

REFERENCES

- Abrahams, S., Goldstein, L. H., Al-Chalabi, A., Pickering, A., Morris, R. G., Passingham, R. E., et al. (1997). Relation between cognitive dysfunction and pseudobulbar palsy in amyotrophic lateral sclerosis. *Journal of Neurology, Neurosurgery, and Psychiatry*, *62*, 464-472.
- Abrahams, S., Leigh, P. N., & Goldstein, L. (2005). Cognitive change in ALS: A prospective study. *Neurology*, *64* (7), 1222-1226.
- Alant, E. (2005). AAC technology for development. In A. Alant, & L. L. Lloyd (Eds.), *Augmentative and alternative communication and severe disabilities: Beyond poverty* (pp. 192-220). London: Whurr Publishers.
- Aron, A., & Fraley, B. (1999). Relationship closeness as including other in the self: Cognitive underpinnings and measures. *Social Cognition*, *17* (2), 140-160.
- Aron, E., Aron, E.N., & Smollan, D. (1992). Inclusion of other in the self scale and the structure of interpersonal closeness. *Journal of Personality and Social Psychology*, *63* (4), 596-612.
- Aron, A., Aron, E. N., Tudor, M., & Nelson, G. (1991). Close relationships as including other in the self. *Journal of Personality and Social Psychology*, *60* (2), 241-253.
- Baikie, E. (2002). The impact of dementia on marital relationships. *Sexual and Relationships Therapy*, *17* (3), 289-299.

- Ball, L. J., Beukelman, D. R., & Pattee, G. L. (2004). Communication effectiveness of individuals with amyotrophic lateral sclerosis. *Journal of Communication Disorders, 37*, 197-215.
- Ball, L. J., Beukelman, D. R., Ullman, C., Maassen, K., & Pattee, G. L. (2005). Monitoring speaking rate by telephone for persons with amyotrophic lateral sclerosis. *Journal of Medical Speech-Language Pathology, 13* (4), 233-238.
- Ball, L. J., Willis, A., Beukelman, D. R., & Pattee, G. L. (2001). A protocol for the identification of early bulbar signs in amyotrophic lateral sclerosis. *Journal of the Neurological Sciences, 191* (1-2), 43-53.
- Beach, S. H., & Arias, I. (1989). Assessment of perceptual discrepancy: Utility of the primary communication inventory. *Family Process, 22*, 309-316.
- Beukelman, D. R., & Garrett, K. L. (1988). Augmentative and alternative communication for adults with acquired severe communication disorders. *Augmentative and Alternative Communication, 4* (2), 104-121.
- Beukelman, D. R., & Mirenda, P. (1998). *Augmentative and alternative communication: Management of severe communication disorders in children and adults* (2nd ed.). Baltimore: Paul H. Brookes.
- Beukelman, D. R., & Mirenda, P. (2005). *Augmentative and alternative communication: Supporting children and adults with complex communication needs* (3rd ed.). Baltimore: Brookes Publishing Company.
- Beukelman, D. R., & Yorkston, K. M. (1998). Augmentative and alternative communication application for persons with severe acquired communication

disorders: An introduction. *Augmentative and Alternative Communication*, 5 (1), 42-48.

Beukelman, D. R., Ball, L. J., & Fager, S. (2008). An AAC personnel framework: Adults with acquired complex communication needs. *Augmentative and Alternative Communication*, 24 (3), 255-267.

Blais, M. C., & Boisvert, J. (2007). Psychological adjustment and marital satisfaction following head injury. Which critical personal characteristics should both partners develop? *Brain Injury*, 21 (4), 357-372.

Brintnell, E. S., Madill, H. M., Montgomerie, T. C., & Stewin, L. L. (1992). Work and family after injury: Do female and male client perspectives differ? *Career Development Quarterly*, 41, 145-160.

Brooks, B. R.; Miller, R. G.; Swash, M.; Munsat, T. L. (2003). *El Escorial Revisited: Revised Criteria for the Diagnosis of Amyotrophic Lateral Sclerosis*. Retrieved February 28, 2009, from World Federation of Neurology Research Group on Motor Neuron Diseases: <http://www.wfnals.org/guidelines/1998elescorial/elescorial1998.htm>

Burleson, B. R., & Denton, W. H. (1997). The relationship between communication skill and marital satisfaction: Some moderating effects. *Journal of Marriage and the Family*, 59, 884-902.

Charmaz, K. (1995). The body, identity, and self: Adapting to impairment. *Sociological Quarterly*, 36 (4), 657-681.

Cheung, J., & Hocking, P. (2004). Caring as worrying: The experience of spousal carers. *Journal of Advanced Nursing*, 47 (5), 475-482.

- Chiò, A., Gauthier, A., Montuschi, A., Calvo, A., Di Vito, N., Ghiglione, P., et.al. (2004). A cross sectional study of determinants of quality of life in ALS. *Journal of Neurology, Neurosurgery and Psychiatry*, 75, 1597-1601.
- Cohen, J. (1992). A power primer. *Psychological Bulletin*, 112, 155-159.
- Cutrona, C. (1996). *Social support in couples*. Thousand Oaks: Sage Publications.
- Cutrona, C. E. (2004). A psychological perspective: Marriage and the social provisions of relationships. *Journal of Marriage and Family*, 66, 992-999.
- Dagenais, P. A., Brown, G. R., & Moore, R. E. (2006). Speech rate effects upon intelligibility and acceptability of dysarthric speech. *Clinical Linguistics and Phonetics*, 20 (2/3), 141-148.
- Darley, F. L., Aronson, A. E., & Brown, J. R. (1975). *Motor speech disorders*. Philadelphia: W. B. Saunders Company.
- Darley, F., Aronson, A., & Brown, J. (1969). Clusters of deviant speech dimensions in the dysarthrias. *Journal of Speech and Hearing Disorders*, 12, 462-496.
- DePaul, R., & Kent, R. D. (2000). A longitudinal case study of ALS: Effects of listener familiarity and proficiency on intelligibility judgements. *American Journal of Speech-Language Pathology*, 9 (3), 230-240.
- Diamanti, T. (2000). Get to know me. In M. B. Krezman, & C. J. Williams (Eds.), *Beneath the surface: Creative expressions of augmented communicators* (pp. 98-99). Toronto: ISAAC Press.

- Dickson, S., Barbour, R. S., Brady, M., Clark, A. M., & Paton, G. (2008). Patients' experiences of disruptions associated with post-stroke dysarthria. *International Journal of Language and Communication Disorders, 43* (2), 135-153.
- Doyle, M., & Phillips, B. (2001). Trends in augmentative and alternative communication use by individuals with amyotrophic lateral sclerosis. *Augmentative and Alternative Communication, 17* (3), 167-178.
- Doyle, M., Kennedy, M. R., Jausalaitis, G., & Phillips, B. (2000). AAC and Traumatic Brain Injury. In D. R. Beukelman, K. M. Yorkston, & J. Reichle (Eds.), *Augmentative and alternative communication for adults with acquired neurological disorders* (pp. 271–304). Maryland: Brookes Publishing Company.
- Duffy, J. (1995). *Motor speech disorders: Substrates, differential diagnosis and management*. Baltimore: Mosby.
- Fong, G. Y., Cheng, T. S., Lam, K., Cheng, W. K., Mok, K. Y., Cheung, C. M., et al. (2005). An epidemiological study of motor neuron disease in Hong Kong. *Amyotrophic Lateral Sclerosis, 6* (3), 164-168.
- Fox, L. E., & Sohlberg, M. M. (2000). Meaningful communication roles. In D. R. Beukelman, K. M. Yorkston, & J. Reichle (Eds.), *Augmentative and alternative communication for adults with acquired neurological disorders* (pp. 3-24). Baltimore: Paul H. Brookes.
- Freed, D. (2000). *Motor speech disorders: Diagnosis and treatment*. San Diego: Singular Publishing.

- Fried, T. R., Bradley, E. H., O'Leary, M. A., & Byers, A. L. (2005). Unmet desire for caregiver-patient communication and increased caregiver burden. *Journal of the American Geriatrics Society, 53* (1), 59-63.
- Fried-Oken, M., Fox, L., Rau, M. T., Tullman, J., Baker, G., Hindal, M., et al. (2006). Purposes of ACC device use for persons with ALS as reported by caregivers. *Augmentative and Alternative Communication, 22* (3), 209-221.
- Ganzini, L., Johnston, W. S., & Hoffman, W. F. (1999). Correlates of suffering in amyotrophic lateral sclerosis. *Neurology, 52*, 1434-1440.
- Gelinas, D. F. (1999). Conceptual approach to diagnostic delay in ALS: A United States perspective. *Neurology, 53* (Suppl 5), S17-S19.
- Goldstein, L. H., Adamson, M., Jeffrey, L., Down, K., Barby, T., Wilson, C., et al. (1998). The psychological impact of MND on patients and carers. *Journal of the Neurological Sciences, 160* (Suppl.1), S114-S121.
- Goldstein, L. H., Atkins, L., & Leigh, P. N. (2002). Correlates of quality of life in people with motor neuron disease (MND). *ALS and other motor neuron diseases, 3*, 123-129.
- Gordon, K. C., Baucom, D. H., Epstein, N., Burnett, C. K., & Rankin, L. A. (1999). The interaction between marital standards and communication patterns: How does it contribute to marital adjustment? *Journal of Marital and Family Therapy, 25* (2), 211-223.
- Gottman, J. M., & Porterfield, A. L. (1981). Communicative competence in the nonverbal behavior of married couples. *Journal of Marriage and Family, 43* (4), 817 – 824.

- Hillel, A.D., Miller, R. M., Yorkston, K., McDonald, E., Norris, F.H., & Konikow, N. (1989). Amyotrophic lateral sclerosis severity scale. *Neuroepidemiology*, 8 (3), 142-150.
- Hillemacher, T., Gräbel, E., Tigges, S., Bleich, S., Neundörfer, B., Kornhuber, J., et al. (2004). Depression and bulbar involvement in amyotrophic lateral sclerosis. *ALS and other motor neuron disorders*, 5, 245-249.
- Hobart, C. W., & Klausner, W. J. (1959). Some social interactional correlates of marital role disagreement, and marital adjustment. *Marriage and Family Living*, 21 (3), 256-263.
- House, A., House, B., & Campbell, M. (1981). Measures of interobserver agreement: Calculation formulas and distribution effects. *Journal of Behavioral Assessment*, 3 (1), 37-57.
- Hunt, C. K. (2003). Concepts in caregiver research. *Journal of Nursing Scholarship*, 35 (1), 27-32.
- Hustad, K. (1999). Optimizing communicative effectiveness. In K. M. Yorkston, D. R. Beukelman, E. A. Strand, & K. R. Bell (Eds.), *Management of motor speech disorders in children and adults* (2nd ed., pp. 483-542). Austin: ProEd.
- Hustad, K. C. (2008). The relationship between listener comprehension and intelligibility scores for speakers with dysarthria. *Journal of Speech, Language and Hearing Research*, 51, 562-573.
- Hustad, K. C., & Cahill, M. A. (2003). Unfamiliar listener's evaluation of speech supplementation strategies for improving the effectiveness of severely dysarthric speech. *Augmentative and Alternative Communication*, 4, 213-220.

- Johnson, P. L. (2000). If I do say so myself. In M. Fried-Oken, & J. H. Bersani (Eds.), *Speaking up and spelling it out* (pp. 47-56). Maryland: Paul H. Brookes.
- Kahn, M. (1970). Non-verbal communication and marital satisfaction. *Family Process*, 9, 449-456.
- Katz, J. (2002). Ill-health. In N. Thompson (Ed.), *Loss and grief: A guide for human service practitioners* (pp. 149-161). Hampshire: Palgrave.
- Kinsella, G., Cooper, B., Picton, C., & Murtagh, D. (1998). A review of the measurement of caregiver and family burden in palliative care. *Journal of Palliative Care*, 14 (2), 37-45.
- Klasner, E. R., & Yorkston, K. M. (2005). Speech intelligibility in ALS and HD dysarthria: The everyday listener's perspective. *Journal of Medical Speech-Language Pathology*, 12 (2), 127-140.
- Kotchoubey, B., Lang, S., Winter, S., & Birbaumer, N. (2003). Cognitive processing in completely paralyzed patients with amyotrophic lateral sclerosis. *European Journal of Neurology*, 10, 551-558.
- Kowal, J., Johnson, S. M., & Lee, A. (2003). Chronic illness in couples: A case for emotionally focused therapy. *Journal of Marital and Family Therapy*, 29 (3), 299-310.
- Lasker, J. P., & Bedrosian, J. L. (2000). Acceptance of AAC by adults with acquired disorders. In D. R. Beukelman, K. M. Yorkston, & J. Reichle (Eds.), *Augmentative and alternative communication for adults with acquired neurologic disorders* (pp. 107-136). Baltimore: Paul H. Brookes.

- Leigh, P. N., Abrahams, S., Al-Chalabi, A., Ampong, M. A., Goldstein, L. H., Johnson, J., et al. (2003). The management of motor neurone disease. *Journal of Neurology, Neurosurgery and Psychiatry*, 74 (Suppl IV), iv32-iv47.
- Lev-Wiesel, R. (1988). Spouses' perceptions of each other's coping ability with possible stressful life events and marital quality. *Contemporary Family Therapy*, 20 (2), 211-220.
- Lewis, J. M. (1998). For better or worse: Interpersonal relationships and individual outcome. *American Journal of Psychiatry*, 155 (5), 582-589.
- Light, J. (1988). Interaction involving individuals using augmentative and alternative communication systems: State of art and future directions. *Augmentative and alternative communication*, 4, 66-82.
- Light, J. (1989). Toward a definition of communicative competence for individuals using augmentative and alternative communication systems. *Augmentative and Alternative Communication*, 5 (2), 137 – 144.
- Light, J. (1997). "Communication is the essence of human life": Reflections on communicative competence. *Augmentative and Alternative Communication*, 13, 61-70.
- Light, J. C., Arnold, K. B., & Clark, E. A. (2003). Finding a place in the 'social circle of life'. In J. C. Light, D. R. Beukelman, & J. Reichle (Eds.), *Communicative competence for individuals who use AAC: From research to effective practice*. Baltimore: Paul H. Brookes Publishing Co.

- Linebaugh, C. W., Kryzer, K. M., Oden, S., & Myers, P. S. (2008). Reapportionment of communicative burden in aphasia: A study of narrative interaction. *Aphasiology*, 20 (1), 84-96.
- Lloyd, L. L., Fuller, D. R., & Arvidson, H. H. (1997). Introduction and overview. In L. L. Lloyd, D. R. Fuller, & H. H. Arvidson (Eds.), *Augmentative and alternative communication: A handbook of principles and practices* (pp. 1-17). Needham Heights: Allyn & Bacon, Inc.
- Locke, J. L. (1998). Where did all the gossip go? Casual conversation in the information age. *ASHA*, 40,26-31.
- Logroscino, G., Traynor, B. J., Hardiman, O., Chio, A., Couratier, P., Mitchell, J. D., et al. (2008). Descriptive epidemiology of amyotrophic lateral sclerosis: New evidence and unsolved issues. *Journal of Neurology, Neurosurgery and Psychiatry*, 79, 6-11.
- Lubinsky, R. (1997). Perspectives on aging and communication. In R. Lubinsky, & D. J. Higginbotham (Eds.), *Communication technologies for the elderly: Vision, hearing and speech* (pp. 1-22). San Diego: Singular Publishing.
- Luterman, D. (1996). *Counseling persons with communication disorders and their family* (3rd ed.). Austin: Pro-Ed.
- Lyon, J. G. (1998). *Coping with aphasia*. San Diego: Singular Publishing Group Ltd.
- Madill, H. M., Brintnell, E. S., Macnab, D., Stewin, L. L., & Fitzsimmons, G. W. (1989). The delicate balance: Working and family role. *International Journal for the Advancement of Counseling*, 11, 219-230.

- Mathy, P. (2005). *Explorations in using a notebook computer as a clinical speech sampling and analysis tool*. Retrieved September 15, 2005, from www.madonna.org/institute/Software/pmathyreport.htm
- Mathy, P., Yorkston, K. M., & Gutmann, M. L. (2000). AAC for individuals with amyotrophic lateral sclerosis. In D. R. Beukelman, K. M. Yorkston, & J. Reichle (Eds.), *Augmentative and alternative communication for adults with acquired neurological disorders* (pp. 183-232). Baltimore: Paul H. Brookes.
- Maxwell, D.L. & Satake, E. (2006). *Research and statistical methods in communication sciences and disorders*. New York: Thomson Delmar Learning.
- McConkey, R. (2005). Service delivery in low-income countries. In E. Alant, & L. L. Lloyd (Eds.), *Augmentative and alternative communication and severe disabilities: Beyond poverty* (pp. 131-154). London: Whurr Publishers.
- McLeod, J. E., & Clarke, D. M. (2007). A review of psychosocial aspects of motor neurone disease. *Journal of the Neurological Sciences*, 258, 4-10.
- McMillan, J. H., & Schumacher, S. (2001). *Research in education: A conceptual introduction* (5th ed.). New York: Addison Wesley Longman.
- Michallet, B., Tètreault, S., & Le Dorze, G. (2003). The consequences of severe aphasia on the spouses of aphasic people: A description of the adaptation process. *Aphasiology*, 17 (9), 835-859.
- Miglioretti, M., Mazzini, L., Oggioni, G. D., Testa, L., & Monaco, F. (2008). Illness perceptions, mood and health-related quality of life in patients with amyotrophic lateral sclerosis. *Journal of Psychosomatic Research*, 65, 603-609.

- Mitsumoto, H. (1997). Diagnosis and progression of ALS. *Neurology*, 48 (Suppl 4), S2-S8.
- Murphy, J. (2004). "I prefer contact this close": Perceptions of AAC by people with motor neuron disease and their communication partners. *Augmentative and Alternative Communication*, 20 (4), 259-271.
- Murray, J. M., Manela, M. V., Shuttleworth, A., & Livingston, G. A. (1997). Caring for an older spouse with psychiatric illness. *Aging and Mental Health*, 1 (3), 256-260.
- Nalini, A., Thennarasu, K., Gourie-Devi, M., Shenoy, S., & Kulshreshtha, D. (2008). Clinical characteristics and survival pattern of 1153 patients with amyotrophic lateral sclerosis: Experience over 30 years from India. *Journal of the Neurological Sciences*, 272, 60-70.
- National Joint Committee for the Communicative Needs of Persons with Severe Disabilities. (1992). Guidelines for meeting the communicative needs of persons with severe disabilities. *ASHA*, 34 (Suppl.7), 1-8.
- Navran, L. (1967). Communication and adjustment in marriage. *Family Process*, 6, 173-184.
- Neary, D., Snowden, J. S., & Mann, D. M. (2000). Cognitive change in motor neurone disease/amyotrophic lateral sclerosis (MND/ALS). *Journal of the Neurological Sciences*, 180 (1-2), 15-20.
- Nishio, M., & Niimi, S. (2000). Changes over time in dysarthric patients with amyotrophic lateral sclerosis (ALS): A study of changes in speaking rate and

maximum repetition rate (MRR). *Clinical Linguistics and Phonetics*, 14 (7), 485-497.

O'Connor, E. J., McCabe, M. P., & Firth, L. (2008). The impact of neurological illness on marital relationships. *Journal of Sex and Marital Therapy*, 34, 115-132.

Prentice, J. (2000). With communication anything is possible. In M. Fried-Oken, & J. H. Bersani (Eds.), *Speaking up and spelling it out* (pp. 208-214). Baltimore: Paul H. Brookes.

Rhoades, G. K., & Stocker, C. M. (2006). Can spouses provide knowledge of each other's communication patterns? A study of self-reports, spouses' reports, and observational coding. *Family Process*, 45, 499-511.

Riviere, M., Meininger, V., Zeisser, P., & Munsat, T. (1998). An analysis of extended survival in patients with amyotrophic lateral sclerosis treated with riluzole. *Archives of Neurology*, 55 (4), 526-528.

Rolland, J. S. (1994). In sickness and in health: The impact of illness on couples' relationships. *Journal of Marital and Family Therapy*, 20 (4), 327-343.

Rolland, J. S. (1999). Chronic illness and the family life cycle. In B. Carter, & M. McGoldrick (Eds.), *The expanded family life cycle: Individual, family, and social perspectives* (3rd ed., pp. 492-551). Needham Heights: Allyn & Bacon.

Rolland, J. S. (2005). Cancer and the family: an integrative model. *Cancer*, 104 (Suppl 11), 2584-2595.

- Ross, E., & Deverell, A. (2004). *Psychosocial approaches to health, illness and disability. A reader for health care professionals*. Pretoria: Van Schaik Publishers.
- Salkind, N. J. (2008). *Exploring research*. New Jersey: Prentice Hall.
- Sapey, B. (2002). Disability. In N. Thompson (Ed.), *Loss and grief: A guide for human service practitioners* (pp. 139-148). Hampshire: Palgrave.
- Savundranayagam, M. Y., Hummert, M. L., & Montgomery, R. J. (2005). Investigating the effects of communication problems on caregiver burden. *The Journals of Gerontology, 60B* (1), S48-S55.
- Segrin, C., & Flora, J. (2001). Perceptions of relational histories, marital quality, and loneliness when communication is limited: An examination of married prison inmates. *The Journal of Family Communication, 1* (3), 151-173.
- Strong, M. J., Grace, G. M., Orange, J. B., Leeper, H. A., Menon, R. S., & Aere, C. (1999). A prospective study of cognitive impairment in ALS. *Neurology, 53* (8), 1665-1670.
- Stuart, S., Lasker, J. P., & Beukelman, D. R. (2000). AAC message management. In D. R. Beukelman, K. M. Yorkston, & J. Reichle (Eds.), *Augmentative and alternative communication for adults with acquired neurologic disorders* (pp. 25-54). Baltimore: Paul H. Brookes.
- Tönsing, K. M., Alant, E., & Lloyd, L. L. (2005). Augmentative and alternative communication . In E. Alant, & L. L. Lloyd (Eds.), *Augmentative and alternative communication and severe disabilities: Beyond poverty* (pp. 30-67). London: Whurr Publishers.

- Trail, M., Nelson, N. D., Van, J. N., Appel, S. H., & Lai, E. C. (2004). Major stressors facing patients with amyotrophic lateral sclerosis (ALS): a survey to identify their concerns and to compare with those of their caregivers. *ALS and other motor neuron disorders*, 5, 40-45.
- Wells, R., Dywan, J., & Dumas, J. (2005). Life satisfaction and distress in family caregivers as related to specific behavioural changes after traumatic brain injury. *Brain Injury*, 19 (13), 1105-1115.
- Williams, B. (2000). More than an exception to the rule. In M. Fried-Oken, & H. Bersani (Eds.), *Speaking up and spelling out: Personal essays on augmentative and alternative communication* (pp. 245–254). Baltimore: Paul H. Brookes.
- Worms, P. M. (2001). The epidemiology of motor neurone disease: a review of recent studies. *Journal of the Neurological Sciences*, 191, 3-9.
- Yorkston, K. M., Beukelman, D. R., Strand, E. A., & Bell, K. R. (1999). *Management in motor speech disorders in children and adults* (2nd ed.). Austin: Pro-Ed.
- Yorkston, K. M., Beukelman, D. R., & Tice, R. (1996). *Sentence Intelligibility Test for Windows*. Lincoln: Institute for Rehabilitation Science and Engineering, Madonna Rehabilitation Hospital.
- Yorkston, K. M., Miller, R. M., & Strand, E. A. (1995). *Management of speech and swallowing disorders in degenerative disease*. Tuscon: Communication Skill Builders.
- Yorkston, K. M., Strand, E., Miller, R. M., Hillel, A. D., & Smith, K. (1993). Speech deterioration in amyotrophic lateral sclerosis: Implications for the timing of intervention. *Journal of Medical Speech-Language Pathology*, 1 (1), 35-46.

Young, J. M., & McNicoll, P. (1998). Against all odds: positive life experiences of people with advanced amyotrophic lateral sclerosis. *Health and Social Work, 23*, 35-43.

Yunusova, Y., Weismer, G., Kent, R. D., & Rusche, N. M. (2005). Breath-group intelligibility in dysarthria: Characteristics and underlying correlates. *Journal of Speech, Language and Hearing Research, 48* (6), 1294-1310.

APPENDICES

APPENDIX A

CLASSIFICATION OF MOTOR NEURON DISEASE

Riviere, M., Meininger, V., Zeisser, P., & Munsat, T. (1998). An analysis of extended survival in patients with amyotrophic lateral sclerosis treated with riluzole. *Archives of Neurology*, 55, 526-528.

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 (ALSS): SPEECH SCALE

Hillel, A.D., Miller, R. M., Yorkston, K., McDonald, E., Norris, F.H., & Konikow, N. (1989). Amyotrophic lateral sclerosis severity scale. *Neuroepidemiology*, 8(3), 142-150.

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)

Yorkston, K. M., Beukelman, D. R., & Tice, R. (1996). *Sentence Intelligibility Test for Windows*. Lincoln: Institute for Rehabilitation Science and Engineering, Madonna Rehabilitation Hospital.

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)

Yorkston, K. M., Beukelman, D. R., Strand, E. A., & Bell, K. R. (1999). *Management in motor speech disorders in children and adults (2nd Ed.)*. Austin: Pro-Ed.

<p>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 <u>very effective</u>, circle the 7. If the communication <u>doesn't occur at all</u>, circle the 1. Circle any number on the scale that best describes communication in that situation.</p>								
	Not at all effective						Very effective	
Having a conversation with familiar persons in a quiet environment	1	2	3	4	5	6	7	V3 <input type="checkbox"/>
Having a conversation with strangers in a quiet environment	1	2	3	4	5	6	7	V4 <input type="checkbox"/>
Having a conversation with a familiar person over the phone	1	2	3	4	5	6	7	V5 <input type="checkbox"/>
Having a conversation with young children	1	2	3	4	5	6	7	V6 <input type="checkbox"/>
Having a conversation with a stranger over the phone	1	2	3	4	5	6	7	V7 <input type="checkbox"/>
Having a conversation while traveling in a car	1	2	3	4	5	6	7	V8 <input type="checkbox"/>
Having a conversation with someone at a distance	1	2	3	4	5	6	7	V9 <input type="checkbox"/>
Having a conversation with someone in a noisy environment	1	2	3	4	5	6	7	V10 <input type="checkbox"/>
Speaking or having a conversation before a group	1	2	3	4	5	6	7	V11 <input type="checkbox"/>
Having a long conversation with someone (over an hour)	1	2	3	4	5	6	7	V12 <input type="checkbox"/>

APPENDIX E

PRIMARY COMMUNICATION INVENTORY (PCI)

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.

	Never	Seldom	Occasionally	Frequently	Very frequently
How often do you and your spouse talk over pleasant things that happen during the day?	1	2	3	4	5
How often do you and your spouse talk over unpleasant things that happen during the day?	1	2	3	4	5
Do you and your spouse talk over things you disagree about or have difficulties over?	1	2	3	4	5
Do you and your spouse talk about things in which you are both interested?	1	2	3	4	5
Does your spouse adjust what s/he says and how s/he says it to the way you seem to feel at the moment?	1	2	3	4	5
When you start to ask a question, does your spouse know what it is before you ask it?	1	2	3	4	5
Do you know the feelings of your spouse from his/her facial and bodily gestures?	1	2	3	4	5
Do you and your spouse avoid certain subjects in conversation?	1	2	3	4	5
Does your spouse explain or express himself/herself to you through a glance or a gesture?	1	2	3	4	5
Do you and your spouse discuss things together before making an important decision?	1	2	3	4	5
Can your spouse tell what kind of day you have had without asking?	1	2	3	4	5
Your spouse wants to visit some close friends or relatives. You don't particularly enjoy their company. Would you tell him/her this?	1	2	3	4	5
Does your spouse discuss matters of sex with you?	1	2	3	4	5



	Never	Seldom	Occasionally	Frequently	Very frequently
Do you and your spouse use words which have special meaning not understood by outsiders?	1	2	3	4	5
How often does your spouse sulk or pout?	1	2	3	4	5
Can you and your spouse discuss your most sacred beliefs without feelings of restraint or embarrassment?	1	2	3	4	5
Do you and your spouse talk about things in which you are both interested?	1	2	3	4	5
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?	1	2	3	4	5
How often can you tell as much from the tone of voice of your spouse as from what s/he actually says?	1	2	3	4	5
How often do you and your spouse talk with each other about personal problems?	1	2	3	4	5
Do you feel that in most matters your spouse knows what you are trying to say?	1	2	3	4	5
Would you rather talk about intimate matters with your spouse than with some other person?	1	2	3	4	5
Do you understand the meaning of your spouse's facial expression?	1	2	3	4	5
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?	1	2	3	4	5
During the marriage, have you and your spouse, in general, talked most things over?	1	2	3	4	5

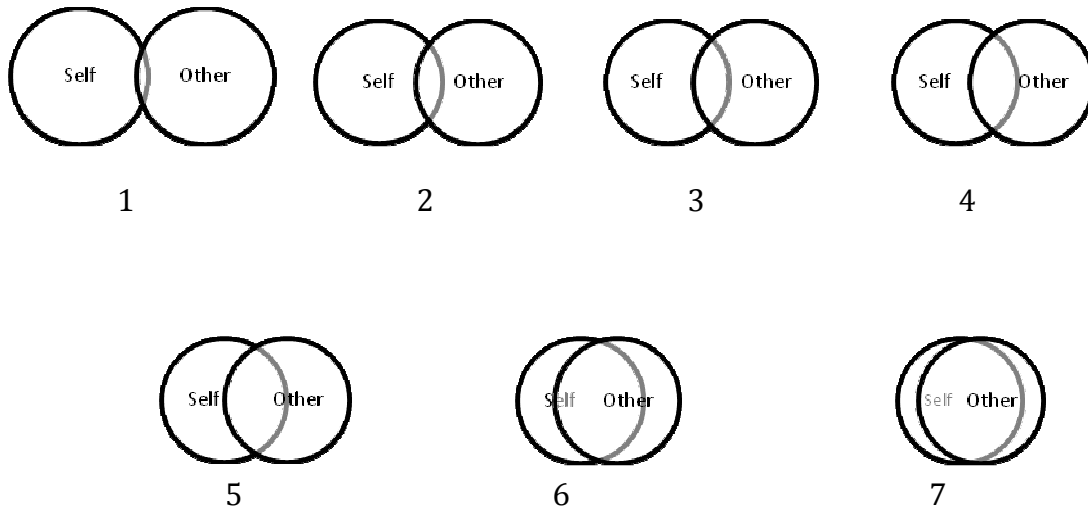
Navran, L. (1967). Communication and adjustment in marriage. *Family Process*, 6, 173-184.

APPENDIX F

INCLUSION OF OTHERS IN THE SELF (IOS) SCALE

Aron, E., Aron, E.N., & Smollan, D. (1992). Inclusion of other in the self scale and the structure of interpersonal closeness. *Journal of Personality and Social Psychology*, 63(4), 596-612.

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

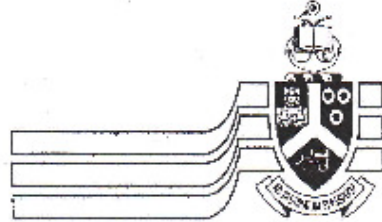




APPENDIX G

UNIVERSITY ETHICS APPROVAL

Members:
Research Proposal and Ethics Committee
Dr P. Chiroro, Dr M-H Coetzee, Prof C Delpoit,
Dr JEH Grubler, Prof KL Harris, Ms H Klupper,
Prof E Krüger, Prof B Louw (Chair), Prof A Mamba,
Prof D Prinsloo, Prof G Prinsloo, Dr E Taljard,
Prof A Wessels, M-HG Wolmarans



University of Pretoria

Research Proposal and Ethics Committee
Faculty of Humanities

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: CAAC
Reference number: 85367169

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.

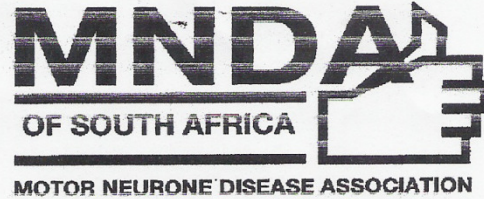
Sincerely

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



APPENDIX H

WRITTEN PERMISSION: MND ASSOCIATION OF SOUTH AFRICA



P.O. BOX 789,
HOWARD PLACE
7450

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

Cape Town
Tel: +27(21) 631 - 6130
Fax: +27(21) 631 - 6131
Email: mndaalsa@global.co.za

Member of the International Alliance
ALS/MND Associations
Website: www.alsmndalliance.org.

Johannesburg
Tel: +27(11) 991-4788
Cell: 082 - 878 - 3716
Email: keth@futurejhb.co.za

Affiliated to the Hospice Association of Southern Africa Fundraising Number : NPO 003-462
PATRON: AVIVA PELHAM (M.MUS.) CHAIRMAN: DR. PETER VURGARELLIS

APPENDIX I

PARTICIPANT INFORMED CONSENT FORM

CENTRE FOR AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

Faculty of Education / Fakulteit Opvoedkunde
UNIVERSITY OF PRETORIA
Lynnwood Road, Pretoria, 0002



Enquiries: Karin Joubert
Tel: (011) 411-3526 or (011) 793-6604
Fax: (011) 792-4054
E-mail: karinjoubert@absamail.co.za

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

CENTRE FOR AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

Faculty of Education / Fakulteit Opvoedkunde
UNIVERSITY OF PRETORIA
Lynnwood Road, Pretoria, 0002



Enquiries: Karin Joubert
Tel: (011) 411-3526 or (011) 793-6604
Fax: (011) 792-4054
E-mail: karinjoubert@absamail.co.za

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

Ons verw: Mr P Woost / 83337100
Tel: 012 420 2736
Faks: 012 420 2656
E-pos: petru.woost@u-p.ac.za



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Fakulteit Geesteswetenskappe

08 Junie 2009

Mev K Joubert
Poubois 400
BROMHOFF
2154

Geachte mev Joubert

TITEL REGISTRASIE: STUDIERIGTING – PHD AANVULLENDE EN ALTERNATIEWE KOMMUNIKASIE

Dit is vir my in jou naam om u mee te deel dat die volgende goedkeuring is:

ONDERWERP: Speech intelligibility and marital communication in Motor Neuron Disease

PROMOTOR: Prof J Bornman

MEDEPROMOTOR: Prof E Alant (UP Extra-ordinary Professor)

NEEM ASSEBLIEF KENNIS VAN DIE INLIGTING HIERONDER GENOEM EN DIE AANGEHEGTE VEREISTES.

1. **REGISTRASIE:**
 - (a) U moet vir minstens een akademiese jaar regstreeks vir die graad voordat u toegeskat kan word om u proefskrif in te dien.
 - (b) U registrasie moet jaarliks voor Aan van elke akademiese jaar maan word luidel u aan al die vereistes van die graad voldoen het. Geen herregistrasie sal na 31 Maan reinnar word nie. U sal slegs peroglij woor op die leiding van u leorindien u jaarlks bewys van registrasie aan hom voorle.
2. **KENNISGEWING VOOR INDIENING:**
Dit is in veridato dat u my ten minste drie maande voor die tyd in kennis stel van u waarneming in u proefskrif in te dien.
3. **GOEDKEURING VIR INDIENING:**
Vir eksamenoeleindes moet u voldoende eksimplare vir elke eksaminator indien, tesame met in skriftelike veridanning van u leor dat u wly die indiening van die proefskrif goedkeur sowel as in verklaring deur u, wat voor in Kommissore van Ede goukan word, wat by Studenteadministrasie ingehandig word.
4. **DATUM VAN EKSAMEN:**
U word vriendelik versoek om my in kennis te stel van die datum van u doktrale eksamen indien dit oors na indiening van die proefskrif aigonom word.

Die rewe

012 DEKAAN: FAKULTEIT GEESTESWETENSKAPPE