

CHAPTER 1

ORIENTATION

1.1 INTRODUCTION

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

1.2 BACKGROUND

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

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

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

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

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

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

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

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

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

1.3 DEFINITION OF TERMS

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

Augmentative and alternative communication

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

Closeness

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

Communication

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

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

Communication Effectiveness

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

Dysarthria

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

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

Marital communication

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

Motor Neuron Disease

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

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

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

Speech intelligibility

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

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

1.4 ABBREVIATIONS

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

1.5 CHAPTER OUTLINES

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

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

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

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

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

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

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

1.6 SUMMARY

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

CHAPTER 2

LITERATURE REVIEW AND PROBLEM STATEMENT

2.1 INTRODUCTION

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

2.2 DESCRIPTION OF MND

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

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

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

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

2.3 THE IMPACT OF MND ON THE INDIVIDUAL

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

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

2.3.1 Physical abilities

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

2.3.2 Communication abilities

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

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

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

2.3.2.1 Speech intelligibility

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

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

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

2.3.2.2 Communication effectiveness

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

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

2.3.2.3 Speech intelligibility and communication effectiveness

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

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

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

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

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

2.3.3 Social roles

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

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

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

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

2.3.4 Psychosocial impact

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

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

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

2.4 IMPACT OF MND ON THE MARITAL RELATIONSHIP

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

2.4.1 Experiences of the spouses

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

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

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

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

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

2.4.2 Moderating effect of communication in marriage

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

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

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

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

2.4.3 Impact of negative life events on marital communication

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

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

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

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

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

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

2.5 SUMMARY

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

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