

CHAPTER 4

RESULTS AND DISCUSSION

4.1 INTRODUCTION

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

4.2 INTERRATER RELIABILITY

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

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

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

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

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

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

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

4.3 DISEASE PROGRESSION

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

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

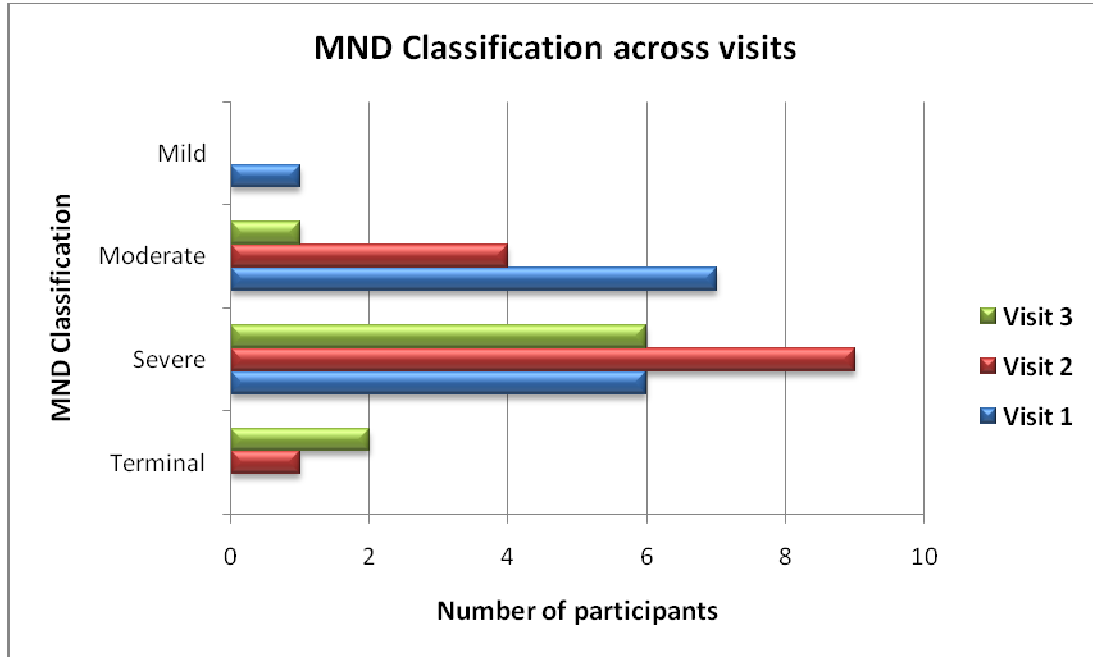


Figure 4.1 MND Classification of participants across visits

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

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

4.4 COMMUNICATION ABILITIES ACROSS THE DISEASE PROGRESSION

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

4.4.1 ALSSS: Speech Scale

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

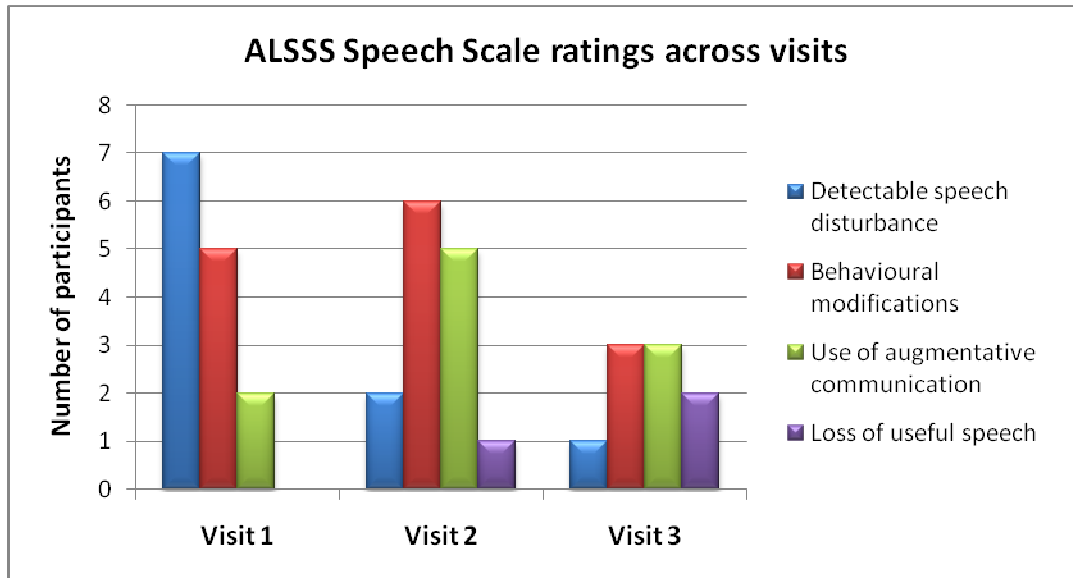


Figure 4.2 Summary of ALSSS Speech Scale ratings across visits

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

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

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

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

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

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

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

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

4.4.2 Speech intelligibility and speaking rate

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

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

Table 4.1 Results of speech intelligibility scores in percentage across visits

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

Mean with different superscript differ significantly at the 5% level

**Significance at the 5% level*

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

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

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

Table 4.2 Results of communication efficiency ratio across visits

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

Mean with different superscript differs significantly at the 5% level

* Significance at the 5% level

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

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

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

4.4.3 Communication effectiveness

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

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

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

Mean with different superscript differs significantly at the 5% level

** Significance at the 5% level*

*** Between visit 1 and visit 3*

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

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

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

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

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

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

4.4.4 Speech intelligibility and communication effectiveness

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

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

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

4.4.5 Communication efficiency ratio and communication effectiveness

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

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

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

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

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

4.5 MARITAL COMMUNICATION

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

4.5.1 Primary Communication Inventory

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

Table 4.4 Marital communication across all visits and between participant groups

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

**Significance at the 5% level*

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

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

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

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

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

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

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

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

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

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

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

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

4.5.2 Inclusion of Others in the Self Scale

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

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

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

Table 4.5 Frequency table for IOS results

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

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

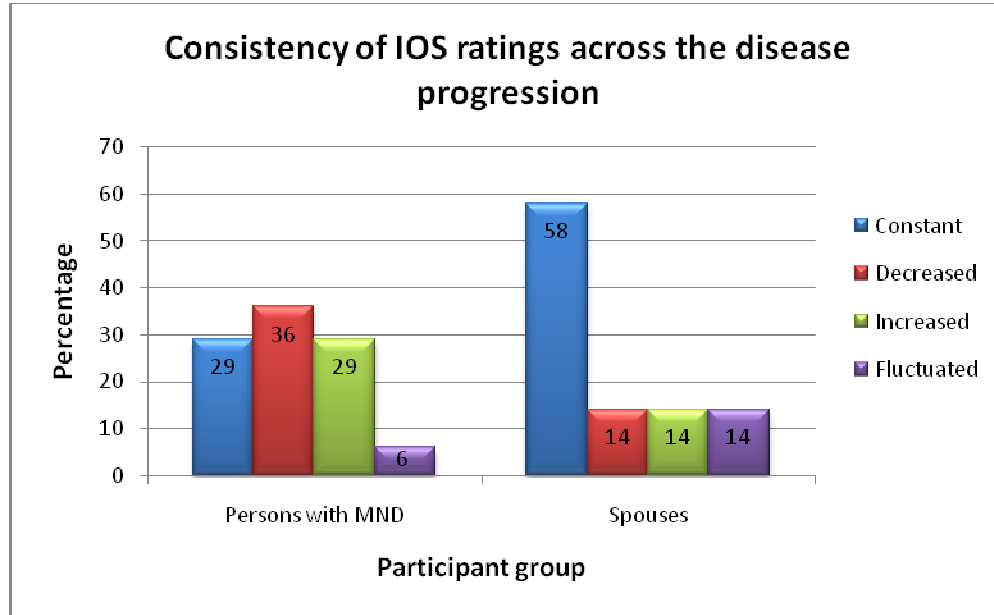


Figure 4.3 Consistency of IOS ratings (percentage) across disease progression

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

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

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

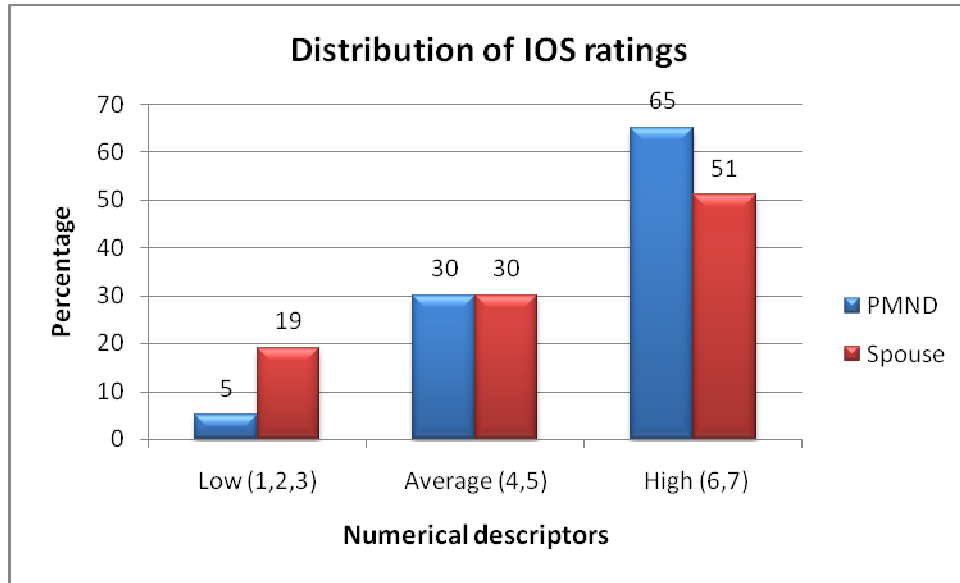


Figure 4.4 Distribution of IOS ratings

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

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

4.6 SPEECH INTELLIGIBILITY AND MARITAL COMMUNICATION

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

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

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

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

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

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

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

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

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

4.7 CONCLUSION

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

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

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

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

5.2 OVERVIEW OF THE RATIONALE AND SUMMARY OF RESULTS

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

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

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

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

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

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

5.3 EVALUATION OF THE STUDY

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

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

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

5.4 CLINICAL IMPLICATIONS

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

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

5.5 RECOMMENDATIONS FOR FUTURE RESEARCH

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

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

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

5.6 SUMMARY

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

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