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REFERENCES

- Abrahams, S, Goldstein, L.H., Al-Chalabi, A., Pickering, A. Morris, R.G., Passingham, R.E., ... Leigh, P.N. (1997). Relation between cognitive dysfunction and pseudobulbar palsy in amyotrophic lateral sclerosis (ALS). *Journal of Neurology Neurosurgery and Psychiatry*, 62(5), 464-72.
- Abrahams, S. Leigh, P.N. & Goldstein, L.H. (2005). Cognitive change in ALS: a prospective study. *Neurology*, 64(7), 1222-26.
- Abrahams, S. (2013). ALS, cognition and the clinic. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, 14(1), 3-5. DOI: 10.3109/21678421.2013.760149.
- Abrahams, S., Newton, J., Niven, E., Foley, J., & Bak, T. H. (2014). Screening for cognition and behaviour changes in ALS. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, 15(1-2), 9-14. DOI: 10.3109/21678421.2013.805784.
- Adler, P. A., & Adler, P. (2002). *The reluctant respondent*. In Handbook of interview research: Context and method, Ed. by: Gubrium, J. F., & Holstein, J. A., Thousand Oaks, CA: Sage.
- Agosta, F., Al-Chalabi, A., Filippi, M., Hardiman, O., Kaji, R., Meininger, V., ... Ludolph, A. (2014). The El Escorial criteria: Strengths and weaknesses. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, 16(1-2), 1-7. DOI: 10.3109/21678421.2014.964258.

Alankaya, N., & Karadakovan, A. (2015). Home Care Needs of Patients with Amyotrophic Lateral Sclerosis and Care Burden of Caregivers. *Health Science Journal*, 9(4), 1-6.

Alberta College of Speech-Language Pathologists and Audiologists. (2015).

Standards of Practice. Retrieved from:

<http://acslpa.ab.ca/download/college/Swallowing%20%28Dysphagia%29%20and%20Feeding.pdf>.

Almerico, G.M. (2014). Food and identity: Food studies, cultural, and personal identity. *Journal of International Business and Cultural Studies*, 8, 1-7.

Almirall, J., Cabré, M., & Clave, P. (2007). Aspiration Pneumonia. *Medicina Clinica (Barcelona)*, 129(11), 424-32.

American Speech-Language-Hearing Association. (2002). Roles of Speech-Language Pathologists in Swallowing and Feeding Disorders: Technical Report. Retrieved from www.asha.org/policy. DOI: 10.1044/policy.TR2001-00150.

Andersen, P.M, Abrahams, S., Borasio, G.D., de Carvalho, M., Chiò, A., Van Damme, P., ... Weber, M. (2012). EFNS guidelines on the Clinical Management of Amyotrophic Lateral Sclerosis (MALS) - revised report of an EFNS task force, *European Journal of Neurology*, 19(3), 360 – 375. DOI: 10.1111/j.1468-1331.2011.03501.x.

Andersen, P.M., Borasio, G.D., Dengler, R., Hardiman, O., Kollewe, K., Leigh, P.N. ... Tomik, B. (2007). Good practice in the management of amyotrophic lateral sclerosis: clinical guidelines. An evidence-based review with good practice points. EALSC Working Group. *Amyotrophic Lateral Sclerosis*, 8(4), 195-213. DOI: 10.1080/17482960701262376.

- Ando, H., Chakrabarti, B., Angus, R. M., Cousins, R., Thornton, E. W., & Young, C. A. (2014). Experience of long-term use of non-invasive ventilation in motor neuron disease: an interpretative phenomenological analysis. *BMJ Supportive & Palliative Care*, 4(1):50-56. DOI: 10.1136/bmjspcare-2013-000494
- Aoun, S. M., Connors, S. L., Priddis, L., Breen, L. J., & Colyer, S. (2012). Motor Neurone Disease family carers' experiences of caring, palliative care and bereavement: An exploratory qualitative study. *Palliative Medicine*, 26(6), 842-850. DOI:10.1177/0269216311416036
- Aoun, S. M., Bentley, B., Funk, L., Toye, C., Grande, G., & Stajduhar, K. J. (2013). A 10-year literature review of family caregiving for motor neurone disease: Moving from caregiver burden studies to palliative care interventions. *Palliative Medicine*, 27(5), 437-446. DOI:10.1177/0269216312455729
- Arai, K. (2005). Experiences of family caregivers for patients suffering from dysphagia - the attempt of subjective caregiving. *Gan to kagaku ryoho. Cancer & chemotherapy*, 32 (Suppl. 1), 50-2.
- Archer, M. (1998). *Realism in the social sciences*. In Archer, M, Bhaskar, R. Collier, R., Lawson, T., & Norrie, A. (Eds), Critical realism: Basic Readings. London; Routledge.
- Armon, C. (2012). What is ALS? In *Amyotrophic Lateral Sclerosis. A Patient Care Guide for Clinicians*. Bedlack, R.S., & Mitsumoto, H. Demos Medical Publishing. New York.
- Aronson, K. J. (1997). Quality of life among persons with multiple sclerosis and their caregivers. *Neurology*, 48, 74–80.

- Aziz, S. J., & Campbell-Taylor, I. (1999). Neglect and abuse associated with under nutrition in long-term care in North America: causes and solutions. *Journal of Elder Abuse and Neglect*, 10, 91–117.
- Back, A. L., & Arnold, R. M. (2006). Discussing Prognosis: How Much Do You Want to Know? Talking to Patients Who Are Prepared for Explicit Information. *Journal of Clinical Oncology*, 24(25), 4209-4213. DOI: 10.1200/JCO.2006.06.007
- Balandin, S., Hemsley, B., Hanley, L., & Sheppard, J.J. (2009). Understanding mealtime changes for adults with cerebral palsy and the implications for support services. *Journal of developmental and intellectual disability*, 34(3), 197-206. DOI: 10.1080/13668250903074489.
- Ball, L.J., Wright, A., & Lewis, S. (2012). Speech & Swallowing Interventions. In *Amyotrophic Lateral Sclerosis. A Patient Care Guide for Clinicians*. Bedlack, R.S., Mitsumoto, H. Dermos Medical Publishing. New York.
- Bakker, M., Creemers, H., Schipper, K., Beelen, A., Grupstra, H., Nollet, F. & Abma, T. (2015). Need and value of case management in multidisciplinary ALS care: A qualitative study on the perspectives of patients, spousal caregivers and professionals. *Amyotrophic Lateral Sclerosis & Frontotemporal Degeneration*, 16(1-7). 180-186. DOI:10.3109/21678421.2014.971811.
- Baxter, G. (2010). West is best for neurologist. *Irish Medical Times* Retrieved from www.imt.ie.
- Bede, P., Oliver, D., Stodart, J., van den Berg, L., Simmons, Z., Brannagáin, D. Ó., ... Hardiman, O. (2011). Palliative care in amyotrophic lateral sclerosis: a review of current international guidelines and

initiatives, *Journal of neurology, neurosurgery, and psychiatry*, 82(4), 413-8. DOI: 10.1136/jnnp.2010.232637.

Bedlack, R. (2017). ALS Reversals: What Are They and How Can We Make

Them Happen More Often? Retrieved from:

<https://alsadotorg.wordpress.com/2016/07/06/als-reversals-what-are-they-and-how-can-we-make-them-happen-more-often/>

Bedlack, R., Vaughan, T., Wicks, P., Heywood, J., Sinani, E., Selsov, R.,

Macklin, E.Sherman, A. (2016) How common are ALS plateaus and reversals? *Neurology*, 86(9), 808-12. DOI: 10.1212/WNL

Bensimon G, Lacomblez L, & Meininger V. (1994). A controlled trial of riluzole in amyotrophic lateral sclerosis. ALS/Riluzole Study Group. *The New England Journal of Medicine*, 330(9), 585-91. DOI: 10.1056/NEJM199403033300901.

Bensimon, G., Lacomblez, L., Delumeau, J.C., Bejuit, R., Truffinet, P., & Meininger,V. (2002). A study of riluzole in the treatment of advanced stage or elderly patients with amyotrophic lateral sclerosis. *Journal of Neurology*, 249, 609-615. DOI: 10.1007/s004150200071.

Benstead T., Jackson-Tarlton, C, & Leddin, J. (2016). Nutirition with gastrostomy feeding tubes for Amyotrophic Lateral Sclerosis in Canada. *The Canadian Journal of Neurological Sciences*, 43(6), 796-800. DOI: 10.1017/cjn.2016.28

Beresford, S. (1995) Motor Neurone Disease: (Amyotrophic Lateral Sclerosis). Therapy in practice series. Chapman & Hall.

- Berndt, T. J. (2002). Friendship quality and social development. *Current Directions in Psychological Science*, 11(1), 7-10. DOI:10.1111/1467-8721.00157
- Bhaskar, R. (1978). *A Realist Theory of Science*, Hassocks: Harvester Press.
- Bhaskar, R. (1998). Critical Realism. Essential Readings. In: Archer, M., Bhaskar, R., Collier, A., Lawson, T., & e Norrie, A. *Centre For Critical Realism*. London: Routledge.
- Bhimani, R. (2014). Understanding the Burden on Caregivers of People with Parkinson's: A Scoping Review of the Literature, Rehabilitation Research and Practice, 2014, DOI:10.1155/2014/718527
- Black, I. (2006). The presentation of interpretivist research. *Qualitative Market Research: An International Journal*, 9(4), 319–324. DOI:10.1108/13522750610689069.
- Blackhall, L.J. (2011). Amyotrophic Lateral Sclerosis and Palliative Care: Where we are and the road ahead. *Muscle and Nerve*, 45(3), 311-318. DOI: 10.1002/mus.22305
- Boerner, K., & Mock, S. K. (2012). Impact of patients suffering on caregivers' well-being: the case of amyotrophic lateral sclerosis patients and their caregivers. *Psychology, Health and Medicine*, 17(4), 457-466. DOI:10.1080/13548506.2011.613942
- Boillee, S., Velde, Ch. V., & Cleveland, D.V. (2006). ALS: A Disease of Motor Neurons Review and Their Nonneuronal Neighbors. *Neuron*, 52(1), 39–59. DOI: 10.1016/j.neuron.2006.09.018

- Borasio, G. D., Gelinas, D. F., & Yanagisawa, N. (1998). Mechanical ventilation in amyotrophic lateral sclerosis: a cross-cultural perspective. *Journal of Neurology*, 245, Suppl 2, 7-12.
- Bordeleau, L., Szalai, J., Ennis, M., Leszcz, M., Speca, M., Sela, R., ... Goodwin, P. J. (2003). Quality of life in a randomized trial of group psychosocial support in metastatic breast cancer: Overall effects of the intervention and exploration of missing data. *Journal of Clinical Oncology*, 21(10), 1944–1951. DOI: 10.1200/JCO.2003.04.080.
- Bouteloup, C., Desport, J. C., Clavelou, P., Guy, N., Derumeaux-Burel, H., Ferrier, A., & Couratier, P. (2009). Hypermetabolism in ALS patients: an early and persistent phenomenon. *Journal of Neurology*, 256(8), 1236-1242. DOI: 10.1007/s00415-009-5100-z.
- Bravata, D. M., Daggett, V. S., Woodward-Hagg, H., Damush, T., Plue, L., Russell, S., ... Chumbler, N. R. (2009). Comparison of two approaches to screen for dysphagia among acute ischemic stroke patients: Nursing admission screening tool versus National Institutes of Health Stroke Scale. *The Journal of Rehabilitation Research and Development*, 46(9), 1127-1134.
- Bricker-Katz, G., Lincoln, M., & Cumming, S. (2013). Stuttering and work life: an interpretative phenomenological analysis. *Journal of Fluency Disorders*, 38(4), 342-55. DOI: 10.1016/j.jfludis.2013.08.001
- Brinkmann, S., & Kvale, S. (2014). *Interviews. Learning the Craft of Qualitative Research Interviewing*. SAGE Publications, Inc; 3rd ed.

- Bromberg, M. & Forshey, D. (2002). Comparison of instruments addressing quality of life in patients with ALS and their caregivers. *Neurology*, 58(2), 320–322.
- Brooke P. & Bullock R. (1999). Validation of a 6 item cognitive impairment test with a view to primary care usage. *International Journal of Geriatric Psychiatry*, 14(11), 936–940. DOI:10.1002/(SICI)1099-1166(199911)14:11<936::AID-GPS39>3.0.CO;2-1
- Brooks, B. R. (1994). El Escorial World Federation of Neurology criteria for the diagnosis of amyotrophic lateral sclerosis. Subcommittee on Motor Neuron Diseases/Amyotrophic Lateral Sclerosis of the World Federation of Neurology Research Group on Neuromuscular Diseases and the El Escorial "Clinical limits of amyotrophic lateral sclerosis" workshop contributors. *Journal of the Neurological Sciences*, 124(Suppl), 96-107.
- Brooks, B.R., Miller, R.G., Swash, M., & Munsat, T.L. (2000). El Escorial revisited: revised criteria for the diagnosis of amyotrophic lateral sclerosis. *Amyotrophic lateral sclerosis and other motor neuron disorders: official publication of the World Federation of Neurology, Research Group on Motor Neuron Diseases*, 1(5), 293-299.
- Brown, J.B. (2003). User, carer and professional experiences of care in motor neuron disease. *Primary Healthcare Research and Development*, 4(3), 207-217. DOI:10.1191/1463423603pc151oa
- Brown, J. B., Lattimer, V. & Tudball, T. (2006). An investigation of patients and providers' views of services for motor neurone disease. *British Journal of Neuroscience Nursing*, 1(5), 249-252. DOI: doi.org/10.12968/bjnn.2005.1.5.20273

- Brown, J., Addington-Hall, J. (2008). How people with motor neuron disease talk about living with their illness: a narrative study. *Journal of Advanced Nursing* 62(2), 200-208. DOI: 10.1111/j.1365-2648.2007.04588.x.
- Brown, K., Worrall, L., Davidson, B., & Howe, T. (2011a). Exploring speech-language pathologists' perspectives about living successfully with aphasia. *International Journal of Language & Communication Disorders*, 46(3), 300-11. DOI:10.3109/13682822.2010.496762.
- Brown, K., Worrall, L., Davidson, B., & Howe, T. (2011b). Living successfully with aphasia: family members share their views. *Topics in Stroke Rehabilitation*, 18(5):536-48. DOI: 10.1310/tsr1805-536.
- Bruletti, G., Comini, L., Scalvini, S., Morini, R., Luisa, A., Paneroni, M., & Vitacca, M. (2014). A two-year longitudinal study on strain and needs in caregivers of advanced ALS patients. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, 16(3-4), 187-195.
DOI:<http://dx.doi.org/10.3109/21678421.2014.974616>.
- Burke, T., Elamin, M., Galvin, M., Gallagher, L., Hardiman, O., & Pender, N. (2015). Erratum to: Caregiver burden in amyotrophic lateral sclerosis: a cross-sectional investigation of predictors. *Journal of Neurology*, 262(12), 2799. DOI: 10.1007/s00415-015-7941-y.
- Burns, N. & Grove, S.K. (1999). *Understanding nursing research*. Philadelphia: W.B. Saunders Company.
- Butts, J.B., & Rich, K.L. (2013) *Nursing ethics: across the curriculum and into practice*. Burlington, MA : Jones & Bartlett Learning

- Byrne, S., Heverin, M., Elamin, M., Bede, P., Lynch, C., Kenna, K., ... Hardiman, O. (2013). Aggregation of neurologic and neuropsychiatric disease in amyotrophic lateral sclerosis kindreds: a population-based case-control cohort study of familial and sporadic amyotrophic lateral sclerosis. *Annals of Neurology*, 74(5), 2013, 699-708. DOI: 10.1002/ana.23969
- Callary, B., Rathwell, S., & Young, B. W. (2015). Insights on the Process of Using Interpretive Phenomenological Analysis in a Sport Coaching Research Project. *The Qualitative Report*, 20(2), 63-75.
- Calzada-Sierra, D.J., & Gomez Fernandez, L. (2001). The importance of multifactorial rehabilitation treatment in amyotrophic lateral sclerosis. *Revista de Neurologia*, 32(5), 423-426.
- Cameron A, Rosenfeld J. (2002). Nutritional issues and supplements in amyotrophic lateral sclerosis and other neurodegenerative disorders. *Current Opinion in Clinical Nutrition and Metabolic Care*, 5(6), 631-43. DOI: 10.1097/01.mco.0000038805.16540.09
- Cantarero, L., Espeix, E., Gil Lacruz, M., & Martín, P. (2013). Human food preferences and cultural identity: the case of Aragón (Spain). *International Journal of Psychology*, 48(5), 881-90. DOI: 10.1080/00207594.2012.692792.
- Capaldi, E.D. (1996). *Why We Eat What We Eat: The Psychology of Eating*. American Psychological Association, Washington DC.
- Carradice, A., Shankland, M. C., & Beail, N. (2002). A qualitative study of the theoretical models used by UK mental health nurses to guide their

assessments with family caregivers of people with dementia.

International Journal of Nursing Studies, 39(1), 17–26.

Carson, D., Gilmore, A., Perry, C., & Gronhaug, K. (2001). *Qualitative Marketing Research*. London: Sage.

Catalano, J.S. (1985). *A Commentary on Jean-Paul Sartre's Being and Nothingness*. University of Chicago Press.

Cedarbaum, J. M., Stambler, N., Malta, E., Fuller, C., Hilt, D., Thurmond, B., ...

Nakanishi, A. (1999). The ALSFRS-R: a revised ALS functional rating scale that incorporates assessments of respiratory function. *Journal of the Neurological Sciences* 169(1-2), 13–21. DOI:10.1016/S0022-510X(99)00210-5.

Centers L. C. (2001). Beyond denial and despair: ALS and our heroic potential for hope. *Journal of Palliative Care*, 17, 259–264.

Chadwick, D.D., Jolliffe, J., Goldbart, J. & Burton, M.H. (2006). Barriers to Caregiver Compliance with Eating and Drinking Recommendations for Adults with Intellectual Disabilities and Dysphagia. *Journal of Applied Research in Intellectual Disabilities*, 19, 153–162, DOI: 10.1111/j.1468-3148.2005.00250.x.

Charlick, S., Pincombe, J., McKellar, L., & Fielder, A. (2016). Making sense of participant experiences: Interpretative phenomenological analysis in midwifery research. *International Journal of Doctoral Studies*, 11, 205–216. Retrieved from http://www.informingscience.org/Publications/3486_

Charmaz K. (2000). *Grounded theory objectivist and constructivist method*. In Denzin N., & Lincoln, Y. (Eds.) *Handbook of Qualitative Research*.

Thousand Oaks, CA: Sage.

Charmaz, K. (2006). *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. Sonoma State University, Rohnert Park, USA.

Cheung, J., & Hocking, P. (2004a). Caring as worrying: the experience of spousal carers. *Journal of Advanced Nursing*, 47(5), 475-82. DOI: 10.1111/j.1365-2648.2004.03126.x.

Cheung, J., & Hocking, P. (2004b). The experience of spousal carers of people with multiple sclerosis. *Qualitative Health Research*, 14(2), 153-66. DOI: 10.1177/1049732303258382.

Chiò, A., Finocchiaro, E., Meineri, P., Bottacchi, E., & Schiffer, D. (1999). Safety and factors related to survival after percutaneous endoscopic gastrostomy in ALS. *ALS Percutaneous Endoscopic Gastrostomy Study Group. Neurology*, 53(5), 1123-1125.

Chiò, A., Mora, G., Leone, M., Mazzini, L., Cocito, D., Giordana, M.T., ...

Multani, R. (2002). Early symptom progression rate is related to ALS outcome: A prospective population-based study. *Neurology*, 59(12), 99-103.

Chiò, A., Gauthier, A., Vignola, A., Calvo, A., Ghiglione, P., Cavallo, E., ... Mutani, R. (2005). Caregiver burden and patients' perceptions of being a burden in ALS. *Neurology*, 64(10): 1780-1782. DOI: 10.1212/01.WNL.0000162034.06268.37.

- Chiò, A., Bottacchi, A., Buffa, C., Mutani, R., & Mora, G. (2006). Positive effects of tertiary centres for amyotrophic lateral sclerosis on outcome and use of hospital facilities. *Journal of Neurology, Neurosurgery, and Psychiatry*, 77(8), 948-950. DOI: 10.1136/jnnp.2005.083402.
- Chiò, A., Gauthier, A., Vignola, A., Calvo, A., Ghiglione, P., Cavallo, E., ... Mutani, R. (2006b) Caregiver time use in ALS. *Neurology*, 67(5), 902-4. DOI: 10.1212/01.wnl.0000233840.41688.df.
- Chiò, A., Logroscino, G., Hardiman, O., Swingler, R., Mitchell, D., Beghi, E., ... Eurals Consortium. (2009). Prognostic factors in ALS: A critical review. *Amyotrophic Lateral Sclerosis : Official Publication of the World Federation of Neurology Research Group on Motor Neuron Diseases*, 10(5-6), 310–323. DOI: 10.3109/17482960802566824
- Chiò, A., Calvo, A., Moglia, C., Gamna, F., Mattei, A., Mazzini, L., & Mora, G. (2012). Non-invasive ventilation in amyotrophic lateral sclerosis: a 10 year population based study. *Journal of Neurology, Neurosurgery, and Psychiatry*, 83(4), 377-81. DOI: 10.1136/jnnp-2011-300472.
- Chiò, A., Logroscino, G., Traynor, B.J., Collins, J., Simenone, J.C., Goldstein L.A., & White, L.A. (2013). Global Epidemiology of Amyotrophic Lateral Sclerosis: A Systematic Review of the Published Literature. *Neuroepidemiology*, 41(2), 118-130. DOI: 10.1159/000351153
- Churchill, G. A. (1996). *Basic Marketing Research* (3rd Ed.), Fort Worth, TX: The Dryden Press.
- Cichero, J. A. Y., & Murdoch, B. E. (2006). *Dysphagia. Foundation, Theory and Practice*. John Wiley & Sons.

- Cichero, J.A., & Altman, K.W. (2012). Definition, prevalence and burden of oropharyngeal dysphagia: A serious problem among older adults worldwide and the impact on prognosis and hospital resources. *Nestle Nutrition Institute Workshop Series*, 72, 1–11. DOI: 10.1159/000339974.
- Clark, H. M. (2003). Neuromuscular treatments for speech and swallowing: A tutorial. *American Journal of Speech and Language Pathology*. 12(4), 400 – 415. DOI:10.1044/1058-0360(2003/086)
- Clave, P., de Kraa, M., Arreola, V., Girvent, M., Farre, R., Palomera, E., & Serra-Prat, M. (2006). The effect of bolus viscosity on swallowing function in neurogenic dysphagia. *Alimentary Pharmacology and Therapeutics*, 24(9), 1385-1394. DOI: 10.1111/j.1365-2036.2006.03118.x
- Cleveland D. W., & Rothstein J. D. (2001). From Charcot to Lou Gehrig: deciphering selective motor neuron death in ALS, *Nature Reviews Neuroscience*, 2(11). DOI: 10.1038/35097565
- Colodny, N. (2005). Dysphagic independent feeders' justifications for noncompliance with recommendations by a speech-language pathologist. *American Journal of Speech-Language Pathology*, 14(1):61-70.
- Conner, M., & Armitage, Christopher J. (2002). *The social psychology of food (Applying social psychology)*. Buckingham: Open University Press.
- Crary M. A., & Groher M. E. (2003). *Introduction to Adult Swallowing Disorders*, Elsevier: St Louis.
- Crary, M. A., Mann, G. D., & Groher, M. E. (2005). Initial psychometric assessment of a functional oral intake scale for dysphagia in stroke

- patients. *Archives of Physical Medicine and Rehabilitation*, 86(8), 1516-20. DOI: 10.1016/j.apmr.2004.11.049
- Creswell, J.W. (2013) *Qualitative Inquiry and Research Design. Choosing Among Five Approaches*. 3rd Ed., SAGE Publications, Inc
- Cruwys, T., Bevelander, K.E., & Hermans, R.C. (2015). Social modeling of eating: a review of when and why social influence affects food intake and choice. *Appetite*, 86, 3-18. DOI: 10.1016/j.appet.2014.08.035.
- Czell, D., Bauer, M., Binek, J., Schoch, O.D., & Weber, M. (2013). Outcomes of percutaneous endoscopic gastrostomy tube insertion in respiratory impaired amyotrophic lateral sclerosis patients under noninvasive ventilation. *Respiratory Care*, 58(5), 838-44. DOI: 10.4187/respcare.02024.
- da Costa Franceschini, A., & Mourão, L. F. (2015). Dysarthria and dysphagia in Amyotrophic Lateral Sclerosis with spinal onset: a study of quality of life related to swallowing. *Neurorehabilitation*, 36(1), 127-134.
DOI:10.3233/NRE-141200
- Dahlberg, K., Dahlberg, H., & Nystrom, M. (2008). *Reflective Lifeworld Research*. (2nd Ed.). Studentlitteratur, Lund.
- Daniels, S. K., & Huckabee M. L. (2008). *Dysphagia Following Stroke (Clinical Dysphagia)*. Plural Publishing Inc.
- Davies, Z., & Turner, M. R. (2010). Public awareness of motor neuron disease. *Amyotrophic Lateral Sclerosis*, 11(5), 490–491. DOI: <http://dx.doi.org/10.3109/17482961003716858>

- Davis, J.W., Lazarus, C., Logemann, J., & Hurst, P.S. (1987). Effect of a maxillary glossectomy prosthesis on articulation and swallowing. *The Journal of Prosthetic Dentistry*, 57(6), 715-719.
- Davis, K.L., Marin, D.B., Kane, R., Patrick, D., Peskind, E.R., Raskind, M.A., & Puder, K.L. (1997). The Carer Activity Survey (CAS): development and validation of a new measure for carers of persons with Alzheimer's disease. *International Journal of Geriatric Psychiatry* 12(10), 978-88.
- Davis, L.A., & Thompson Stanton, S. (2004). Characteristics of dysphagia in elderly patients requiring mechanical ventilation. *Dysphagia*. 19(1), 7-14. DOI: 10.1007/s00455-003-0017-7.
- Dawson, S., & Kristjanson, L. J. (2003). Mapping the journey: family carers' perceptions of issues related to end-stage care of individuals with muscular dystrophy or motor neurone disease. *Journal of Palliative Care*, 19(1), 36-42.
- Desport, J. C., Preux, P. M., Magy L., Boirie, Y., Vallat, J. M., Beaufrère, B., & Couratier, P. (2001). Factors correlated with hypermetabolism in patients with amyotrophic lateral sclerosis. *American Journal of Clinical Nutrition*, 74(3), 328-334.
- Desport, J. C., Torney, F., Lacoste, M., Preux, P. M., & Couratier P. (2005a). Hypermetabolism in ALS: correlations, with clinical and paraclinical parameters. *Neurodegenerative Diseases*, 2(3-4), 202-7. DOI: 10.1159/000089626
- Desport, J. C., Mabrouk, T., Bouillet, P., Perna, A., Preux, P. M., & Couratier, P. (2005b). Complications and survival following radiologically and endoscopically-guided gastrostomy in patients with amyotrophic lateral

- sclerosis. *Amyotrophic Lateral Sclerosis and other Motor Neuron Disorders*, 6(2), 88-93. DOI:10.1080/14660820410021258
- Donaghy, C., Dick A., Hardiman, O., & Patterson, V., (2008). Timeliness of diagnosis in Motor Neurone Disease: A population-based study, *Ulster Medical Journal*, 77(1), 18 – 21.
- Drew, N. (1999). A return to Husserl and researcher self-awareness. In: Polifroni, E. C. & Welch, M. (eds.) *Perspectives on philosophy of science in nursing: An historical and contemporary anthology*. Philadelphia: Lippincott Williams & Wilkins.
- Dreyfus, H. L. (1995). *Being-in-the-world: a commentary on Heidegger's being and time*. Division 1. MIT Press.
- Drummond, J. (2003). The Structure of Intentionality. In Welton (ed.) *The New Husserl: A Critical Reader*. Bloomington: Indiana University Press.
- Dworkin, J. P. & Hartman, D. E. (1979). Progressive speech deterioration and dysphagia in amyotrophic lateral sclerosis: case report. *Archives of Physical Medicine and Rehabilitation*, 60(9): 423-5.
- Easton, G. (2010). Critical realism in case study research. *Industrial Marketing Management*, 39(1):118–128 DOI: 10.1016/j.indmarman.2008.06.004
- Ekberg, O., Hamdy, S., Woisard, V., Wuttge-Hannig, A., & Ortega, P. (2002). Social and psychological burden of dysphagia: Its impact on diagnosis and treatment. *Dysphagia*, 17(2), 139–46. DOI: 10.1007/s00455-001-0113-5.
- Elamin, M., Bede, P., Byrne, S., Jordan, N., Gallagher, L., Wynne, B., ... Hardiman O. (2013). Cognitive changes predict functional decline in

- ALS: A population-based longitudinal study. *Neurology*, 80(17), 1590-1597. DOI:10.1212/WNL.0b013e31828f18ac
- Elamin, M., Phukan J., Bede, P., Jordan, N., Byrne, S., Pender, N., & Hardiman O. (2011). Executive dysfunction is a negative prognostic indicator in patients with ALS without dementia. *Neurology*, 76(14), 1263-1269. DOI:10.1212/WNL.0b013e318214359f
- Ely, M., Anzul, M., Friedman, T., Garner, D., & Steinmetz, A. M. (1991). *Doing qualitative research: Circles within circles*. London: Falmer.
- Emery, C.F., Schein, R.L., Hauck, E.R., & MacIntyre, N.R. (1998). Psychological and cognitive outcomes of a randomized trial of exercise among patients with chronic obstructive pulmonary disease. *Health Psychology*, 17, 232-240.
- England, K.V.L. (1994). Getting personal: Reflexivity, positionality, and feminist research. *The Professional Geographer*, 46(1), 80–89. DOI: 10.1111/j.0033-0124.1994.00080.x
- Enns, P. (2014). The Moody Handbook of Theology. Moody Publishers
- Eurostat. (2017). Retrieved from: http://ec.europa.eu/eurostat/statistics-explained/index.php/Main_Page.
- Epton, J., Harris, R., & Jenkinson, C. (2009). Quality of life in amyotrophic lateral sclerosis/motor neuron disease: a structured review. *Amyotrophic Lateral Sclerosis*, 10(1), 15-26. DOI: 10.1080/17482960802163721
- Fattori, B., Grosso, M., Bongioanni, P., Nacci, A., Cristofani, R., AlSharif, A., ... Mariani G. (2006). Assessment of swallowing by oropharyngoesophageal scintigraphy in patients with amyotrophic lateral sclerosis. *Dysphagia*, 21(4), 280-6 DOI: 10.1007/s00455-006-9052-5.

- Ferguson, T. A., & Elman, L. B. (2007). Clinical presentation and diagnosis of Amyotrophic Lateral Sclerosis. *NeuroRehabilitation*, 22(6), 409-416.
- Finlay, L. (2009). Debating Phenomenological Research Methods. *Phenomenology & Practice*, 3(1), 6-25.
- Finlay, L. (2011). *Phenomenology for Therapists. Researching the Lived World*. Wiley-Blackwell.
- Finucane, T.E. & Bynum, J.P. (1996) Use of tube feeding to prevent aspiration pneumonia. *The Lancet* 348(9039), 1421-1424. DOI: 10.1016/S0140-6736(96)03369-7.
- Finucane, T. E., Christmas, C., & Travis, K. (1999). Tube feeding in patients with advanced dementia: a review of the evidence. *JAMA*, 282(14), 1365-70. DOI:10.1001/jama.282.14.1365
- Finucane, T. E., Christmas, C., & Leff, B. A. (2007). Tube feeding in dementia: how incentives undermine health care quality and patient safety. *Journal of the American Medical Directors Association*, 8(4), 205-8. DOI: 10.1016/j.jamda.2007.01.007
- Fitremann, J.- M. (2017). The Symbiosis Complex. Structuralpsy. Psychology of building and structure of the psyche. New approach of the psychology. Retrieved from: <http://structuralpsy.over-blog.com/page-5556358.html>
- Fletcher, A. J. (2017). Applying critical realism in qualitative research: methodology meets method. *International Journal of Social Research Methodology*, 20(2), 181-194. DOI: 10.1080/13645579.2016.1144401
- Flick, U. (2014). *An Introduction to Qualitative Research*. 5th Ed. SAGE Publishing.

Flowers, P. (2008). Temporal tales: the use of multiple interviews with the same participant. *Qualitative Methods in Psychology Section Newsletter*, 5, 24-27.

Foley, G., Timonen, V., & Hardiman, O. (2012). Experience of services as a key outcome in amyotrophic lateral sclerosis (ALS) care: the case for a better understanding of patient experiences. *The American Journal of Hospice & Palliative Care*, 29(5), 362-7. DOI: 10.1177/1049909111423774

Foley, G., Timonen, V., & Hardiman, O. (2014). Acceptance and decision making in amyotrophic lateral sclerosis from a life-course perspective. *Qualitative Health Research*, 24(1), 67 – 77. DOI: 10.1177/1049732313516545

Foley, G. (2016). Burdened by obligation: Recognising the caring roles of people with motor neurone disease. *Palliative Medicine*, 30(10), 981-982. DOI: 10.1177/0269216316661687.

Foley, G., Timonen, V., & Hardiman, O. (2016). “I hate being a burden”: The patient perspective on carer burden in amyotrophic lateral sclerosis. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, 17(5-6), 351-357. DOI: 10.3109/21678421.2016.1143512.

Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). “Mini-mental state”. A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12(3), 189–198. DOI: 10.1016/0022-3956(75)90026-6

- Forbes, R. B., Colville, S., & Swingler, R. J. (2004). Frequency, timing and outcome of gastrostomy tubes for amyotrophic lateral sclerosis/motor neurone disease - a record linkage study from the Scottish Motor Neurone Disease Register. *Journal of Neurology*, 251(7), 813-817. DOI: 10.1007/s00415-004-0429-9
- Ford, H., & Kent, S. (2013). The Experiences of Bilingualism within the Deaf and the Hearing World: The Views of Deaf Young People. *Deafness & Education International*, 15(1), 29-51.
DOI:10.1179/1557069X12Y.0000000013
- Ford, K. & Kent, S. (2013). The Experiences of Bilingualism Within the Deaf and the Hearing World: The Views of d/Deaf Young People. *Deafness & Education International*, 15(1),
DOI:10.1179/1557069X12Y.0000000013
- Fossey, E., Harvey, C., McDermott, F., & Davidson, L. (2002). Understanding and evaluating qualitative research. *Australian and New Zealand Journal of Psychiatry* 36(6). DOI: 10.1046/j.1440-1614.2002.01100.x
- Frost, N. (2011). Qualitative Research Methods in Psychology: Combining core approaches. Open University. 44-65
- Funalot, B., Desport, J. C., Sturtz, F., Camu, W., & Couratier, P. (2009). High metabolic level in patients with familial amyotrophic lateral sclerosis. *Amyotrophic Lateral Sclerosis* 16, 1-5. DOI: 10.1080/17482960802295192
- Gadamer, H. (1966). *The Universality of Hermeneutic Problem*. in D. E. Linge (trans. and ed.). (1976), *Philosophical Hermeneutics: Hans-George Gadamer*, London: University of California Press.

- Gadamer, H. G. (2004). *Truth and method* (2nd Ed.). London: Continuum International Publishing Group.
- Gale, C. (2015). Assisting patients with motor neurone disease to make decisions about their care. *International Journal of Palliative Nursing*, 21(5), 251-255. DOI: 10.12968/ijpn.2015.21.5.251.
- Gallagher, S. (2012). *Phenomenology*. Palgrave Macmillan UK
- Galvin, M., Corr, B., Madden, C., Mays, I., McQuillan, R., Timonen, V., ... Hardiman, O. (2016). Caregiving in ALS – a mixed methods approach to the study of burden. *BMC Palliative Care*, 15(1), 81. DOI:10.1186/s12904-016-0153-0.
- Garcia, J. M., Chambers, E., & Molander, M. (2005). Thickened liquids: practice patterns of speech-language pathologists. *American Journal of Speech-Language Pathology*, 14, 4–13. DOI: 10.1044/1058-0360(2005/003).
- Gauthier, A., Vignola, A., Calvo, A., Cavallo, E., Moglia, C., Sellitti, L., ... Chiò A. (2007). A longitudinal study on quality of life and depression in ALS patient-caregiver couples. *Neurology*, 68(12), 923-26. DOI: 10.1212/01.wnl.0000257093.53430.a8.
- Gibson, .E.L. (2006). Emotional influences on food choice: sensory, physiological and psychological pathways. *Physiology & Behaviour*, 89(1), 53-61. DOI: 10.1016/j.physbeh.2006.01.024.
- Gillick, M. R. (2000). Rethinking the role of tube feeding in patients with advanced dementia. *The New England Journal of Medicine*, 342(3), 206-10. DOI: 10.1056/NEJM200001203420312.

- Goldstein, L. H., Atkins, L., Landau, S., Brown, R., & Leigh, P. N. (2006). Predictors of psychological distress in carers of people with amyotrophic lateral sclerosis: a longitudinal study. *Psychological Medicine* 36(6), 865-75. DOI: 10.1017/S0033291706007124.
- Gollick, M.R. (2000) Rethinking the role of tube feeding in patients with advanced dementia. *The New England Journal of Medicine*. 342, 206-210. DOI: 10.1056/NEJM200001203420312.
- Graner, D. E., & Strand, E. A. (2010). Management of dysarthria and dysphagia in patients with amyotrophic lateral sclerosis. *Perspectives on Neurophysiology & Neurogenic Speech & Language Disorders*, 20(2), 39-44. DOI:10.1044/nnsld20.2.39.
- Grant, M. M., & Rivera, L. M. (1995). Anorexia, cachexia, and dysphagia: the symptom experience. *Seminars in Oncology Nursing*, 11(4), 266-71. DOI: 10.1016/S0749-2081(05)80007-5.
- Greenaway, L. P., Martin, N. H., Lawrence, V., Janssen, A., Al-Chalabi, A., Leigh P. N., & Goldstein, L. H. (2015). Accepting or declining non-invasive ventilation or gastrostomy in amyotrophic lateral sclerosis: patients' perspectives. *Journal of Neurology*, 262(4), 1002-13. DOI: 10.1007/s00415-015-7665-z.
- Groher M.E. & Groher, T.P. (2012). When safe oral feeding is threatened. End-of-Life options and decisions. *Topics in Language Disorders*, 32(2),146-167. DOI: 10.1097/TLD.0b013e3182543547.
- Groher, M. E., & Crary, M. A. (2009). *Dysphagia: Clinical Management in Adults and Children*. Mosby; 1 Har/Psc edition.

- Guidetti, M., Cavazza, N., & Graziani, A. R. (2014). Healthy at home, unhealthy outside: food groups associated with family and friends and the potential impact on attitude and consumption. *Journal of Social and Clinical Psychology*, 33(4), 343-364. DOI: 10.1521/jscp.2014.33.4.343
- Gum, A., & Snyder, C. R. (2004). Coping with terminal illness: the role of hopeful thinking. *Journal of Palliative Medicine* 5(6), 883-894 DOI: 10.1089/10966210260499078
- Handy, C.R., Krudy, C., Boulis, N., & Federici, T. (2011). Pain in Amyotrophic Lateral Sclerosis: A Neglected Aspect of Disease. *Neurology Research International*, 2011, DOI:10.1155/2011/403808.
- Hardiman, O. (2007) MND researchers look for answers. *FORUM, May 2007* pg. 19.
- Hardiman, O., Van den Berg, L. H., Kiernan M. C. (2011). Clinical diagnosis and management of amyotrophic lateral sclerosis. *Nature reviews Neurology* 7, 639-649. DOI: 10.1038/nrneurol.2011.153.
- Hardiman, O. (2014) Irish key to motor neurone disease. *World of Irish Nursing and Midwifery*. 22(8), 61-61.
- Harwood, C. A., McDermott, C. J., & Shaw P. J. (2012). Clinical aspects of motor neurone disease. *Medicine*, 40(10), 540-545. DOI:10.1016/j.mpmed.2012.07.003.
- Hauck-Lawson, A. (2004). Introduction to special issue on the food voice. *Food, Culture, and Society*, 7(1), 24-25.
- Health Research Board. (2010). The Identification of Research Priorities for Therapy Professions in Ireland. Retrieved from:

http://www.hrb.ie/uploads/tx_hrbpublications/Physical_Therapies_Priorities_Summary_Report_01.pdf

- Hebert, R.S., Lacomis, D., Easter, C., Frick, V., & Shear, M.K. (2005). Grief support for informal caregivers of patients with ALS: A national survey. *Neurology*, 64(1), 137-8. DOI: 10.1212/01.WNL.0000148586.79290.A6
- Heidegger, M. (2017). *Bycie i czas*. [Being and time]. Wydawnictwo: Wydawnictwo Naukowe PWN. [in Polish]. (Original work published in 1927).
- Heiss, C. J., Goldberg, L., & Dzarnoshi, M. (2010). Registered dietitians and speech and language pathologists: an important partnership in dysphagia management. *Journal of the American Dietetics Association*, 110(9), 1290–1293. DOI: 10.1016/j.jada.2010.07.014.
- Hebert, R.S., Lacomis, D., Easter, C., Frick, V., & Shear, M.K. (2005). Grief support for informal caregivers of patients with ALS: a national survey. *Neurology*. 64(1), 137-138. DOI: 10.1212/01.WNL.0000148586.79290.A6.
- Herman, C.P., Roth, D.A., & Polivy, J. (2003). Effects of the presence of others on food intake: a normative interpretation. *Psychological Bulletin*, 129(6), 873–886. DOI: 10.1037/0033-2909.129.6.873.
- Herman, C. P. (2015). The social facilitation of eating. A review. *Appetite*, 86, 61-73. DOI: 10.1016/j.appet.2014.09.016.
- Hickenbottom, S.L., Fendrick, A.M., Kutcher, J.S., Kabeto, M.U., Katz, S.J., & Langa, K.M. (2002). A national study of the quantity and cost of informal caregiving for the elderly with stroke. *Neurology*, 58(12), 1754-1759. DOI: 10.1212/WNL.58.12.1754

- Higo, R., Tayama, N., & Nito, T. (2004). Longitudinal analysis of progression of dysphagia in amyotrophic lateral sclerosis. *Auris Nasus Larynx*, 31(3), 247-254. DOI:10.1016/j.anl.2004.05.009
- Hillel, A.D., Miller, R.M., Yorkston, K., McDonald, E., Norris, F.H., & Konikow, N. (1989). Amyotrophic Lateral Sclerosis Severity Scale. *Neuroepidemiology*, 8, 142–150. DOI:10.1159/000110176.
- Hinchy, J. A., Shephard, T., Furie, K., Smith, D., Wang, D., & Tonn, S. (2005). Formal dysphagia screening protocols prevent pneumonia. *Stroke* 36, 1972–1976. DOI: 10.1161/01.STR.0000177529.86868.8d.
- Hirschman, E. (1985). Primitive Aspects of Consumption in Modern American Society. *Journal of Consumer Research*, 12(2), 142-154.
- Hocking, C., Brott, T., & Paddy, A. (2006). Caring for people with motor neurone disease. *International Journal of Therapy and Rehabilitation*, 13(8) 351-356.
- Hodgen, A., Greenfield, D., Nugus, P., & Kiernan, M.C. (2012a). Engaging in patient decision-making in multidisciplinary care for amyotrophic lateral sclerosis: the views of health professionals. *Patient Preference and Adherence*, 6, 691-701. DOI: 10.2147/PPA.S36759.
- Hogden, A., Greenfield, D., Nugus, P., & Kiernan, M. C. (2012b). What influences patient decision-making in amyotrophic lateral sclerosis multidisciplinary care? A study of patient perspectives. *Patient Preference and Adherence*, 6, 829–838. DOI: 10.2147/PPA.S37851

- Hollway, W. (2007). *Methods and knowledge in social psychology*. In W. Hollway, H. Lucey, & A. Phoenix (Eds.), Social psychology matters. Milton Keynes: The Open University.
- Holm, T., Maier, A., Wicks, P., Lang, D., Linke, P., Münch, C., ... Meyer, T. (2013). Severe Loss of Appetite in Amyotrophic Lateral Sclerosis Patients: Online Self-Assessment Study. *Interactive Journal of Medical Research*, 2(1). DOI: 10.2196/ijmr.2463
- Holmes, S. (2004). Enteral feeding and percutaneous endoscopic gastrostomy. *Nursing Standard*, 18(20), 41-43. DOI: 10.7748/ns2004.01.18.20.41.c3536
- Houston, S. (2001). Beyond social constructionism: Critical realism and social work, *British Journal of Social Work*, 31(6), 845-61.
- Hu, T., Zhang, D., Wang, J., Mistry, R., Ran, G., & Wang X. (2014). Relationship between emotional regulation and mental health: a meta-analysis review. *Psychological Reports*, 114, 341–362. DOI: 10.2466/03.20.PR0.114k22w4
- Hudson, L., & Ozanne, J. (1988). Alternative Ways of Seeking Knowledge in Consumer Research. *Journal of Consumer Research*, 14(4), 508–521.
- Hugel, H., Grundy, N., Rigby, S., & Young, C. A. (2006). How does current care practice influence the experience of a new diagnosis of motor neurone disease? A qualitative study of current guidelines-based practice. *Amyotrophic Lateral Sclerosis*, 7(3), 161-166. DOI: 10.1080/14660820600601051.
- Hughes, R. A., Sinha, A., Higginson, I., Down, K., & Leigh, P. N. (2005). Living with motor neurone disease: lives, experiences of services and

- suggestions for change. *Health and Social Care in the Community*, 13(1), 64-74. DOI: 10.1111/j.1365-2524.2005.00530.x.
- Hunt, S. D. (1983). *Marketing Theory*. Homewood, IL: Richard D. Irwin.
- Husserl, E. (1962). *Ideas: general introduction to pure phenomenology*. Collier Books.
- Husserl, E. (1970). *The Crisis of European Sciences and Transcendental Phenomenology: An Introduction to Phenomenological Philosophy (Northwestern University Studies in Phenomenology & Existential Philosophy)*. Evanston: Northwestern University Press.
- Institute of Medicine. Committee on Quality of Health Care in America. (2001). *Crossing the quality chasm: a new health system for the 21st century*. Washington, DC: National Academies Press. Retrieved from: <https://www.ncbi.nlm.nih.gov/pubmed/25057539>.
- Irish Association of Speech and Language Therapists [IASLT]. (2016). *Position Statement on Swallow Screening*.
- Irish Association of Speech and Language Therapists [IASLT]. (2015). *Standards of Practice for Speech and Language Therapists on the Management of Feeding, Eating, Drinking and Swallowing Disorders*.
- Irish Association of Speech and Language Therapists, Irish Nutrition and Dietetic Institute. (2009). *Irish Consistency Descriptors for Modified Fluids and Food Consensus Document*. Retrieved from: http://dysphagia.ie/uploads/documents/IASLT_INDI_Irish_Consistency_Descriptors.pdf
- Irish Motor Neurone Disease Association [IMNDA] (2017). Retrieved from: www.imnda.ie/about-mnd/more-facts-about-motor-neurone-disease/

Jones, A.J., Kuijer, R.G., Livingston, L., Myall, D., Horne, K., MacAskill, M., ... Dalrymple-Alford, J.C. (2017). Caregiver burden is increased in Parkinson's disease with mild cognitive impairment (PD-MCI) *Translational Neurodegeneration* 6(17). DOI: 10.1186/s40035-017-0085-5.

Jacobsson, C., Axelsson, K., Osterlind, P. O., & Norberg, A. (2000). How people with stroke and healthy older people experience the eating process. *Journal of Clinical Nursing*, 9(2), 255-64. DOI: 10.1046/j.1365-2702.2000.00355.x

Jakobsson Larsson, B., Nordin, K., Askmark, H., & Nygren, I. (2014). Coping strategies among patients with newly diagnosed amyotrophic lateral sclerosis. *Journal of Clinical Nursing*, 23(21-22), 3148-55. DOI: 10.1111/jocn.12557

Jakobsson Larsson, B., Fröjd, C., Nordin, K., & Nygren, I. (2015). Relatives of patients with amyotrophic lateral sclerosis: Their experience of care and support. *Palliative and Supportive Care*, 13(6), 1569–1577. DOI: 10.1017/S1478951515000188

Jasper, D. (2004). *A short introduction to hermeneutics*. WKJ.
Jawaid, A., Murthy S. B., Wilson, A. M., Qureshi, S. U., Amro M. J., Wheaton, M., ... Schulz, P. E. (2010). A decrease in body mass index is associated with faster progression of motor symptoms and shorter survival in ALS. *Amyotrophic Lateral Sclerosis*, 11(6), 542–8. DOI: 10.3109/17482968.2010.482592.

- Jenkinson C, Fitzpatrick R, Swash M, & Peto V. (2000). The ALS Health Profile Study: quality of life of amyotrophic lateral sclerosis patients and carers in Europe. *Journal of Neurology*, 247(11), 835-40.
- Jeong, H., & Othman, J. (2016). Using Interpretative Phenomenological Analysis from a Realist Perspective. *The Qualitative Report*, 21(3), 558-570.
- Jiménez, G. I., Sala, M. N., Riera, M, M., Herrera, H. M. V., Povedano, P. M., & Virgili, C. M. N. (2015). The patient's opinion matters: experience in the nutritional care in an ALS multidisciplinary team. *Nutrición Hospitalaria*, 31 Suppl 5, 56-66. DOI:10.3305/nh.2015.31.sup5.9132
- Johansson, A.E., & Johansson, U. (2009) Relatives' experiences of family members' eating difficulties. *Scandinavian Journal of Occupational Therapy*, 16(1), 25-32. DOI: 10.1080/11038120802257195.
- Johnson, J., Leigh, P. N., Shaw, C. E., Ellis, C., Burman, R., & Al-Chalabi, A. (2012). Eating-derived pleasure in amyotrophic lateral sclerosis as a predictors of non-oral feeding. *Amyotrophic Lateral Sclerosis*, 13(6), 555-559. DOI: 10.3109/17482968.2012.704925
- Johnson, S. (2007). Hope in terminal illness: an evolutionary concept analysis. *International Journal of Palliative Nursing* 13(9), 451-459. DOI:10.12968/ijpn.2007.13.9.27418.
- Kak, M., Issa, N.P., Roos, R.P., Sweitzer, B.J., Gottlieb, O., Guralnick. A., ... Rezania, K. (2017). Gastrostomy tube placement is safe in advanced amyotrophic lateral sclerosis. *Neurological Research*, 39(1), 16-22. DOI: 10.1080/01616412.2016.1259028.

- Kamminga, J., Leslie, F. V. C., Hsieh, S., Caga, J., Mioshi, E., Hornberger, M., ... Burrell, J. (2016). Syntactic comprehension deficits across the FTD-ALS continuum. *Neurobiology of Aging*, 41, 11-8. DOI: 10.1016/j.neurobiolaging.2016.02.002.
- Kasarskis, E.J., Scarlata, D., Hill, R., Fuller, C., Stambler, N., & Cedarbaum, J. M. (1999). A retrospective study of percutaneous endoscopic gastrostomy in ALS patients during the BDNF and CNTF trials. *Journal of the Neurological Sciences*, 169(1-2), 118-25. DOI: 10.1016/S0022-510X(99)00230-0.
- Katzberg, H. D., & Benatar, M. (2011). Enteral tube feeding for amyotrophic lateral sclerosis/motor neuron disease. The Cochrane Collaboration. Cochrane Database Systematic Review. John Wiley & Sons Ltd. DOI: 10.1002/14651858.CD004030.pub3.
- Katzman, R., Brown, T., Fuld, P., Peck, A., Schechter, R., & Schimmel, H. (1983). Validation of a short Orientation-Memory-Concentration Test of cognitive impairment. *The American Journal of Psychiatry*, 140(6), 734-739.
- Kaub-Wittemer, D., Steinbüchel, N., Wasner, M., Laier-Groeneveld, G., & Borasio, G. D. (2003). Quality of life and psychosocial issues in ventilated patients with amyotrophic lateral sclerosis and their caregivers. *Journal of Pain and Symptom Management*, 26(4), 890–897. DOI:10.1016/S0885-3924(03)00323-3.
- Kaw, M., & Sekas, G. (1994). Long-term follow-up of consequences of percutaneous endoscopic gastrostomy (PEG) tubes in nursing home

patients. *Digestive Diseases and Sciences*, 39(4), 738-43.

DOI:10.1007/BF02087416.

Kawai, S., Tsukuda, M., Mochimatsu, I., Enomoto, H., Kagesato, Y., Hirose, H.,

. . . Suzuki, Y. (2003). A study of the early stage of dysphagia in amyotrophic lateral sclerosis. *Dysphagia*, 18(1), 1-8.

DOI:10.1007/s00547-002-0074-z.

Kelly, G. J. (2008). *Inquiry, activity, and epistemic practice*. In R. Duschl & R. Grandy (Eds.), *Teaching scientific inquiry: Recommendations for research and implementation*. Rotterdam, The Netherlands: Sense.

Kelly, J., D'Cruz, G., & Wright, D. (2010). Patients with dysphagia: experiences of taking medication. *Journal of Advanced Nursing*, 66(1), 82-91. DOI: 10.1111/j.1365-2648.2009.05145.x.

Kernis, M. H., Cornell, D. P., Sun, C. R., Berry, A., Harlow, T., & Bach, J. S. (1993). There's more to self-esteem than whether it is high or low: The importance of stability of self-esteem. *Journal of Personality and Social Psychology*, 65(6), 1190-1204.

Kindell, J. (2002). *Feeding and Swallowing Disorders in Dementia*. Speechmark Practical Therapy Resource. Routledge.

King, J.M., & Ligman, K. (2011). Patient Noncompliance With Swallowing Recommendations: Reports From Speech-Language Pathologists. *Contemporary Issues in Communication Science & Disorders*, 38, 53-60.

Kittler, P.G., Sucher, K.P., & Nelms, M.N. (2012). *Food and culture* (6th ed.). Belmont, CA:Wadsworth.

- Klinke, M.E., Hafsteinsdóttir, T.B., Thorsteinsson, B., & Jónsdóttir, H. (2014). Living at home with eating difficulties following stroke: a phenomenological study of younger people's experiences. *Journal of Clinical Nursing*, 23(1-2), 250-60. DOI:10.1111/jocn.12401.
- Knight, R.G., Devereux, R.C., & Godfrey, H.P. (1997). Psychosocial consequences of caring for a spouse with multiple sclerosis. *Journal of Clinical and Experimental Neuropsychology*, 19(1), 7-19. DOI: 10.1080/01688639708403832.
- Knox, S., Burkard, A.W. (2009). Qualitative research interviews. *Psychotherapy Research*, 19(4-5). DOI: 10.1080/10503300802702105.
- Körner, S., Hendricks, M., Kollewe, K., Zapf, A., Dengler, R., Silani, V., & Petri, S. (2013). Weight loss, dysphagia and supplement intake in patients with amyotrophic lateral sclerosis (ALS): impact on quality of life and therapeutic options. *BMC Neurology*, 13(1), 81-84. DOI:10.1186/1471-2377-13-84.
- Krivickas, L.S., Shockley, L., & Mitsumoto, H. (1997). Home care of patients with amyotrophic lateral sclerosis (ALS). *Journal of the Neurological Sciences*, 152 Suppl. 1, 82-9.
- Kühnlein, P., Gdynia, H.J., Sperfeld, A.D., Lindner-Pfleghar, B., Ludolph, A.Ch., Prosiegel, M., & Riecker, A. (2008). Diagnosis and treatment of bulbar symptoms in amyotrophic lateral sclerosis. *Nature Clinical Practice Neurology* 4(7), 366-74. DOI: 10.1038/ncpneuro0853.
- Kuncl, R.W. (2002). *Motor Neurone Disease*. Ed. WB Saunders.

- Kurt, A., Njboer, F., Matuz T., Kübler, A. (2007). Depression and Anxiety in Individuals with Amyotrophic Lateral Sclerosis. *CNS Drugs*, 21(4), 279-291.
- Laasch, H.-U., Wilbraham, L., Bullen, K., Marriott, A., Lawrence, J.A.L., Johnson, J. R., ... Martin, D. (2003). Gastrostomy insertion: comparing the options--PEG, RIG or PIG?. *Clinical radiology*, 58(5), 398-405.
- LaDonna, K. A., Koopman, W. J., Ray, S. L., & Venance, S. L. (2016). Hard to Swallow: A Phenomenological Exploration of the Experience of Caring for Individuals With Myotonic Dystrophy and Dysphagia. *Journal of Neuroscience Nursing*, 48(1), 42–51. DOI: 10.1097/JNN.0000000000000178.
- Lamont, E. B., & Christakis, N. A. (2001). Prognostic disclosure to patients with cancer near end of life. *Annals of International Medicine*, 134(12), 1096-1105.
- Langridge, D. (2007) *Phenomenological Psychology: Theory, Research and Method*. 1st Edition. Pearson Education Canada.
- Langmore, S. E., Terpenning, M. S., Schork, A., Chen, Y., Murray, J. T., Lopatin, D., & Loesche, W. J. (1998). Predictors of aspiration pneumonia: How important is dysphagia? *Dysphagia*, 13(2), 69–81. DOI: 10.1007/PL00009559.
- Langmore, S. E., Skarupski, K., Parks, P., & Fries B. (2002). Predictors of Aspiration Pneumonia in Nursing Home Residents. *Dysphagia*, 17(4), 298-307. DOI: 10.1007/s00455-002-0072-5.

- Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, 3(2), 102-120. DOI: 10.1191/1478088706qp062oa.
- Larsson, B. J., Nordin, K., Askmark, H. & Nygren, I. (2014). Coping strategies among patients with newly diagnosed amyotrophic lateral sclerosis. *Journal of Clinical Nursing*, 23(21-22), 3148-3155. DOI: 10.1111/jocn.12557.
- Lazzara, G.L., Lazarus, C.L. & Logeman, J.A. (1986). Impact of thermal stimulation on the triggering of the swallowing reflex. *Dysphagia*, 1(2), 73–77.
- Leah, P. N., Abrahams, S., Al-Chalabi, A., Ampong, M. A., Goldstein, L. H., Johnston, J., (...) Willey, E. (2003). *The management of motor neurone disease*. *Journal of Neurology, Neurosurgery & Psychiatry*, 74(4), 32-47. DOI: 10.1136/jnnp.74.suppl_4.iv32.
- Leder, S.B., Novella, S. & Patwa, H. (2004). Use of Fiberoptic Endoscopic Evaluation of Swallowing (FEES) in Patients with Amyotrophic Lateral Sclerosis. *Dysphagia* 19(3), 177-181. DOI: 10.1007/s00455-004-0009-2.
- Lee, C. N. (2012). Reviewing evidences on the management of patients with motor neuron disease. *Hong Kong: Medical Journal*, 18(1), 48-55.
- Lee, J. R. J., Annegers, J. F., & Appel, S. H. (1995). Prognosis of amyotrophic lateral sclerosis and the effect of referral selection. *Journal of the Neurological Science*, 132(2), 207-215. DOI:10.1016/0022-510X(95)00154-T.
- Lee, J.N., Rigby, S.A., Burchardt, F., Thornton, E.W., Dougan, C., & Young, C.A. (2001). Quality of life issues in motor neurone disease: the

development and validation of a coping strategies questionnaire, the MND Coping Scale. *Journal of the Neurological Sciences*, 191(1-2), 79-85.

Lefter, S., Hardiman, O., & Ryan, A. M., (2017). A population-based epidemiologic study of adult neuromuscular disease in the Republic of Ireland. *Neurology*, 88(3), 304 – 313, DOI: 10.1212/WNL.0000000000003504

Leigh, P.N., Abrahams, S., Al-Chalabi, A., Ampong, M-A., Goldstein, L.H., Johnson, R., ... & Willey, E. (2003). The management of motor neurone disease. *Journal of Neurology and Neurosurgery*. 74(4), 32-47. DOI: 10.1136/jnnp.74.suppl_4.iv32.

Leiter, A.E., & Winsor, J. (1996) Compliance of geriatric dysphagic patients with safe-swallowing instructions. *Journal of Medical Speech-Language Pathology*, 4, 289-300.

Leonard, R., & Kendall K. A. (2007). *Dysphagia Assessment and Treatment Planning* (2nd ed.), Plural Publishing, Co.: San Diego, CA.,

Leopold, N. A., & Kagel, M. C. (1996). Prepharyngeal dysphagia in Parkinson's disease. *Dysphagia*, 11(1), 14–22.

Lerum, S.V, K., Solbrække, K.N., & Frich, J.C. (2016). Family caregivers' accounts of caring for a family member with motor neurone disease in Norway: a qualitative study. *BMC Palliative Care*, 15(22). DOI: 10.1186/s12904-016-0097-4

LeVasseur, J. J. (2003). The problem of bracketing in phenomenology. *Qualitative Health Research*. 13(3), 408-420. DOI: 10.1177/1049732302250337.

Lewis, M. & Staehler, T. (2013). *Phenomenology. An Introduction*. Bloomsbury Academic.

Lilo, P. & Hedges, J. R. (2010). Cognition and behaviour in motor neurone disease. *Current Opinion in Neurology*, 23(6), 638-42. DOI: 10.1097/WCO.0b013e3283400b41.

Limousin, N., Blasco, H., Corcia, P., Gordon, P. H., De Toffol, B., Andres, C., & Praline, J. (2010). Malnutrition at the time of diagnosis is associated with a shorter disease duration in ALS. *Journal of The Neurological Science* 297(1–2), 36–39. DOI: 10.1016/j.jns.2010.06.028.

Lincoln, Y., & Guba, E. (1985). *Naturalistic Inquiry*. London: Sage.

Locock, L., Brown, J.B. (2010). ‘All in the same boat’? Patient and carer attitudes to peer support and social comparison in Motor Neurone Disease (MND). *Social Science and Medicine*, 71(8), 1498–1505. DOI: 10.1016/j.socscimed.2010.06.043.

Logemann, J. A., Shanahan, T., Rademaker, A. W., Kahrilas, P. J., Lazar, R., & Halper, A. (1993). Oropharyngeal swallowing after stroke in the left basal ganglion/internal capsule. *Dysphagia*, 8(3), 230–234.

Logemann, J. A. (1998). *Evaluation and treatment of swallowing disorders*. (2nd ed.). Austin, TX:Pro-Ed.

Logroscino, G., Traynor, B. J., Hardiman, O., Chiò, A., Mitchell, D., Swingler, ... Beghi, E. (2010). Incidence of amyotrophic lateral sclerosis in Europe, *Journal of Neurology, Neurosurgery and Psychiatry*, 81(4), 385 – 390. DOI: 10.1136/jnnp.2009.183525

- Loret, C. (2015). Using Sensory Properties of Food to Trigger Swallowing: A Review. *Critical Reviews in Food Science and Nutrition*, 55(1), 140–145. DOI:10.1080/10408398.2011.649810.
- Low, J., Wyles, C., Wilkinson, T., & Sainsbury, R. (2001). The effects of compliance on clinical outcomes for patients with dysphagia on videofluoroscopy. *Dysphagia*, 16(2), 123–127.
- Love, A., Street, A., Ray R., Lowe, R. (2005). Social aspects of caregiving for people living with motor neurone disease: their relationships to carer well-being. *Palliative and Supportive Care*, 3(1), 33-38.
- Lu, X. & Johnson, B. A. (2016). Direct estimation for adaptive treatment length policies: Methods and application to evaluating the effects of delayed PEG insertion. *Biometrics*, 64, 1-20. DOI: 10.1111/biom.12639.
- Luchesi, K. F., Kitamura, S., & Mourão, L. F. (2014). Amyotrophic Lateral Sclerosis survival analysis: Swallowing and non-oral feeding. *Neurorehabilitation*, 35(3), 535-542. DOI:10.3233/NRE-141149.
- Ludolph A., Drory, V., Hardiman, O., Nakano, I., Ravits, J., Robberecht, W., & Shefner, J., (2015). A revision of the El Escorial criteria – 2015. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, 16(5-6), 291–292. DOI: 10.3109/21678421.2015.1049183.
- Ludolph, A.C., Langen, K.J., Regard, M., Herzog, H., Kemper, B, Kuwert, T., ... Feinendegen, L. (1992). Frontal lobe function in amyotrophic lateral sclerosis: a neuropsychologic and positron emission tomography study. *Acta Neurologica Scandinavica*, 85(2), 81-89.

- Lyall, R. A., Donaldson, N., Polkey, M. I., Leigh, P. N., & Moxham, J. (2001). Respiratory muscle strength and ventilatory failure in amyotrophic lateral sclerosis. *Brain: A Journal of Neurology*, 124(10), 2000-2013.
- Magnus, M. B. T., Giess, R., Puls, I., Naumann, M., & Toyka, K. V. (2002). Disease progression in amyotrophic lateral sclerosis: Predictors of survival. *Muscle & Nerve* 25(5), 709-714. DOI: 10.1002/mus.10090.
- Malim, T., Birch, A., & Wadeley, A. (1992). *Perspectives in psychology*. MacMillan.
- Mardsen, R. (2011). Motor Neuron Disease: an overview. *Primary Health Care* 21(10), 31036.
- Marik, P. E., & Kaplan, D. (2003). Aspiration Pneumonia and Dysphagia in the Elderly. *Chest*, 124(1), 328-336. DOI:10.1378/chest.124.1.328
- Martin, N. H., Lawrence, V., Murray, J., Janssen, A., Higginson, I., Lyall, R., . . . Goldstein, L. H. (2016). Decision Making About Gastrostomy and Noninvasive Ventilation in Amyotrophic Lateral Sclerosis. *Qualitative Health Research*, 26(10), 1366-1381. DOI:10.1177/1049732315583661.
- Masahiko, T., Takeshi, S., Palumbo, J., & Makoto, A. (2016). A 24-Week, Phase III, Double-Blind, Parallel-Group Study of Edaravone (MCI-186) for Treatment of Amyotrophic Lateral Sclerosis (ALS), *Neurology*, 86(16).
- Masiero, S., Pierobon, R., Previato, & C., Gomiero, E. (2008). Pneumonia in Stroke Patients with known Oro-pharyngeal dysphagia: A six month follow up study. *Neurological Sciences*, 29(3), 139-45. DOI: 10.1007/s10072-008-0925-2.
- Mathus-Vliegen, L. M., Louwerse, L. S., Merkus, M. P., Tytgat, G. N., & Vianney de Jong, J. M. (1994). Percutaneous endoscopic gastrostomy in

patients with amyotrophic lateral sclerosis and impaired pulmonary function. *Gastrointestinal Endoscopy*, 40(4), 463-9. DOI: 10.1016/S0016-5107(94)70211-X.

Maxwell, J. A. (2013). *Qualitative Research Design. An Interactive Approach* (3rd Ed.), SAGE Publications, Inc.

May, K. A. (1991). *Interview techniques in qualitative research: Concerns and challenges*. In J. M. Morse (Ed.), Qualitative nursing research: A contemporary dialogue (Rev. ed) (188-201). Thousand Oaks, CA: Sage.

Mayre-Chilton, K.M., Talwar, B.P., & Goff, L.M. (2011). Different experiences and perspectives between head and neck cancer patients and their caregivers on their daily impact of a gastrostomy tube. *Journal of Human Nutrition and Dietetics*, 24(5), 449-59. DOI: 10.1111/j.1365-277X.2011.01165.x.

Mazzini, L., Corra, T., Zaccala, M., Mora, G., Del Piano, M, & Galante, M. (1995). Percutaneous endoscopic gastrostomy and enteral nutrition in amyotrophic lateral sclerosis. *Journal of Neurology*, 242(10), 695-708.

McCabe, M. P., Roberts, C., & Firth, L. (2008). Satisfaction with services among people with progressive neurological illnesses and their carers in Australia. *Nursing & Health Sciences*, 10(3), 209-215. DOI: 10.1111/j.1442-2018.2008.00399.x.

McCabe, M.P., Firth, L., & O'Connor, E.J. (2009). A comparison of mood and quality of life among people with progressive neurological illnesses and their carers. *Journal of Clinical Psychology in Medical Settings*, 16(4), 355-362.

McCombe, P.A., & Henderson, R.D.(2010). Effects of gender in amyotrophic lateral sclerosis. *Gender Medicine*, 7(6), 557-70. DOI: 10.1016/j.genm.2010.11.010.

McCombe, P.A., Wray, N.R., & Henderson, R.D. (2017). Extra-motor abnormalities in amyotrophic lateral sclerosis: another layer of heterogeneity. *Expert Review of Neurotherapeutics*, 17(6), 561-577. DOI: 10.1080/14737175.2017.1273772.

McCurtin, A., Healy, C., Kelly, L., Murphy, F., Ryan, J., & Walsh, J. (2017). Plugging the patient evidence gap: what patients with swallowing disorders post-stroke say about thickened liquids. International Journal of Language and Communication Disorders. DOI:10.1111/1460-6984.12324.

McHorney, C.A., Robbins, J., Lomax, K., Rosenbek, J.C., Chignell, K., Kramer, A.E., & Bricker, D.E. (2002). The SWAL-QOL and SWAL-CARE outcomes tool for oropharyngeal dysphagia in adults: III. Documentation of reliability and validity. *Dysphagia*, 17(2), 97–114. DOI: 10.1007/s00455-001-0109-1.

McKeown, L. P., Porter-Armstrong, A. P., & Baxter, G. D. (2003). The needs and experiences of caregivers of individuals with multiple sclerosis: A systematic review. *Clinical Rehabilitation*, 17(3), 234-248.

McKeown, L.P., Porter-Armstrong, A.P., & Baxter, G.D. (2004). Caregivers of people with multiple sclerosis: experiences of support. *Multiple Sclerosis*, 10(2), 219-30. DOI: 10.1191/1352458504ms1008oa.

- MacQueen, C.A., Taubert, S., Cotter, D., Stevens, S., & Frost, G.S. (2003). Which Commercial Thickening Agent Do Patients Prefer? *Dysphagia*, 18, 46–52. DOI:10.1007/s00455-002-0084-1
- McQuestion, M., Fitch, M., & Howell, D. (2011). The changed meaning of food: Physical, social and emotional loss for patients having received radiation treatment for head and neck cancer. *European Journal of Oncology Nursing*, 15(2), 145-51. DOI:10.1016/j.ejon.2010.07.006.
- Meininger, V., Lacomblez, L., & Salachas, F. (2000). What has changed with riluzole? *Journal of Neurology*, 247(6), 19–22.
- Merico, A., & Cavinato, M. (2011). Autonomic dysfunction in the early stage of ALS with bulbar involvement. *Amyotrophic Lateral Sclerosis*, 12(5), 363-367. DOI: 10.3109/17482968.2011.584628.
- Merleau-Ponty, M. (1967). *Phenomenology of Perception* (C. Smith, Trans.). New York: Routledge.
- Mill, R. H. (2008). Dysphagia Management: Using Thickened Liquids. *The ASHA Leader*, 13, 12-13. DOI: 10.1044/leader.FTR3.13142008.12.
- Miller, F. H., Choi, M. J., Angeli, L. L., Harland, A. A., Stamos, J. A., Thomas, S. T., . . . Rubin, L. H. (2009). Web site usability for the blind and low-vision user. *Technical Communication*, 57, 323-335.
- Miller, N., Noble, E., Jones, D., & Burn, D. (2006). Hard to swallow: dysphagia in Parkinson's disease. *Age Ageing*, 35(6), 614-8. DOI: 10.1093/ageing/afl105.
- Miller, R. G., Rosenberg, J. A., Gelinas, D. F., Mitsumoto, H., Newman, D., Sufit, R., . . . Oppenheimer, E.A. (1999). Practice parameter: the care of the patient with amyotrophic lateral sclerosis (an evidence-based review):

report of the Quality Standards Subcommittee of the American Academy of Neurology: ALS Practice Parameters Task Force. *Neurology*, 52(7); 1311-23.

Miller, R.G., Jackson, C.E., Kasarskis, E.J., England, J.D., Forshew, D., Johnston, W., ... Woolley, S.C. (2009). Quality Standards Subcommittee of the American Academy of Neurology. Practice parameter update: the care of the patient with amyotrophic lateral sclerosis: drug, nutritional, and respiratory therapies (an evidence-based review): report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology*, 73(15), 1218-26.

Miller, R. G., Mitchell, J. D., Lyon, M., & Moore, D. H. (2012). Riluzole for amyotrophic lateral sclerosis (ALS)/motor neuron disease (MND).

Cochrane Database of Systematic Reviews 3:CD001447. DOI: 10.1002/14651858.CD001447.

Mingers, J., & Willcocks, L. P. (Ed) (2004). *Social Theory and Philosophy for Information Systems*. Wiley.

Mistry K., & Simpson J. (2013). Exploring the transitional process from receiving a diagnosis to living with motor neurone disease. *Psychology & Health*, 28(8), 939–953. DOI: 10.1080/08870446.2013.770513.

Mitchell, J. D., Callagher, P., Gardham, J., Mitchell, C., Dixon, M., Addison-Jones, R., ... O'Brien, M. R. (2010). Timelines in the diagnostic evaluation of people with suspected amyotrophic lateral sclerosis (ALS)/motor neuron disease (MND)—a 20-year review: Can we do better? *Amyotrophic Lateral Sclerosis*, 11(6), 537–541. DOI: 10.3109/17482968.2010.495158.

- Mitchell, J. D., O'Brien, M. R., & Joshi, M. (2006). Audit of outcomes in motor neuron disease (MND) patients treated with riluzole. *Amyotrophic Lateral Sclerosis*, 7(2), 67-71. DOI: 10.1080/14660820500396984
- Mitchell, J..D., & Borasio, G.D. (2007). Amyotrophic Lateral Sclerosis. *Lancet* 369(9578), 2031-41. DOI: 10.1016/S0140-6736(07)60944-1
- Mitchell, S.L., Kiely, D.K., & Lipsitz, L.A. (1997). The risk factors and impact on survival of feeding tube placement in nursing home residents with severe cognitive impairment. *Archives of Internal Medicine*, 157(3), 327-332.
- Mitsumoto, H., & Rabkin, J. (2007). Palliative care for patients with amyotrophic lateral sclerosis. "Prepare for the worst and hope for the best". *JAMA*, 298(2), 207-216. DOI: 10.1001/jama.298.2.207.
- Mitsumoto, H., Chad, D.A., & Pioro, E.P. (1998). *Amyotrophic lateral sclerosis*. FA Davis, Philadelphia.
- Miyashita, M., Narita, Y., Sakamoto, A., Kawada, N., Akiyama, M., Kayama, M., ... Fukuhara, S. (2009). Care burden and depression in caregivers caring for patients with intractable neurological diseases at home in Japan. *Journal of the Neurological Sciences*, 276(1-2), 148-52. DOI: 10.1016/j.jns.2008.09.022.
- Mock, S. & Berner, K. (2010). Sense making and benefit finding among patients with amyotrophic lateral sclerosis and their primary caregivers. *Journal of Health Psychology*, 15(1), 115-121. DOI: 10.1177/1359105309344897.

- Mockford, C., Jenkinson, C., & Fitzpatrick, R. (2006). A review: carers, MND and service provision. *Amyotrophic Lateral Sclerosis*, 7(3), 132–4. DOI: 10.1080/14660820600601028.
- Moran , D. (2000). *Introduction to Phenomenology*. Routledge.
- Moran, C., & O'Mahoney, S. (2015). When is feeding via a percutaneous endoscopic gastrostomy indicated? *Current Opinions in Gastroenterology*, 31(2), 137-42. DOI: 10.1097/MOG.0000000000000152
- Morgan, A., & Ward, E. (2001). *Swallowing: Neuroanatomical and physiological framework*. In B.E. Murdoch and D.G. Theodoros, Traumatic Brain Injury: Associated Speech, Language and Swallowing Disorders. Australia: Singular Publishing.
- Morris, A., Walsh, S., Raheja, D., Kovacik-Eicher, M. E., & Simmons, Z. (2016). Longitudinal analysis of patient communication and treatment preferences in an ALS clinic. Sessions 1-11, *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, 17, Sup1, 1-80. DOI:10.1080/21678421.2016.1231971.
- Morton, P. (2006). Using Critical Realism to Explain Strategic Information Systems Planning. *Journal of Information Technology Theory and Application (JITTA)*, 8(1).
- Moura, M. C., Novaes, M. R. C. G., Eduardo, E. J., Zago, Y. S. S. P., Freitas, R. D. N. B., & Casulari, L. A. (2015). Prognostic Factors in Amyotrophic Lateral Sclerosis: A Population-Based Study. *PLoS ONE*, 10(10).
- Murphy, J. (2004). I Prefer Contact This Close: Perceptions of AAC by People with Motor Neurone Disease and their Communication Partners.

Augmentative and Alternative Communication, 20(4). DOI:

10.1080/07434610400005663

Murphy, J., Henry, R., & Lomen-Hoerth, C. (2007). Establishing subtypes of the continuum of frontal lobe impairment in amyotrophic lateral sclerosis. *Archives Neurology, 64*(3), 330-334. DOI: 10.1001/archneur.64.3.330.

Murphy, L. M., & Lipman, T. O. (2003). Percutaneous endoscopic gastrostomy does not prolong survival in patients with dementia. *Archives of Internal Medicine, 163*(11), 1351-3. DOI: 10.1001/archinte.163.11.1351.

Murphy, V., Felgoise, S. H., Walsh, S. M., & Simmons, Z. (2009). Problem solving skills predict quality of life and psychological morbidity in ALS caregivers. *Amyotrophic Lateral Sclerosis, 10*(3), 147-153. DOI: 10.1080/17482960802245007.

Murry, T., Carrau, R.L., & Chan, K.M.K. (2016). *Clinical Management of Swallowing Disorders*, 4th Edition. Plural Publishing.

Muscaritoli, M., Kushta, I., Molfino, A., Inghilleri, M., Sabatelli, M., & Rossi Fanelli, F. (2012). Nutritional and metabolic support in patients with amyotrophic lateral sclerosis. *Nutrition, 28*(10), 959–66. DOI: 10.1016/j.nut.2012.01.011

National Institute for Clinical Excellence [NICE] (2004). *Improving supportive & palliative care for adults with cancer*. London. NICE. Retrieved from: <https://www.nice.org.uk/guidance/csg4>.

National Institute for Clinical Excellence [NICE] (2016). *Motor neurone disease: assessment and management*. London. NICE. Retrieved from: <https://www.nice.org.uk/guidance/ng42>.

National Institute for Health and Care Excellence [NICE] (2010). Quality Statement 4: Swallow Screening and Nutrition Management. Retrieved from: www.nice.org.uk/guidance/qs2/chapter/quality-statement-4-swallow-screening.

Navaie-Waliser, M., Feldman, P. H., Gould, D. A., Levine, C., Kuerbis, A. N., & Donelan, K. (2002). When the Caregiver Needs Care: The Plight of Vulnerable Caregivers. *American Journal of Public Health, 92*(3), 409–413.

Neuman, L. W. (2000). *Social Research Methods: Qualitative and Quantitative Approaches* (4th Ed.), USA: Allyn and Bacon.

Neurological Alliance of Ireland (2015) Report on National Survey of Neurology Services. Retrieved from:
http://www.nai.ie/assets/22/E622B527-41E1-4471-9EFDAE484E1745B2_document/NAI_Report_on_National_Services_2015_C.pdf.

Nguyen, N. P., Frank, C., Moltz, C. C., Vos, P., Smith, H. J., Karlsson, U., Dutta, S., Midyett, A., ... Sallah, S. (2005). The impact of dysphagia on quality of life after treatment of head and neck cancer. *International Journal of Radiation, Oncology, Biology, Physics, 61*(3), 772-778. DOI: 10.1016/j.ijrobp.2004.06.017.

Nowlan, J. S., Wuthrich, V. M., & Rapee, R. M. (2014). Positive reappraisal in older adults: a systematic literature review. *Aging and Mental Health* 9(1–10).

Nund, R. L., Ward, E. C., Scarinci, N. A., Cartmill, B., Kuipers, P., & Porceddu, S. V. (2014a). Application of the International Classification of Functioning, Disability and Health (ICF) to People with Dysphagia Following Non-surgical Head and Neck Cancer Management. *Dysphagia* 29(6), 692–703. DOI: 10.1007/s00455-014-9563-4.

Nund, R. L., Ward, E. C., Scarinci, N. A., Cartmill, B., Kuipers, P., & Porceddu, S.V. (2014b). Carers' Experiences of Dysphagia in People Treated for Head and Neck Cancer: A Qualitative Study. *Dysphagia*, 29(4). 450-458. DOI: 10.1007/s00455-014-9527-8.

Nund, R. L., Ward, E. C., Scarinci, N. A., Cartmill, B., Kuipers, P., & Porceddu, S.V. (2014c). Survivors' experiences of dysphagia-related services following head and neck cancer: Implications for clinical practice. *International Journal of Language and Communication Disorders*, 49(3), 354–363. DOI: 10.1111/1460-6984.12071.

Nund, R. L., Ward, E. C., Scarinci, N. A., Cartmill, B., Kuipers, P., & Porceddu, S.V. (2014d). The lived experience of dysphagia following non-surgical treatment for head and neck cancer. *International Journal of Speech-Language Pathology*, 16(3): 282–289. DOI: 10.3109/17549507.2013.861869.

- Nund, R. L., Ward, E. C., Scarinci, N. A., Cartmill, B., Kuipers, P., & Porceddu, S.V. (2016). Third-party disability in carers of people with dysphagia following non-surgical management for head and neck cancer. *Disability and Rehabilitation. An International, Multidisciplinary Journal* 38(5): 462–471. DOI: 10.3109/09638288.2015.1046563.
- Nunes, G., Santos, C. A., Grunho, M., & Fonseca, J. (2016). Enteral feeding through endoscopic gastrostomy in amyotrophic lateral sclerosis. *Nutrition Hospitalaria*, 33(5), 1015-1021. DOI:10.20960/nh.561.
- O'Brien, M. R., Whitehead, B., Jack, B. A., & Mitchell, J. D. (2011). From symptom onset to a diagnosis of amyotrophic lateral sclerosis / motor neurone disease; experiences of people with ALS/MND and family caregivers: a qualitative study. *Amyotrophic Lateral Sclerosis*, 12(2), 97-104 DOI: 10.3109/17482968.2010.546414.
- O'Connor, E. J., McCabe, M. P., & Firth, L. (2008). The impact of neurological illness on marital relationship. *Journal of Sex & Marital Therapy*, 34(2): 115-132. DOI: 10.1080/00926230701636189.
- O'Connor, E.J. & McCabe, M.P. (2011). Predictors of quality of life in carers for people with a progressive neurological illness: a longitudinal study. *Quality of Life Research*, 20(5), 703–711. DOI: 10.1007/s11136-010-9804-4.
- O'Brien, M. R. (2004). Information-seeking behaviour among people with motor neurone disease. *British Journal of Nursing*, 13(16), 964-8. DOI: 10.12968/bjon.2004.13.16.15972.
- OFarrell, B.M., Strong, M. J., Zou, G. Y., & Rowe, A. M. (2005). The ALS Research Consortium of Canada. The impact of enteral nutritional

support on the quality of life of ALS patients and their primarily caregivers. *Journal of Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration* 6; 36-38.

Oliveira, A. S., & Pereira, R. D. (2009). Amyotrophic lateral sclerosis (ALS): Three letters that change the people's life. For ever. *Arquivos De Neuro-Psiquiatria*, 67(3a), 750-782. DOI: 10.1590/S0004-282X2009000400040.

Oliver D. (1996). The quality of care and symptom control—the effects on the terminal phase of amyotrophic lateral sclerosis/motor neurone disease. *Journal of Neurological Sciences*, 139, 134–6. DOI: 10.1016/0022-510X(96)00087-1.

Oliver D, Borasio GD, Walsh D. (2006). *Palliative care in amyotrophic lateral sclerosis. From diagnosis to bereavement*. 2nd ed. Oxford: University Press.

Oliver, C. (2012). Critical Realist Grounded Theory: A New Approach for Social Work Research. *British Journal of Social Work* 42(2), 371-387

Oliver, D. J., & Turner, M. R. (2010). Some difficult decision in ALS/MND. *Amyotrophic Lateral Sclerosis*, 11(4), 339-343.

DOI:10.3109/17482968.2010.487532.

Olsson, A. G., Markhede, I., Strang, S., & Persson, L. I. (2010a). Well-being in patients with amyotrophic lateral sclerosis and their next of kin over time. *Acta Neurologica Scandinavica*, 121(4), 244-250. DOI: 10.1111/j.1600-0404.2009.01191.x.

Olsson, A., Markhede, I., Strang, S., & Persson, L. I. (2010b). Differences in quality of life modalities give rise to needs of individual support in

patients with ALS and their next of kin. *Palliative Support Care*, 8(1), 75-82.

Orpen, J. (2017). "I was given a death sentence of 1000 days" - Mum on her devastating Motor Neuron Disease (MND) diagnosis. *Independent. Life Health Features*, June, 26th. Retrieved from:

<http://www.independent.ie/life/health-wellbeing/health-features/i-was-given-a-death-sentence-of-1000-days-mum-on-her-devastating-motor-neuron-disease-mnd-diagnosis-35845602.html>

O'Toole O. & Traynor B.J. & Brennan P. & Sheehan C. & Frost E. & Corr B. & Hardiman O. (2008). Epidemiology and clinical features of amyotrophic lateral sclerosis in Ireland between 1995 and 2004. *Journal of Neurology, Neurosurgery and Psychiatry*, 79(1). DOI: 10.1136/jnnp.2007.117788.

O'Toole O. (2011) *Motor neuron disease in Ireland: epidemiology, risk factors and prognostic indicators*, <http://epubs.resi.ie/mdtheses/20/>. Retrieved on 25.07.2017.

Pagnini, F., Rossi, G., Lunetta, C., Banfi, P., Castelnovo, G., Corbo, M., & Molinari, E. (2010). Burden, depression, and anxiety in caregivers of people with amyotrophic lateral sclerosis. *Psychology, Health & Medicine*, 15(6), 685-693, DOI:10.1080/13548506.2010.507773.

Pagnini, F., Lunetta, C., Rossi, G., Banfi, P., Gorni, K., Cellotto, N., . . . Corbo, M. (2011). Existential well-being and spirituality of individuals with amyotrophic lateral sclerosis is related to psychological well-being of their caregivers. *Amyotrophic Lateral Sclerosis*, 12(2), 105–108. DOI: 10.3109/17482968.2010.502941.

- Palmieri, A., Sorarú, G., Albertini, E., Semenza, C., Vottero-Ris, F., D'Ascenzo, C., ... Angelini, C. (2010). Psychopathological features and suicidal ideation in amyotrophic lateral sclerosis patients. *Neurological Science*, 31(6), 735-740. DOI: 10.1007/s10072-010-0332-3.
- Palovcak, M., Mancinelli, J. M., Elman, L. B., & McCluskey, L. (2007). Diagnostic and therapeutic methods in the management of dysphagia in the ALS population: issues in efficacy for the out-patient setting. *Neurorehabilitation*, 22(6), 417-423.
- Paris, G., Martinaud, O., Petit, A., Cuvelier, A., Hannequin, D., Roppeneck, P., & Verin, E. (2013). Oropharyngeal dysphagia in amyotrophic lateral sclerosis alters quality of life. *Journal of Oral Rehabilitation*, 40(3), 199-204. DOI: 10.1111/joor.12019.
- Parker, G. (1993). With this Body: Caring and Disability in Marriage. Open University Press, Buckingham.
- Parker, C., Power, M., Hamdy, S., Bowen, A., Tyrrell, P., & Thompson, D.G. (2004). Awareness of dysphagia by patients following stroke predicts swallowing performance. *Dysphagia*, 19(1), 28-35. DOI: 10.1007/s00455-003-0032-8.
- Patel, M.X., Doku, V. & Tennakoon, L. (2003). Challenges in recruitment of research participants. *Advances in Psychiatric Treatment*. 9(3), 229-238. DOI: 10.1192/apt.9.3.229.
- Paterson W.G. (1996). Dysphagia in the elderly. *Canadian Family Physician* 42(5).

- Patterson, J. M., Rapley, T., Carding, P. N., Wilson, J. A., & McColl, E. (2013). Head and neck cancer and dysphagia; caring for carers. *Psychoncology*, 22(8), 1815–1820, DOI: 10.1002/pon.3226.
- Pearce, C. B., & Duncan, H. D. (2002). Enteral feeding. Nasogastric, nasojejunal, percutaneous, endoscopic gastrostomy, or jejunostomy: its indications and limitations. *Postgraduate Medical Journal*, 78(918).
- Pena, M. J., Ravasco, P., Machado, M., Pinto, A., Pinto, S., Rocha, L., ... Pinto H.C. (2012). What is the relevance of percutaneous endoscopic gastrostomy on the survival of patients with amyotrophic lateral sclerosis? *Amyotrophic Lateral Sclerosis* 13(6), 550-4 DOI: 10.3109/17482968.2012.684215.
- Penner, J. L., & McClement, S. E. (2008). Using Phenomenology to Examine the Experiences of Family Caregivers of Patients with Advanced Head and Neck Cancer: Reflections of a Novice Researcher. *The International Journal of Qualitative Methods*, 7(2), 92-101. DOI: 10.1177/160940690800700206.
- Penner, J. L., McClement, S., Lobchuk, M., Daeninck, P. (2012). Family Members' Experiences Caring for Patients with Advanced Head and Neck Cancer Receiving Tube Feeding: A Descriptive Phenomenological Study. *Journal of Pain and Symptom Management*, 44(4), 563-571. DOI: 10.1016/j.jpainsymman.2011.10.016.

- Perry, L. (2001a). Screening swallowing function of patients with acute stroke. Part one: identification, implementation and initial evaluation of a screening tool for use by nurses, *Journal of Clinical Nursing*, 10(4), 463–473.
- Perry, L. (2001b). Screening swallowing function of patients with acute stroke. Part two: detailed evaluation of the tool used by nurses, *Journal of Clinical Nursing*, 10(4), 474–481.
- Peters, M., Fitzpatrick, R., Doll, H., Playford, E. D., & Jenkinson, C. (2012). The impact of perceived lack of support provided by health and social care services to caregivers of people with motor neuron disease. *Amyotrophic Lateral Sclerosis*, 13(2), 223-228. DOI: 10.3109/17482968.2011.649759.
- Phukan, J., Elamin, M., Bede, P., Jordan, N., Gallagher, L., Byrne, S., ... Hardiman, O. (2012). The syndrome of cognitive impairment in amyotrophic lateral sclerosis: a population-based study. *Journal of neurology, neurosurgery, and psychiatry*, 83(1), 102-108. DOI: 10.1136/jnnp-2011-300188.
- Plowman, E.K. (2014). *Nutrition and feeding placement for people with ALS: Best practice in clinical decision making*. Retrieved from: <http://dysphagiacafe.com/2014/10/23/nutrition-and-feeding-tube-placement-for-people-with-als-best-practice-in-clinical-decision-making/>.

- Plowman, E.K. (2015). Is There a Role for Exercise in the Management of Bulbar Dysfunction in Amyotrophic Lateral Sclerosis? *Journal of Speech, Language, and Hearing Research*, 58(4), 1151-66. DOI: 10.1044/2015_JSLHR-S-14-0270.
- Pollio, H. R., Henley, T. B., & Thompson, C. J. (1997). *The Phenomenology of Everyday Life: Empirical Investigations of Human Experience*. Cambridge University Press.
- Polt, R. (1999). *Heidegger: An Introduction*. Cornell University Press. Ithaca, New York.
- Porter, L. S., Keefe, F. J., Garst, J., Baucom, D. H., McBride, C., McKee, D. C., ... Scipio, C. (2011). Caregiver-Assisted Coping Skills Training for Lung Cancer: Results of a Randomized Clinical Trial. *Journal of Pain and Symptom Management*, 41(1), 1-13. DOI:10.1016/j.jpainsymman.2010.04.014.
- ProGas Study Group. (2015). Gastrostomy in patients with amyotrophic lateral sclerosis (ProGas): a prospective cohort study. *Lancet Neurology*, 14(7), 702-709. DOI:10.1016/S1474-4422(15)00104-0.
- Rabkin, J. G., Albert, S. M., Rowland, L. P. & Mitsumoto, H. (2009) 'How common is depression among ALS caregivers? A longitudinal study' Amyotrophic Lateral Sclerosis. 10 (5-6) pp. 448-455. DOI: 10.3109/17482960802459889.
- Radunovic, A., Annane, D., Rafiq, M.K. & Mustfa, N. (2013). Mechanical ventilation for amyotrophic lateral sclerosis/motor neuron disease. *The*

Cochrane Database of Systematic Reviews, 28(3). DOI:

10.1002/14651858.CD004427.pub2.

Ray, R. A., & Street, A. F. (2006). Caregiver bodywork: family members' experiences of caring for a person with motor neurone disease. *Journal of Advanced Nursing*, 56(1), 35-43. DOI: 10.1111/j.1365-2648.2006.03977.x.

Ray, R.A., & Street, A.F. (2007) Non-finite loss and emotional labour: family caregivers' experiences of living with motor neurone disease. *Journal of Clinical Nursing*, 16(3A), 35-43. DOI: 10.1111/j.1365-2702.2006.01722.x.

Regan, J., & Walshe, M. (2012). Neuromuscular Conditions. Chapter in *Videofluoroscopy. A Multidisciplinary Team Approach*. Ed. by: Newman, R.D., Nightingale, J.M. Plural Publishing. Inc.

Reid, J., McKenna, H., Fitzsimons, D., & McCance, T. (2009) Fighting over food: patient and family understanding of cancer cachexia. *Oncology Nursing Forum*, 36(4), 439-45. DOI: 10.1188/09.ONF.439-445.

Reilly, S., Ward, E. C. (2005). The epidemiology of dysphagia: Describing the problem - are we too late? *Advances in Speech-Language Pathology*, 7(1); 14-23. DOI: 10.1080/14417040500055110.

Reilly, R., Frankel, F., & Edelstein, S. (2013). Molecular Gastronomy: Transforming Diets for Dysphagia. *Journal of Nutritional Health and Food Science*, 1(1). DOI:10.15226/jnhfs.2013.00101

Research Motor Neurone. (2017). Retrieved from www.mnd.ie.

Rickman, J. (1998). Percutaneous endoscopic gastrostomy: psychological effects. *British Journal of Nursing*, 7(12), 723-729.

- Ringholz, G. M., Appel, S. H., Bradshaw, M., Cooke, N. A., Mosnik, D. M., & Schulz, P. E. (2005). Prevalence and patterns of cognitive impairment in sporadic ALS. *Neurology*, 65, 586–90. DOI: 10.1212/01.wnl.0000172911.39167.b6.
- Ritchie, J. & Lewis, J. (2003). *Qualitative Research Practice. A Guide for Social Science Students and Researchers*. SAGE Publications, London, Thousand Oaks, New Delhi.
- Rivera, F. J., Guevara, C.O., Gallego, I.S, Valiente, B.S, Recuerda, A.S, Mendieta, M. A., . . . Tejedor, E.D (2011). Outcome of patients with amyotrophic lateral sclerosis attending in a multidisciplinary care unit. *Neurologia (Barcelona, Spain)*, 26(8), 455-460. DOI: 10.1016/j.nrl.2011.01.021.
- Robbins R. A., Simmons Z., Bremer B. A., Walsh S. M., & Fischer S. (2001). Quality of life in ALS is maintained as physical function declines. *Neurology*, 56(4), 442–44410.
- Robbins, J.A., Logemann, J.A, & Kirshner, H.S.(1986). Swallowing and speech production in Parkinson's disease. *Annals of Neurology*, 19, 283–287, DOI: 10.1002/ana.410190310.
- Robinson, E., Otten, R. & Hermans, R. C. J. (2016). Descriptive peer norms, self-control and dietary behaviour in young adults. *Psychology of Health*, 31(1), 9-20. DOI: 10.1080/08870446.2015.1067705.
- Robson, C. (2011). *Real World Research*, 3rd Edition. Wiley.
- Rodriguez, K. L., & Young, A. J. (2006). Patients' and healthcare providers' understanding of life-sustaining treatment: Are perceptions of goals

shared or divergent? *Social Science & Medicine* 62, 125-133. DOI: 10.1016/j.socscimed.2005.05.023.

Roe, J. W., Leslie, P., & Drinnan, M. J. (2007). Oropharyngeal dysphagia: the experience of patients with non-head and neck cancers receiving specialist palliative care. *Palliative Medicine*, 21(7), 567-74. DOI: 10.1177/0269216307082656.

Roe, J.W.G. & Leslie, P. (2010). Beginning of the end? Ending the therapeutic relationship in palliative care. *International Journal of Speech & Language Pathology* 12(4), 304-308. DOI: 10.3109/17549507.2010.485330.

Rofes L., Arreola V., Almirall J., Cabr'e M., Campins L., Garc'ia-Perria P., ... & Clav P. (2011). Diagnosis and management of oro-pharyngeal dysphagia and its nutritional and respiratory complications in the elderly. *Hindawi Publishing Corporation Gastroenterology Research and Practice*, 11. DOI:10.1155/2011/818979.

Rooney, J., Byrne, S., Heverin, M., Corr, B., Elamin, M., Staines, A., .. Hardinam, O. (2013). Survival Analysis of Irish Amyotrophic Lateral Sclerosis Patients Diagnosed from 1995-2010. *PLoS One*, 8(9). DOI: 10.1371/journal.pone.0074733.

Rooney, J., Heverin, M., Vajda, A., Crampsie, A., Tobin, K., Byrne, S, ... Hardiman, O. (2014). An Exploratory Spatial Analysis of ALS Incidence in Ireland over 17.5 Years (1995 - July 2013)., *PLoS One*, 9 (5). DOI: 10.1371/journal.pone.0096556.

Rooney, J., Vajda, A., Heverin, M., Elamin, M., Crampsie, A., McLaughlin, R., ... Hardiman, O. (2015). Spatial cluster analysis of population

amyotrophic lateral sclerosis risk in Ireland, *Neurology*, 84(15), 1537-1544. DOI: 10.1212/01.wnl.0000473800.89178.a9.

Rosenberk, J. & Jones, H. *Dysphagia in Movement Disorder*. San Diego:Plural. 2009.

Røthing, M., Malterud, K., & Frich, J.C. (2014). Caregiver roles in families affected by Huntington's disease: a qualitative interview study. Scandinavian Journal of Caring Sciences, 28(4), 700-705. DOI: 10.1111/scs.12098.

Rowland, L.P. (1994). Amyotrophic Lateral Sclerosis. *Current Opinions in Neurology*, 7(4), 310-315.

Royal College of Speech and Language Therapists [RCSLT]. (2005). Clinical Guideline for Disorders of Feeding, Eating, Drinking and Swallowing. Retrieved from: <http://almacen-gpc.dynalias.org/publico/ClinicalGuidelines%20Speech%20Therapists.pdf>.

Royal College of Speech and Language Therapists [RCSLT]. (2007). Policy Statement: The specialist contribution of speech and language therapists along the care pathway for stroke survivors. Retrieved from: <http://www.stroke-in-stoke.info/otherfiles/policynov07.pdf>

Royal College of Speech and Language Therapists [RCSLT]. (2010). Policy Statement: Speech and Language Therapists' Clinical Responsibility around Delegation and the Provision of Training to the Wider Workforce. Retrieved from:

https://www.rcslt.org/members/docs/training_wider_workforce

Royal College of Speech and Language Therapists [RCSLT]. (2014). Resource Manual for Commissioning and Planning Services for SLCN: Dysphagia – updated 2014. Retrieved from:

[https://www.rcslt.org/speech_and_language_therapy
/commissioning/dysphagia_manual_072014](https://www.rcslt.org/speech_and_language_therapy/commissioning/dysphagia_manual_072014)

Ruoppolo, G., Schettino, I., Frasca, V., Giacomelli, E., Prosperini, L., Cambieri, C., . . . Inghilleri, M. (2013). Dysphagia in amyotrophic lateral sclerosis: prevalence and clinical findings. *Acta Neurologica Scandinavica*, 128(6), 397-401. DOI:10.1111/ane.12136.

Russ, K. B., Phillips, M. C., Mel Wilcox, C., & Peter, S. (2015). Percutaneous endoscopic gastrostomy in amyotrophic lateral sclerosis. *The American Journal of The Medical Sciences*, 350(2), 95-97. DOI: 10.1097/MAJ.0000000000000517

Rutter-Locher, Z., Turner, M.R., Leigh, P.N. & Al-Chalabi, A. (2016). Analysis of terms used for the diagnosis and classification of amyotrophic lateral sclerosis and motor neurone disease. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, 17(7-8), 600-604. DOI: 10.1080/21678421.2016.1181766.

Sarfaty, M., Nefussy, B., Gross, D., Shapira, Y., Vaisman, N., & Drory, V.E. (2013). Outcome of Percutaneous Endoscopic Gastrostomy Insertion in Patients with Amyotrophic Lateral Sclerosis in Relation to Respiratory Dysfunction. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, 14(7-8), 528-532. DOI: 10.3109/21678421.2013.812659

Sayer A. (2000). *Realism and social science*. London, Sage.

- Schindler, J. S., & Kelly, J. H. (2002). Swallowing Disorders in the Elderly. *Laryngoscope Volume*, 112(4), 589–602.
- Schreiber, H., Gaigalat, T., Wiedemuth-Catrinescu, U., Graf, M., Uttner, I., ... Ludolph, Ch. A. (2005). Cognitive function in bulbar- and spinal-onset amyotrophic lateral sclerosis. A longitudinal study in 52 patients. *Journal of Neurology*, 252(7), 772–781. DOI: 10.1007/s00415-005-0739-6.
- Schulz, R., Beach, S. R., Cook, T. B., Martire, L. M., Tomlinson, J. M., & Monin, J. K. (2012). Predictors and Consequences of Perceived Lack of Choice in Becoming an Informal Caregiver. *Aging & Mental Health*, 16(6), 712–721. DOI: 10.1080/13607863.2011.651439
- Seidman, I. E. (1991). *Interviewing as qualitative research: A guide for researchers in education and the social sciences*. New York: Teachers College Press.
- Seikel, J. A., King, D. W., & Drumright, D. G. (2010). *Anatomy and Physiology for Speech, Language and Hearing*. 4th edition, Thomson Delmar
- Sejvar, J.J., Holman, R.C., Breses J.S., Kochanek, K. D., & Schonberger, L.B. (2005). Amyotrophic Lateral Sclerosis Mortality in the United States, 1979-2001. *Neuroepidemiology*, 25(3), 144-152. DOI: 10.1159/000086679
- Seki, H., Kameya, T., & Kimura, I. (2000). A survey of current nutrition therapy for ALS patients in Japanese national sanatoriums. *Rinsho Shinkeigaku, Clinical Neurology*, 40(11), 1083-1089.
- Sherman, D.W., McSherry, C. B., Parkas, V., Calabrese, M., & Gatto, M. (2005). Recruitment and retention in a longitudinal palliative care study.

Applied Nursing Research, 18(3), 167–177. DOI:

10.1016/j.apnr.2005.04.003.

Shinebourne, P. (2011a). *Interpretative Phenomenological Analysis*. In N. Frost (ed). Qualitative Research Methods in Psychology: Combining core approaches. Open University.

Shinebourne, P. (2011b). The Theoretical Underpinnings of Interpretative Phenomenological Analysis (IPA). *Existential Analysis: Journal of the Society for Existential Analysis*, 22(1), 16-31.

Simmons, Z., Bremer, B.A., Robbins, R.A., Walsh, S.M., & Fischer, S. (2000) Quality of life in ALS depends on factors other than strength and physical function. *Neurology*, 55(3), 388–392.

Simmons, Z. (2005). Management strategies for patients with amyotrophic lateral sclerosis from diagnosis through death. *Neurologist*, 11(5), 257-270. DOI: 10.1097/01.nrl.0000178758.30374.34

Skinner, B.F. (1966). *Operant behavior*. In W.K. Honig (Ed.), Operant behavior: Areas of research and application. New York: Appleton-Century-Crofts.

Smith, J. A. (1996). Beyond the divide between cognition and discourse. *Psychology & Health*, 11(2), 261–271. DOI: 10.1080/08870449608400256

Smith, J. A., Jarman, M. & Osborne, M. (1999). Doing Interpretative Phenomenological Analysis. In M. Murray & K. Chamberlain (Eds.) *Qualitative Health Psychology: Theories and Methods*. London: Sage.

Smith, J. A., & Osborn, M. (2003). *Interpretative Phenomenological Analysis*. In J. A. Smith (Ed.), Qualitative Psychology: A Practical Guide to Methods. London: Sage.

Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative psychology. *Qualitative Research in Psychology, 1*(1), 39–54.

Smith, J. A., Flower, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage

Sorenson, E. J., Crum, B., & Stevens J. C. (2007a). Incidence of aspiration pneumonia in ALS in Olmsted County MN. *Amyotrophic Lateral Sclerosis* 8:87-89 DOI: 10.1080/17482960601147461.

Sorenson, E. J., Mandrekar, J., Crum, B., & Stevens, J. C. (2007). Effect of referral bias on assessing survival in ALS. *Neurology, 68*, 600-602. DOI: 10.1212/01.wnl.0000254501.58158.e7.

Spataro, R., Ficano, L., Piccoli, F., & La Bella, V. (2011). Percutaneous endoscopic gastrostomy in amyotrophic lateral sclerosis: Effect on survival. *Journal of the Neurological Sciences, 304*(1/2), 44-48.
DOI:10.1016/j.jns.2011.02.016.

Speech Pathology Australia. (2004). Position Paper: Dysphagia – General.

Retrieved from:

<https://www.speechpathologyaustralia.org.au/SPAweb/Members/>

- Clinical_Guidelines/spaweb/Members/Clinical_Guidelines/Clinical_Guidelines.aspx?hkey=f66634e4-825a-4f1a-910d-644553f59140
- Speziale, H. J. S., & Carpenter, D. R. (2007). *Qualitative Research in Nursing: Advancing the Humanistic Imperative*, 4th edn. Lipincott Williams and Wilkins, Philadelphia.
- Stambler, N., Charatan, M., & Cedarbaum, J.M. (1998). Prognostic indicators of survival in ALS. ALS CNTF Treatment Study Group. *Neurology*, 50(1), 66-72.
- Stavroulakis, T., Walsh, T., Shaw, P. J., & McDermott, C.J. (2013). Gastrostomy use in motor neurone disease (MND): a review, meta-analysis and survey of current practice. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration* 14(2), 96-104. DOI: 10.3109/17482968.2012.723722.
- Stavroulakis, T., Baird, W. O., Baxter, S. K., Walsh, T., Shaw, P. J., & McDermott, C. J. (2014). Factors influencing decision-making in relation to timing of gastrostomy insertion in patients with motor neurone disease. *BMJ Supportive & Palliative Care*, 4(1), 57-63. DOI: 10.1136/bmjspcare-2013-000497.
- Stavroulakis, T., Baird, W. O., Baxter, S. K., Walsh, T., Shaw, P. J., & McDermott, C. J. (2016). The impact of gastrostomy in motor neurone disease: challenges and benefits from a patient and carer perspective. *BMJ Supportive & Palliative Care*, 6(1), 52-9. DOI: 10.1136/bmjspcare-2013-000609.
- Steele, C. M., Alsanei, W. A., Ayanikalath S., Barbon C. E., Chen, J., Cichero J.A.Y.,... Wang, H. (2015). The influence of food texture and liquid consistency modification on swallowing physiology and function: A

systematic review. *Dysphagia*, 30(1), 2-26. DOI: 10.1007/s00455-014-9578-x.

Steinhauser, K. E., Clipp, E. C., Hays, J. C., Olsen, M., Arnold, R., Christakis, N. A., ... Tulsky, J. A. (2006). Identifying, recruiting, and retaining seriously-ill patients and their caregivers in longitudinal research.

Palliative Medicine, 20(8), 745-54. DOI: 10.1177/0269216306073112.

Stierwalt, J.A.G., Youmans, S.R. (2007). Tongue Measures in Individuals with Normal and Impaired Swallowing. *American Journal of Speech-Language Pathology*, 16(2), 148-156. DOI: 10.1044/1058-0360(2007/019).

Stiver, D. R. (1996). The Philosophy of Religious Language. Oxford: Blackwell Publishers Ltd.

Strand, E. A., Miller, R. M., Yorkston, K. M., & Hillel, A. D. (1996).

Management of oral-pharyngeal dysphagia symptoms in amyotrophic lateral sclerosis. *Dysphagia*, 11(2), 129-139.

Swan, K., Speyer, R., Heijnen, B. J., Wagg, B., & Cordier, R. (2015). Living with oropharyngeal dysphagia: effects of bolus modification on health-related quality of life - a systematic review. *Quality of Life Research*, 24(10), 2447-2456. DOI: 10.1007/s11136-015-0990-y.

Tabor, L., Gaziano, J., Watts, S., Robison, R., & Plowman, E. K. (2016).

Defining Swallowing-Related Quality of Life Profiles in Individuals with Amyotrophic Lateral Sclerosis. *Dysphagia*, 31(3), 376-382.

DOI:10.1007/s00455-015-9686-2.

- Tanaka, M., Akimoto, M., Palumbo, J., & Sakata, T. (2016). A Double-Blind, Parallel-Group, Placebo-Controlled, 24-Week, Exploratory Study of Edaravone (MCI-186) for the Treatment of Advanced Amyotrophic Lateral Sclerosis (ALS), *Neurology*, 86(16), Supplement P3.191.
- Taylor, L. J., Brown, R. G., Tsermentseli, S., Al-Chalabu, A., Shaw, C. E., Ellis, C. M., ... & Goldstein, L. H. (2013). Is language impairment more common than executive dysfunction in amyotrophic lateral sclerosis? *Journal of Neurology, Neurosurgery and Psychiatry*, 84(5), 494-8. DOI: 10.1136/jnnp-2012-303526.
- The American Speech-Language-Hearing Association [ASHA]. (2004). Speech-Language Pathologists Training and Supervising other Professions in the Delivery of Services to Individuals with Swallowing and Feeding Disorders: Technical Report. DOI:10.1044/policy.TR2004-00135.
- Thorne, S. E. (1991). Methodological orthodoxy in qualitative nursing research: analysis of the issues. *Qualitative Health Research*, 1(2), 178-199. DOI: 10.1177/104973239100100203.
- Thornton, F. J., Fotheringham, T., Alexander, M., Hardiman, O., McGrath, F. P., & Lee, M. J. (2002). Amyotrophic lateral sclerosis: Enteral nutrition provision - Endoscopic or radiologic gastrostomy? *Radiology*, 224(3), 713 – 717. DOI: 10.1148/radiol.2243010909.
- Todd, D., Simpson, J. & Murray, C. (2010). An interpretative phenomenological analysis of delusions in people with Parkinson's disease. *Disability Rehabilitation*, 32(15), 1291–1299. DOI: 10.3109/09638280903514705.
- Tong, M. C. F., Lee, K. Y. S., Yuen, M. T. Y., & Lo, P. S. (2011). Perceptions and experiences of post-irradiation swallowing difficulties in

nasopharyngeal cancer survivors. *European Journal of Cancer Care*

20(2), 170-178. DOI: 10.1111/j.1365-2354.2010.01183.x.

Tortelli, R., Copetti, M., Panza, P., Cortese, R., Capozzo, R., D'Errico, E., ... & Logroscino, G. (2016). Time to generalisation as a predictor of prognosis in amyotrophic lateral sclerosis. *Journal of Neurology, Neurosurgery and Psychiatry*, 87(6), 678-679. DOI: 10.1136/jnnp-2014-308478.

Trick, L.R. (1993). Patient compliance--don't count on it! *Journal of the American Optometric Association*, 64(4), 264-70.

Trail, M., Nelson, N. D., Van J. N, Appel, S.H., & Lai, E.C. (2003). A study comparing patients with amyotrophic lateral sclerosis and their caregivers on measures of quality of life, depression, and their attitude towards treatment options. *Journal of the Neurological Sciences*, 209(1-2), 79-85.

Traynor, B. J., Alexander, M., Corr, B., Frost, E., & Hardiman, O. (2003). Effect of a multidisciplinary amyotrophic lateral sclerosis (ALS) clinic on ALS survival: A population based study, 1996-2000, *Journal of Neurology, Neurosurgery and Psychiatry*, 74(9), 258 – 1261. DOI: 10.1136/jnnp.74.9.1258.

Turner, M. R., Hardiman, O., Benatar, M., Brooks, B. R., Chiò, A., De Carvalho, M., ... Kiernan, M. C. (2013). Controversies and priorities in amyotrophic lateral sclerosis, *The Lancet Neurology*, 12(3), 310 – 322. DOI: 10.1016/S1474-4422(13)70036-X.

U.S. Food and Drug Administration [FDA] (2017). *FDA approves drug to treat ALS*. Retrieved from:

<https://www.fda.gov/newsevents/newsroom/pressannouncements/ucm557102.htm>.

Utton, D. (2015). Try to walk a slackline: it's all about balance. *The Telegraph*, 6th July, Accessed from: <http://www.telegraph.co.uk/sponsored/why-not/11686931/what-is-slacklining.html>.

Van den Berg, J. P., Kalmijn, S., Lindeman, Veldink, J. H., de Visser, M., Van der Graaff, M. M., ... Van den Berg, L. H. (2005). Multidisciplinary ALS care improves quality of life in patients with ALS. *Neurology*, 65(8), 1264-1267. DOI: 10.1212/01.wnl.0000180717.29273.12.

Van der Graaff, M.M., De Jong, J.M., Baas, F, & de Visser, M., (2009). Upper motor neuron and extra-motor neuron involvement in amyotrophic lateral sclerosis: a clinical and brain imaging review, *Neuromuscular Disorders*, 19(1), 53-8. DOI: 10.1016/j.nmd.2008.10.002.

Van der Hulst, E. J., Bak, T. H., & Abrahams, S. (2015). Impaired affective and cognitive theory of mind and behavioural change in amyotrophic lateral sclerosis. *Journal of Neurology, Neurosurgery, And Psychiatry*, 86(11), 1208-1215. DOI: 10.1136/jnnp-2014-309290.

Van Rosendaal, G. M., Verhoef, M. J., & Kinsella, T. D. (1999). How are decisions made about the use of percutaneous endoscopic gastrostomy for long-term nutritional support? *The American Journal of Gastroenterology*, 94(11), 3225-8. DOI: 10.1111/j.1572-0241.1999.01522.x .

- Van Teijlingen, E. R., Friend, E., & Kamal, A. D. (2001). Service use and needs of people with motor neurone disease and their carers in Scotland. *Health & Social Care in the Community*, 9(6), 397-403 397.
- Vartanian, L.R. (2015). Impression management and food intake. Current directions in research. *Appetite*, 86, 74-80, DOI: 10.1016/j.appet.2014.08.021.
- Vesey, S., Leslie, P., & Exley, C. (2008). A pilot study exploring the factors that influence the decision to have PEG feeding in patients with progressive conditions. *Dysphagia*, 23(3):310-6. DOI: 10.1007/s00455-008-9149-0.
- Vögele, C., Gibson, L. (2010). "Mood, emotions and eating disorders," in *Oxford Handbook of Eating Disorders*. Series: Oxford Library of Psychology, ed. W. S. Agras (New York: Oxford University Press), 180–205.
- Walshe, M. (2014) Oropharyngeal Dysphagia in Neurodegenerative Disease. *Journal of Gastroenterology and Hepatology Research*. 3(10), 1265-1271.
- Wang, C.L., Shyu, Y.L., Wang, J.Y., & Lu, C.H. (2017). Progressive compensatory symbiosis: spouse caregiver experiences of caring for persons with dementia in Taiwan, *Aging & Mental Health*, 21(3), 241-252. DOI: 10.1080/13607863.2015.1081148.
- Watt, E., & Whyte, F. (2003). The experience of dysphagia and its effect on the quality of life of patients with oesophageal cancer. *European Journal of Cancer Care*, 12(2), 183-93.
- Webber, J. (2006). Sartre's Theory of Character. *European Journal of Philosophy*, 1(1), 94-116.

- Wegener, D. T., & Petty, R. E. (1994). Mood management across affective states: The hedonic contingency hypothesis. *Journal of Personality and Social Psychology*, 66, 1034-1048.
- Whitehead, B., O'Brien, M.R., Jack, B.A., Mitchell, D. (2011). Experiences of dying, death and bereavement in motor neuron disease: A qualitative study. *Palliative Medicine*, 26(4), 368 – 378.
- Wijesekera, L. C., & Leigh, P. N. (2009). Amyotrophic lateral sclerosis. *Orphanet Journal of Rare Diseases*, 4(3), 1-22. DOI: 10.1186/1750-1172-4-3.
- World Health organisation (WHO) (2001) *International Classification of Functioning, Disability and Health, ICF*. Geneva.
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, 15, 215-228. DOI: 10.1080/08870440008400302.
- Yardley, L. (2011). *Demonstrating validity in qualitative research*. In J. A. Smith (Ed.), Qualitative psychology: A practical guide to research methods. London: SAGE.
- Yorkston, K. M., & Beukelman, D. R. (1981). *Assessment of Intelligibility of Dysarthric Speech*. C.C. Publications.
- Yorkston, K. M., Strand, E., Miller, R., Hillel, A. & 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.

Yorkston, K.M., Beukelman, D., Hakel M., & Dorsey, M.(2007). *Sentence Intelligibility Test, Speech Intelligibility Test*. Lincoln, Neb, USA: Madonna Rehabilitation Hospital.

Youll, J., & Meekosha, H. (2013). Always look at the bright side of life. Cancer and positive thinking. *Journal of Sociology*, 4 (1), 22-40. DOI: 10.1177/1440783311417742.

Zahavi, D. (2003). *Husserl's Phenomenology*. Stanford University Press.

Zhang, Q., Liao, J., Liao, X., Wu, X., Wan, M., Wang, Ch., & Ma, Q. (2014). Disease knowledge level is a noteworthy risk factor of anxiety and depression in patients with chronic obstructive pulmonary disease: a cross-sectional study. *BMC Pulmonary Medicine*, 14(92). DOI: 10.1186/1471-2466-14-92.