


Nishio, M., & Niimi, S. (2000). Changes over time in dysarthric patients with amyotrophic lateral sclerosis (ALS): A study of changes in speaking rate and


APPENDICES

APPENDIX A

CLASSIFICATION OF MOTOR NEURON DISEASE


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

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

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

**STATE 4 (TERMINAL)**
- Non-functional use of at least 2 regions and moderate or non-functional use of the third region
APPENDIX B

AMYOTROPHIC LATERAL SCLEROSIS SEVERITY SCALE (ALSSS): SPEECH SCALE


NORMAL SPEECH PROCESSES

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

DETECTABLE SPEECH DISTURBANCE

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

BEHAVIOURAL MODIFICATIONS

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

USE OF AUGMENTATIVE COMMUNICATION

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

LOSS OF USEFUL SPEECH

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

X – Tracheostomy
APPENDIX C

SENTENCE INTELLIGIBILITY TEST (SIT) SAMPLE SENTENCES
(ACTUAL SHORT TEST FORM)


File: Sample SIT
Date: 20/4/2009
Examiner:
Agency:
Comment:

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

MODIFIED COMMUNICATION EFFECTIVENESS INDEX (CETI-M)


Please evaluate how effectively you communicate in these situations. Read the item describing each of the situations and decide how successful you communicate. If you think the communication is **very effective**, circle the 7. If the communication **doesn't occur at all**, circle the 1. Circle any number on the scale that best describes communication in that situation.

<table>
<thead>
<tr>
<th></th>
<th>Not at all effective</th>
<th>Very effective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Having a conversation with familiar persons in a quiet environment</td>
<td>1 2 3 4 5 6 7</td>
<td>V3</td>
</tr>
<tr>
<td>Having a conversation with strangers in a quiet environment</td>
<td>1 2 3 4 5 6 7</td>
<td>V4</td>
</tr>
<tr>
<td>Having a conversation with a familiar person over the phone</td>
<td>1 2 3 4 5 6 7</td>
<td>V5</td>
</tr>
<tr>
<td>Having a conversation with young children</td>
<td>1 2 3 4 5 6 7</td>
<td>V6</td>
</tr>
<tr>
<td>Having a conversation with a stranger over the phone</td>
<td>1 2 3 4 5 6 7</td>
<td>V7</td>
</tr>
<tr>
<td>Having a conversation while traveling in a car</td>
<td>1 2 3 4 5 6 7</td>
<td>V8</td>
</tr>
<tr>
<td>Having a conversation with someone at a distance</td>
<td>1 2 3 4 5 6 7</td>
<td>V9</td>
</tr>
<tr>
<td>Having a conversation with someone in a noisy environment</td>
<td>1 2 3 4 5 6 7</td>
<td>V10</td>
</tr>
<tr>
<td>Speaking or having a conversation before a group</td>
<td>1 2 3 4 5 6 7</td>
<td>V11</td>
</tr>
<tr>
<td>Having a long conversation with someone (over an hour)</td>
<td>1 2 3 4 5 6 7</td>
<td>V12</td>
</tr>
</tbody>
</table>
Below is a list of items on communication between you and your spouse. Using the scale described here, tick the column which best represents the extent to which you and your spouse behave in the specified way.

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Seldom</th>
<th>Occasionally</th>
<th>Frequently</th>
<th>Very frequently</th>
</tr>
</thead>
<tbody>
<tr>
<td>How often do you and your spouse talk over pleasant things that happen during the day?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>How often do you and your spouse talk over unpleasant things that happen during the day?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Do you and your spouse talk over things you disagree about or have difficulties over?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Do you and your spouse talk about things in which you are both interested?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Does your spouse adjust what s/he says and how s/he says it to the way you seem to feel at the moment?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>When you start to ask a question, does your spouse know what it is before you ask it?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Do you know the feelings of your spouse from his/her facial and bodily gestures?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Do you and your spouse avoid certain subjects in conversation?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Does your spouse explain or express himself/herself to you through a glance or a gesture?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Do you and your spouse discuss things together before making an important decision?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Can your spouse tell what kind of day you have had without asking?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Your spouse wants to visit some close friends or relatives. You don't particularly enjoy their company. Would you tell him/her this?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Does your spouse discuss matters of sex with you?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Never</td>
<td>Seldom</td>
<td>Occasionally</td>
<td>Frequently</td>
<td>Very frequently</td>
</tr>
<tr>
<td>-----------------------------------------------------------------</td>
<td>-------</td>
<td>--------</td>
<td>--------------</td>
<td>------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>Do you and your spouse use words which have special meaning not understood by outsiders?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>How often does your spouse sulk or pout?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Can you and your spouse discuss your most sacred beliefs without feelings of restraint or embarrassment?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Do you and your spouse talk about things in which you are both interested?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>You and your spouse are visiting friends. Something is said by the friends which causes you to glance at each other. Would you understand each other?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>How often can you tell as much from the tone of voice of your spouse as from what s/he actually says?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>How often do you and your spouse talk with each other about personal problems?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Do you feel that in most matters your spouse knows what you are trying to say?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Would you rather talk about intimate matters with your spouse than with some other person?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Do you understand the meaning of your spouse's facial expression?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>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?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>During the marriage, have you and your spouse, in general, talked most things over?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

APPENDIX F

INCLUSION OF OTHERS IN THE SELF (IOS) SCALE


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

1. ![Diagram](image1)
2. ![Diagram](image2)
3. ![Diagram](image3)
4. ![Diagram](image4)
5. ![Diagram](image5)
6. ![Diagram](image6)
7. ![Diagram](image7)
APPENDIX G

UNIVERSITY ETHICS APPROVAL

Members:
Research Proposal and Ethics Committee
Dr P Chi_con, Dr M M Coetzee, Prof C De Jongh,
Dr L M du Toit, Prof G H Daniels, Dr H N Kappes,
Prof J P Krog and Prof E Alain (Chair).

7 February 2006

Dear Professor Alant

Project: Partner’s perspective: Communication challenges and quality of life in Motor Neuron Disease
Researcher: K Joubert
Supervisor: Prof E Alant
Department: CAAG
Reference number: 85387169

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

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

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

We wish you success with the project.

Sincerely,

[Signature]

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

WRITTEN PERMISSION: MND ASSOCIATION OF SOUTH AFRICA

24 November 2005

The Centre for Augmentative and
Alternative Communication

To Whom it May Concern

Student: Karen Joubert

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

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

Dr Peter Vurgarellis
Chairperson
INFORMED CONSENT

Speech Intelligibility and Marital Communication in Motor Neuron Disease

AIM OF THE RESEARCH:

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

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

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

POTENTIAL BENEFITS AND RISKS

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

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

PARTICIPANT’S RIGHTS

Should you choose to participate please note that:

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

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

Thank you

KARIN JOUBERT
Ph.D. Student

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

Participant signature: _______________________________ Date: ___________
(Person with MND)

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

Participant signature: _______________________________ Date: ___________
(Spouse of person with MND)

Researcher signature: _______________________________ Date: ____________
APPENDIX J

LETTER OF THANKS FOR RESEARCH PARTICIPANTS

20 December 2008

Dear ________________________

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

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

Kind regards

Karin Joubert
APPENDIX K

TITLE REGISTRATION FORM

Omskrif: MSc - Width: 10737; 003
Tel: 012 396 2776
Fax 012 396 2333
E-mail: mwng@upc.ac.za

09 June 2004

Mew K. Joubert
Promotie: 42
Browne

Geografie: Zuid-Afrika

TITEL REGISTRASIE: STUDIERISTING – PHD AANVULLENDE EN ALTERNATIEF KOMMUNIKASIE

ONDERwerp:

Sprachverständigung und marktliche kommunikation in Motor Neurone Disease

PROMOTOR:

Prof J. Beinman

MEDER-PROMOTOR:

Prof E. Allard (UP Extra-ordinary Professor)

NEEM AANBIEFF KENNIS VAN DIE INLISING DERGROOT GENOMEN EN DIE AANHENGSTE VEREISTE.

1. REGISTRASIE:

(a) Indien muiu smens een akademiese jaar regasone sy die grond voorste looie is, kan die resn seistie diens seistie net jaarlik aan en van die akademiese jaar jy rooi die verslag van dien en die sal het vir die akademiese jaar van jy rooi deur die sukses van die jaar en die jaar van die verslag van die jaar van jy rooi deur die sukses van die jaar.

(b) Die resn seistie jy rooi deur die sukses van die jaar van jy rooi deur die sukses van die jaar en die jaar van die verslag van die jaar van jy rooi deur die sukses van die jaar.

2. KEURING VOOR INDIENING:

Onderwerp met die sukses van die jaar en die jaar van jy rooi deur die sukses van die jaar.

3. GOEDEERKURING VAN INDIENING:

Vir sukses van die jaar en jy rooi deur die sukses van die jaar en jy rooi deur die sukses van die jaar.

4. DATUUM VAN EXAMEN:

Onderwerp met die sukses van die jaar en jy rooi deur die sukses van die jaar en jy rooi deur die sukses van die jaar.

Een draai

[Signature]

[Deanal: Fakulteit Geesteswetenskappe]