

CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION

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

3.2 METHODOLOGY

3.2.1 Main research aim

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

3.2.2 Sub-aims

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

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

3.3 RESEARCH DESIGN

3.3.1 Research design

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

3.3.2 Research phases

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

Table 3.1 Research phases

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

3.4 DEVELOPMENTAL PHASE

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

3.4.1 Factor analysis: Primary Communication Inventory

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

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

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

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

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

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

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

3.4.2 Pilot Study

3.4.2.1 Objectives

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

3.4.2.2 Context and participants

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

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

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

3.4.2.3 Procedures

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

3.4.2.4 Results and recommendations

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

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

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

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

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

3.4.2.5 Summary

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

3.4.3 Participant selection and description

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

3.4.3.1 Participant selection

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

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

3.4.3.2 Selection criteria

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

Table 3.4 Participant selection criteria

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

3.4.3.3 Descriptive information on participants

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

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

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

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

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

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

Participant group 1: Persons with MND

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

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

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

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

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

Participant group 2: Spouse

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

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

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

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

3.5 MAIN STUDY

3.5.1 Equipment and Measuring instruments

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

3.5.1.1 Equipment

The equipment used for data collection and analysis included:

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

3.5.1.2 Measuring Instruments

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

i. Disease progression

a. Classification on MND

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

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

ii. Communication abilities and speech intelligibility

a. Amyotrophic Lateral Sclerosis Severity Scale: Speech Scale

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

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

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

b. Sentence Intelligibility Test

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

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

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

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

c. Modified Communication Effectiveness Index

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

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

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

iii. Marital relationship

a. Primary Communication Inventory

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

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

b. Inclusion of Others in the Self Scale

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

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

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

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

3.5.2 Data collection procedures

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

3.5.2.1 Ethical considerations

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

3.5.2.2 Specific considerations

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

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

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

3.5.2.3 Procedures

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

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

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

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

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

3.5.2.4 Data analysis and statistical procedures

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

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

Table 3.8 Statistical procedures conducted

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

3.6 SUMMARY

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