Dr. Shakila Dada
Supervisor

Date

168

Motor Neuron Association of South Africa: Permission Reply Slip

Name of Institution: _____

Date: _____

Project title: Message banking: comparing perceptions of people with Motor Neuron Disease, their significant others and speech language therapists

Researcher: Imke Oosthuizen
Speech Language Therapist
0721308739

Supervisor: Dr. Shakila Dada.
Centre for AAC, University of Pretoria
012 4202001

We hereby (*please tick to indicate*):

- Grant permission to recruit participants from the database of the Motor Neuron Association of South Africa.
- Grant permission to conduct a research project at the support group meeting in Bellville, Cape Town.

OR

- Do not grant permission to recruit participants from the database of the Motor Neuron Association of South Africa.
- Do not grant permission to conduct a research project at the support group meeting in Bellville, Cape Town.

Name of Person Granting Permission

Signature

Researcher: Imke Oosthuizen

Signature

Stamp: 



Appendix L

Consent Letter to: People with MND

Dear Sir/Madam

Re: Request to participate in research study

I am currently a Masters student at the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria. In order for me to comply with the requirements set to complete the degree, I have to do a research study.

The title of my study is: “Message banking: comparing perceptions of people with Motor Neuron Disease, their significant others and speech language therapists”. The aim of the study is to determine and compare the perceptions about Message banking for people with MND, significant others and speech language therapists.

Message banking is an early communication intervention option for people with MND pioneered by John Costello at the Boston Children’s Hospital (Costello, 2014). It involves digitally recording and storing words, phrases, sentences, personally meaningful sounds and stories using a person’s own voice, natural inflection and intonation before their intelligibility becomes significantly affected.

Participation in this study is voluntary and you may withdraw from the study at any time. All information will be treated confidentially.

Participants who express an interest to participate in the study will be met by the researcher at the monthly support group meetings held by the Motor Neuron Association of South Africa in Bellville, Cape Town. The researcher will ask some biographical information questions. This will be followed by a 15 – 20 minute information session about message banking. Following the information session participants will complete a questionnaire as part of the research study. The entire process will be videotaped. There is no right or wrong answers to the questions as it is an expression of your personal opinion.

170

Potential benefits of this study may include extending research within the field of AAC and particular AAC strategies can be advocated for with evidence from this research.

Data for this study will be stored for 15 years at the Centre for AAC, for the purpose of archiving but should you decide to withdraw from the study at any time, any data pertaining to you will be destroyed immediately. The videotaped sessions may be presented for teaching and conference presentations.

I would appreciate your consideration of my request. Kindly complete the reply slip and email it back to imkeoosthuizen@gmail.com. For any further information, please do not hesitate to contact me.

Kind regards



Imke Oosthuizen
imkeoosthuizen@gmail.com
0721308739



Dr. Shakila Dada
Supervisor

Date

Reply Slip

Name of Participant: _____

Name(s) of significant others: _____

Study title:

Message banking: comparing perceptions of people with Motor Neuron Disease, their significant others and speech language therapists

Researcher: Imke Oosthuizen
Speech Language Therapist
Cel: 0721308739

Supervisor: Dr. Shakila Dada
Centre for AAC, University of Pretoria
012 4202001

I understand my rights as a participant. I understand the scope of this study and the way in which it will be conducted.

I hereby (*please tick to indicate consent*):

- Voluntarily declare my consent to participate in this study as described in the consent letter.
- Consent to the video recordings of the data collection sessions for teaching or conference presentations.

OR

- Decline to participate in this study.

Name of Participant

Date

Signature

Contact Number



Appendix M

Consent Letter to Participants Significant Others of People with MND

Dear Sir/Madam

Re: Request to take part in a master's research study

I am currently a Masters student at the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria. In order for me to comply with the requirements set to complete the degree, I have to do a research study.

The title of my study is: "Message banking: comparing perceptions of people with Motor Neuron Disease, their significant others and speech language therapists". The aim of the study is to determine and compare the perceptions about message banking for people with MND, significant others and speech language therapists.

Message banking is an early communication intervention option for people with MND pioneered by John Costello at the Boston Children's Hospital (Costello, 2014). It involves digitally recording and storing words, phrases, sentences, personally meaningful sounds and stories using a person's own voice, natural inflection and intonation before their intelligibility becomes significantly affected.

Participation in this study is voluntary and you may withdraw from the study at any time. All information will be treated confidentially. Participants who express an interest to participate in the study will be met by the researcher at the monthly support group meetings held by the Motor Neuron Association of South Africa in Bellville, Cape Town. The researcher will ask some biographical information questions. This will be followed by a 15 – 20 minute information session about message banking. Following the information session participants will complete a questionnaire as part of the research study. The entire process will be videotaped. There is no right or wrong answers to the questions as it is an expression of your personal opinion.

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Potential benefits of this study may include extending research within the field of AAC and particular AAC strategies can be advocated for with evidence from this research.

Data for this study will be stored for 15 years at the Centre for AAC, for the purpose of archiving but should you decide to withdraw from the study at any time, any data pertaining to you will be destroyed immediately. The videotaped sessions may be presented for teaching and conference presentations.

I would appreciate your consideration of my request. Kindly complete the reply slip and email it back to imkeoosthuizen@gmail.com. For any further information, please do not hesitate to contact me.

Kind regards



Imke Oosthuizen

imkeoosthuizen@gmail.com

0721308739



Dr. Shakila Dada

Supervisor

Date

174

Significant other of Person with MND: Consent Reply Slip

Name of Participant: _____

Name of Significant Other

With MND: _____

Project title:

Message Banking: comparing perceptions of people with Motor Neuron Disease, their significant others and speech language therapists

Researcher: Imke Oosthuizen
Speech Language Therapist
0721308739

Supervisor: Dr. Shakila Dada.
Centre for AAC, University of Pretoria
012 4202001

I understand my rights as a participant. I understand the scope of this study and the way in which it will be conducted.

I hereby (*please tick to indicate consent*):

- Voluntarily declare my consent to participate in this study as described in the consent letter.
- Consent to the video recordings of the data collection sessions for teaching or conference presentations.

OR

- Decline to participate in this study.

Name of Participant

Date

Signature

Contact Number



Appendix N

Consent Letter: Speech language therapists

Dear Sir/Madam

Re: Request to take part in a master's research study

I am currently a Masters student at the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria. In order for me to comply with the requirements set to complete the degree, I have to do a research study.

The title of my study is: "Message banking: comparing perceptions of people with Motor Neuron Disease, their significant others and speech language therapists". The aim of the study is to determine and compare the perceptions about message banking for people with MND, significant others and speech language therapists.

Participants, who express an interest to participate in the study, will be met by the researcher at a convenient venue or alternatively a private meeting can be scheduled at your practice.

Once informed consent has been obtained, you will be given biographical questionnaires to complete. Thereafter, a 15-20 minute explanation about message banking will take place and an information leaflet will be provided. After the presentation you will be required to complete a questionnaire to determine their perceptions about message banking. There are no right or wrong answers to the questions as it is an expression of your personal opinion.

176

Potential benefits of this study may include extending research within the field of AAC and particular AAC strategies can be advocated for with evidence from this research.

Data for this study will be stored for 15 years at the Centre for AAC, for the purpose of archiving but should you decide to withdraw from the study at any time, any data pertaining to you will be destroyed immediately. The videotaped sessions may be presented for teaching and conference presentations.

I would appreciate your consideration of my request. Kindly complete the reply slip and email it back to imkeoosthuizen@gmail.com. For any further information, please do not hesitate to contact me.

Kind regards



Imke Oosthuizen
imkeoosthuizen@gmail.com
0721308739



Dr. Shakila Dada
Supervisor

Date

Speech Language Therapists: Consent Reply Slip

Name of Participant: _____

Project title:

Message Banking: comparing perceptions of people with Motor Neuron Disease, their significant others and speech language therapists

Researcher: Imke Oosthuizen
Speech Language Therapist
0721308739

Supervisor: Dr. Shakila Dada.
Centre for AAC, University of Pretoria
012 4202001

I understand my rights as a participant. I understand the scope of this study and the way in which it will be conducted.

I hereby (*please tick to indicate consent*):

- Voluntarily declare my consent to participate in this study as described in the consent letter.
- Consent to the video recordings of the data collection sessions for teaching or conference presentations.

OR

- Decline to participate in this study.

Name of Participant

Date

Signature

Contact Number

Appendix O: Classification of motor neurone disease (Riviere et al., 1998)

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 the other 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 / needs assistance with upper extremity activities 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 P: Ethics Approval from UP

2 June 2015

Faculty of Humanities
Research Ethics Committee

Dear Dr Dada

Project: Message banking: comparing perceptions of people with Motor Neuron Disease, significant others and speech language therapists
Researcher: I Oosthuizen
Supervisor: Dr S Dada
Department: Augmentative and Alternative Communication
Reference number: 14432430 (GW20150527HS)

Thank you for the application that was submitted for ethical consideration.

I am pleased to inform you that the above application was **approved** by the **Research Ethics Committee** on 28 May 2015. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

Prof Karen Harris
Acting Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail:Karen.harris@up.ac.za



Association of South Africa

Motor Neurone Disease / Amyotrophic Lateral Sclerosis

PO Box 789 Howard Place 7450 * Telephone 021 531 6130 * Fax 021 531 6131

Email : mndaofsa@global.co.za * www.mnda.org.za

11 May 2015

Ms Imke Oosthuizen
Speech Therapist
University of Pretoria

Dear Ms Oosthuizen

Re: Permission to perform research

We are pleased to grant you permission to approach members of the MND / ALS Association of SA regarding your proposed study, entitled "*Message banking: comparing perceptions of people with motor neuron disease, their significant others and speech language therapists*". We would, however, like to request the following:

1. A study protocol summary (or relevant portion thereof explaining the study procedures), approved by the relevant ethics committee, to be submitted to the association before members are approached.
2. You undertake to inform the association as well as the participating members of the main findings of your study.
3. It should be explained to the members that the study has no relation to the MNDA of SA and that you merely obtained their contact details from the association. We would like to ensure that members do not to feel obliged to participate in the study.

I hope you find above acceptable. Regards, and good luck with the study.

A handwritten signature in black ink, appearing to read 'Franclou Henning'.

Dr. Franclou Henning, FC Neurol (SA),
Neurologist, Division of Neurology, Tygerberg Hospital / Stellenbosch University
Chairperson: MND / ALS Association of SA

Appendix R: Scripts

Research: Message Banking in AAC



Research: Message Banking in AAC

- **Where:** University of Pretoria, Centre for AAC.
- **What:** Masters in Augmentative and Alternative Communication (AAC).
- **Title:** “Message banking: comparing perceptions of people with Motor Neuron Disease, their significant others and speech language therapists”.
- **Aim:** The aim is to determine and compare the perceptions about message banking for people with MND, significant others and speech language therapists.

Research: Message Banking in AAC

- **Participation:** Entirely voluntary. You do not have to complete the questionnaires.
- **Potential benefits:**
 - You are contributing to research in the field of MND.
 - AAC strategies can potentially be advocated for from data for this research.
- **Please note:**
 - Your data will be kept entirely confidential.
 - Data will be stored for 15 years for research purposes.
 - You can discontinue participation at any stage and your data will be destroyed immediately.

Research: Message Banking in AAC

Speech Language Therapists: Consent Reply Slip

Name of Participant:

Date:

Voluntarily declare my consent to participate in this study.

– *Accordingly, I consent to the following research conditions:*

- The use of audio / video recordings of the data collection sessions. I understand that these recordings will be used for data collection and analysis purposes and may be used as part of a presentation of the research findings at conferences.

OR

Decline participation in this study.

Research: Message Banking in AAC

Procedure

- 1. Complete Biographical Questionnaire**
- 2. Watch Message Banking Presentation**
- 3. Complete Research Questionnaire**
- 4. Receive Message Banking Pamphlet**

Complete Biographical Questionnaire

- Please complete in writing
- There are no right or wrong answers
- If you are done, please turn your page face down and a researcher will collect
- Do not discuss any of the information with other participants

Watch Message Banking Presentation

- Please enjoy the presentation
- Do not discuss anything during the presentation



Complete Research Questionnaire

- Please complete in writing
- There are no right or wrong answers
- If you are done, please turn your page face down and a researcher will collect
- Do not discuss any of the information with other participants

Question 13:

- We communicate for various reasons listed below.
- **Given limited time it is not always possible to record everything in one's own voice.**
- Read the various types of messages in the table below.
- Please indicate if you would be satisfied with a **computer voice** saying these messages or would it be important to have it in your **own voice**.
- Remember there are no right and wrong answers. I want to know what you would prefer.

Receive Message Banking Pamphlet

- **Thank you for your participation!**

