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**Speech intelligibility and marital communication  
in Motor Neuron Disease**

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“In all change there is loss. For anyone undergoing catastrophic change, it is the loss of the expected future that is grieved so deeply...”

(Luterman, 1996, p. 48-49)

***Dedicated to Taedes, Riemer and Leroux –***

***The men in my life!***

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## ABSTRACT

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The onset of a progressive, fatal illness such as Motor Neuron Disease (MND) inevitably results in physical and communication disabilities that impinge on the individuals' ability to remain functionally independent. The loss of speech as a result of dysarthria, a motor speech disorder, is one of the most profound changes that the person with MND will experience. The decline in the individuals' speech intelligibility, that negatively influences communication effectiveness, implies that in 80% of cases alternative and augmentative communication (AAC) strategies are required to support the daily communication needs of individuals with MND.

The dyadic nature of chronic illness implies that multiple aspects of one of the most important adult relationships, marriage, will be affected. Roles and responsibilities performed by each member of the couple will continually change as the disease progresses. The emotional trauma of adjusting to the unavoidable alteration in their relationship elicits strong emotions such as guilt, anger and frustration. Communication is one of the most constructive ways of dealing with these emotions. The ability of spouses to convey their innermost thoughts, feelings and intimacy through communicative interaction is vitally important in marital communication.

The aim of this study was to compare how persons with MND and their spouses perceive changes in their marital communication in relation to the deteriorating speech of persons with MND. Fourteen couples divided into two participant groups, persons with MND and spouses, participated in this non-experimental correlational research study. Data was collected during three visits at six-monthly intervals over a 12 month period. At each of these visits both participant groups completed a variety of objective and subjective measures, of which twenty percent were interratered by independent raters.

Results confirmed the inevitable decline in speech intelligibility of persons with MND across the disease progression. The persons with MND did not report a change in their perception of marital communication although their spouses indicated a statistically

significant decrease between the first and last visits. Interestingly, there was no statistically significant relationship between the deteriorating speech of persons with MND and the couples' perception of marital communication, confirming that marital communication was not influenced by decreased speech intelligibility.

**Key words:** Amyotrophic Lateral Sclerosis (ALS), Augmentative and Alternative Communication (AAC), Closeness, Communication, Communication effectiveness, Dysarthria, Marital communication, Motor Neuron Disease (MND), Progressive neurodegenerative disease, Speech intelligibility, Spouses.

## OPSOMMING

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Die diagnose van Motor Neuron Siekte (MNS), 'n progressiewe, noodlottige siekte het die onvermydelike impak op individue se vermoë om funksioneel onafhanklik te wees as gevolg van fisiese- en kommunikasie gestremdhede. Die verlies van spraak as gevolg van disartrie, 'n motoriese spraakafwyking, word beskou as een van die mees diepgaande veranderinge wat hierdie individue sal ervaar. Die afname in spraakverstaanbaarheid beïnvloed ook kommunikasie effektiwiteit, en daar is bevind dat in 80% van gevalle aanvullende en alternatiewe kommunikasie (AAK) strategieë ingespan moet word om aan die kommunikasie behoeftes van individue met MNS te voldoen.

Die tweeledige natuur van kroniese siektes impliseer dat veelvoudige aspekte van die huwelik affekteer sal word. Die rolle en verantwoordelikhede van albei eggenote sal deurentyd verander met die verloop van die siekte. Die emosionele trauma wat deur die egpaar ervaar word as gevolg van die veranderinge in hulle verhouding, ontlok emosies soos frustrasie, skuldgevoelens en gebelgdheid. Daar is gevind dat kommunikasie een van die mees konstruktiewe wyses is om hierdie emosies aan te spreek. Die vermoë van egpare om deur kommunikasie hulle diepste gevoelens, gedagtes en intimiteit aan mekaar te ontbloot, is essensieël vir suksesvolle huwelikskommunikasie.

Die doel van die studie was om die verband tussen die spraak agteruitgang van persone met MNS en die egpare se persepsie van huwelikskommunikasie te bepaal. Veertien egpare, verdeel in twee groepe (die persone met MNS en eggenote) het deelgeneem in hierdie nie-eksperimentele korrelasie studie. Data is ingesamel oor 'n periode van twaalf maande tydens drie besoeke met ses-maandelike tussenposes. Tydens hierdie besoeke het die deelnemers verskeie objektiewe en subjektiewe meetinstrumente voltooi, waarvan twintig persent deur 'n onafhanklike evalueerder geëvalueer is.

Resultate het die onafwendbare afname in spraakverstaanbaarheid van die persone met MNS bevestig. Die persone met MNS het aangedui dat hulle persepsie van huwelikskommunikasie nie beduidend verander het nie. Die eggenote het wel aangedui

dat daar 'n statisties betekenisvolle verskil was in hulle persepsie van huwelikskommunikasie tussen die eerste en laaste besoeke. Die interessantste bevinding was dat daar nie 'n statisties betekenisvolle verband tussen die spraak agteruitgang van persone met MNS en die persepsie van huwelikskommunikasie van die egpare was nie. Hierdie bevinding bevestig dat huwelikskommunikasie nie deur die afname in spraakverstaanbaarheid beïnvloed word nie.

**Sleutel woorde:** Aanvullende en Alternatiewe Kommunikasie (AAK), Disartrie, Eggenote, Huwelikskommunikasie, Kommunikasie, Kommunikasie effektiwiteit, Motor Neuron Siekte (MNS), Nabyheid, Progressiewe neurodegeneratiewe siekte, Spraakverstaanbaarheid.



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