

Cuidados de Enfermagem à Pessoa com Doença Neurológica Degenerativa

Serafim Silva. Especialista em Enfermagem de Reabilitação, Pós-Graduado em Cuidados Continuados. Enfermeiro Coordenador UCC Santa Casa Misericórdia Santiago Cacém, Enfermeiro na Unidade Local Saúde Litoral Alentejano.

Introdução

As doenças neurológicas resultam de dano ou lesão do sistema nervoso central e/ou periférico com impacto na pessoa e na sua família para o resto da sua vida (Department of Health, 2005) e constituem a principal causa de restrição à participação (Kirton *et al.*, 2011) e afetam cerca de um bilião de pessoas no mundo (Organização Mundial da Saúde, 2007), valor que tenderá a aumentar devido ao envelhecimento da população (Kirton *et al.*, 2011).

No Reino Unido cerca de 10 Milhões de pessoas são afetadas por doenças neurológicas e representam cerca de 20% das admissões em hospitais de agudos. Estima-se que 350 mil pessoas apresentam dependência nas suas atividades de vida associadas a uma doença neurológica (Kirton *et al.*, 2011), com alterações cognitivas, comunicacionais e comportamentais (Baker, 2009).

Podem apresentar múltiplas etiologias, como predisposição genética, acidentes cerebrovasculares, traumatismo crânio-encefálico, infecções do sistema nervoso, doenças metabólicas, doenças degenerativas e causas congénitas (Jani & Gore, 2014).

Incluem-se nas doenças neurológicas degenerativas, patologias como a: doença de Huntington, doença de Parkinson, a esclerose múltipla (Baker & Kakora-Shiner, 2009) e doença do neurônio motor (Marsden, 2011). Estas caracterizam-se por uma deterioração progressiva da função cognitiva e com um aumentar da dependência na progressão da doença (Sleeman *et al.*, 2013). Os sintomas

variam de acordo com a doença e de como estes são vividos (Wilson *et al.*, 2008).

Esta experiência vai afetar física e psicologicamente a pessoa, e diminuir a sua qualidade de vida e das pessoas que lhe são próximas (Mendes, 2014).

Caracterização das principais Doenças Neurológicas Degenerativas

Doença de Parkinson

É uma doença crónica, neurodegenerativa progressiva, que resulta na diminuição dos níveis de dopamina nos gânglios basais do cérebro. É a segunda doença neurodegenerativa mais frequente, atrás da doença de Alzheimer (Parkinson UK, 2015). Apresenta um elevado número de sintomas motores e não motores (Hand & Martin, 2015). A prevalência global é de 0,3% e aumenta a partir da sexta década de vida. Apenas 5 a 10% das pessoas apresentam a doença com menos de 40 anos de idade (Parkinson UK, 2015).

Os sintomas mais frequentes são o tremor em repouso (sintoma de início em 75% dos casos), a rigidez, a bradicinesia, instabilidade postural (Hellqvist & Bertero, 2015), a lentidão e a diminuição dos movimentos voluntários. Existe uma diminuição da capacidade de realizar movimentos coordenados, com fácies inexpressiva, alteração do andar, dificuldade em falar, mastigar e deglutar (Lesmes *et al.*, 2014). É uma doença flutuante, em que os sintomas podem variar e mudar a qualquer momento (Heisters, 2011).



LUSODIDACTA

Direitos reservados® 2017

LUSODIDACTA – Soc. Port. de Material Didáctico, Lda.

Título:

CUIDADOS DE ENFERMAGEM DE REABILITAÇÃO À PESSOA AO LONGO DA VIDA

Autores Coordenadores:

Cristina Marques-Vieira

Luís Sousa

Prefácio:

João Santos

Ilustração e capa:

Maria Caroço

Pré-impressão:

Estúdio Lusodidacta

Impressão e acabamento:

Rainho & Neves, Artes Gráficas

© LUSODIDACTA – Soc. Port. de Material Didáctico, Lda.

Rua Dário Cannas, 5-A – 2670-427 Loures

Tel.: 21 983 98 40 – Fax: 21 983 98 48

E-mail: lusodidacta@lusodidacta.pt

www.lusodidacta.pt

ISBN: 978-989-8075-73-4

Depósito Legal: 418 394/16

1^a Edição: Dezembro de 2016

Consulte o site da Lusodata em <http://www.lusodidacta.pt>

Para adquirir o livro “Cuidados de enfermagem de reabilitação à pessoa ao Longo da vida” pode aceder ao *link*:

http://www.lusodidacta.pt/index.php?page=shop.product_details&flypage=flypage.tpl&product_id=348&category_id=6&keyword=cuidados+de+enfermagem&option=com_virtuemart&Itemid=1

Reservados todos os direitos.

É proibida a duplicação ou reprodução deste volume, ou de partes do mesmo, sob quaisquer formas ou por quaisquer meios (electrónico, mecânico, gravação, fotocópia ou outro) sem permissão escrita do Editor. Os artigos são da responsabilidade dos seus autores.

REFERÊNCIAS

- Ahlskog, J. E. (2014). Parkinson disease treatment in hospitals and nursing facilities: Avoiding pitfalls. *Mayo Clinic Proc*, 9(7), 997-1003.
- Akkus, Y. & Duru, G. (2011). Problems and Factors Affecting the Sexual Lives of Patients with Multiple Sclerosis Living in Turkey. *Sex Disabil*, 29, 55-63.
- Aspinal, F., Grindley, K., Bernard, S. & Parker, G. (2012) Promoting continuity of care for people with long-term neurological conditons: the role of the neurology nurse specialist. *Blackwell Publishing*. 2309-2319.
- Aubeeluck, A. & Wilson, E. (2008). Huntingdon's disease. Part 1: Essential background and management. *British Journal of Nursing*, 17(3), 146-151.
- Aubeeluck, A. & Moskowitz, C. B. (2008). Huntingdon's disease. Part 3: family aspects of HD. *British Journal of Nursing*, 17(5), 328-331.
- Baker, M., & Kakora-Shiner, N. (2009). Long-term invasive mechanical ventilation for patients with neurological impairments. *British Journal of Neuroscience Nursing*, 5(9), 409-415.
- Baker, M. (2009). Providing care for adults with complex neurorogical disabilities. *Britsh Journal of Nursing*. 18(17), 1050-1054.
- Baker, M., McLaren, S., & Crichton, N. (2009). A review of the literature on nursing in Huntington's disease: A need for specialist knowledge. *British Journal of Neuroscience Nursing*, 5(8), 360-366.
- Baxter, S. K., Baird, W. O., Thompson, S., Bianchi, S. M., Walters, S. J., Lee, E., ... McDermott, C. J. (2013). The impact on the family carer of motor neurone disease and intervention with noninvasive ventilation. *Journal of Palliative Medicine*, 16(12), 1602-1609.
- Blumlein, D., Baker, M., Parker, D. & Armah, S. (2009). Huntington's disease part 2: suggestions for practice. *British Journal of Healthcare Assistants*, 03(06), 272-276.
- Boeije, H. & Janssens. A. (2008). "It might happen or it might not": how patients with multiple sclerosis explain their perception of prognostic rick. *Social Science & Medicine*, 59, 861-868.
- Bourne, C. (2006). Cognitive impairment and behavioural difficulties in patients with huntingons disease. *Nursing Standar*, 20(35), 41-44.
- Borsook, D. (2011). Neurological diseases and pain. *Brain a Journal of Neurology*, 135, 320-344.
- Britton, T. (2005). Sleep disorders associated with neurological disease. *Nurse & Residential Care*, 7(12), 560-562.
- Buchanan, R. J., Wang, S., Tai-Seale, M. & Ju, H. (2003). A nalyses of nursing home residents with multiple sclerosis and depression using the Minimum Data Set. *Multiple Sclerosis*, 9, 171-188.
- Calne, S. M. (2005). Late-stage Parkinson's disease for the rehabilitation specialist a nursing perspective. *Topics in Gerlairic Rehabilitation*, 21(3), 233-246.
- Campos, D. M., Tosin, M. H. S., Blanco, L., Santana, F. R. & Oliveira, B. G. R. B. (2015). Nursing diagnoses for urinary disorders in patients with Parkinson's disease. *Acta Paulista de Enfermagem*, 28(2), 190-195.
- Cassani, R. (2014). Promoting intermittent self-catheterisation to encourage self-care in district nursing patients. *British Journal of Community Nursing*, 19(4), 177-181.
- Chaudhuri, R. K. (2003). Nocturnal Sympton Complex in PD and its management. *Neurology*, 61, 17-23.
- Crabb, L. (2001) Sleep disorders in Parkinson's disease: the nursing role. *British Journal of Nursin*,10(1), 42-47.
- Dancis, A. & Cotter, V. T. (2015). Diagnosis and management of cognitive impairment in parkinson's disease. *The Journal for Nurse Practitioners*, 11(3), 307-313.
- Dand, P. & Sakel, M. (2010). The management of drooling in motor neurone disease. *International Journal of Palliative Nursing*. 16(11), 560-564.
- Demakis, G. J., Buchanan, R. & DeWald, L. (2009). A longitudinal study of cognition in nursing home residents with multiple sclerosis. *Informa Healthcare*, 31(21), 1734-1741.
- Department of Health (2005). *National Service Framework for Long-Term Conditions*.

- Ertekin, O., Ozakbas, S. & Idiman, E. (2014). Caregiver burden, quality of life and walking ability in different disability levels of multiple sclerosis. *NeuroRehabilitation*, 34, 313–321.
- Figved, N., Myhr, K., Larsen, J. & Aarsland, D. (2007). Caregiver burden in multiple sclerosis: the impact of neuropsychiatric symptoms. *J Neurol Neurosurg Psychiatry*, 78, 1097–1102.
- Finesilver, C. (2003). Multiple sclerosis. *RN*, 66 (4), 36-44.
- Forbes R. (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, 813-817.
- Fowler, C. J., Panicker, J. N., Drake, M., Harris, C., Harrison, S. C. W., Kirby, M., ... Porter, B. (2009). A UK consensus on the management of the bladder in multiple sclerosis. *Journal of Neurology, Neurosurgery & Psychiatry*, 80(5), 470-477.
- Freeman, J., Cowan, P., Hourihan, S., Johansson-Charles, E., McDowall, K., Nock, A. & Rowlands, H. (2013). Management of sleep disturbance in multiple sclerosis: a survey of current practice in the UK. *British Journal of Neuroscience Nursing*, 9(6), 279-285.
- Gale, C. (2015). Assisting patients with motor neurone disease to make decisions about their care. *International Journal of Palliative Nursing*, 21(5), 251-255.
- Greenfield, J., Treacy, C. & Giunti, P. (2006). Centres of excellence for the care of people with progressive ataxias. *British Journal of Nursing*, 15 (17), 932-936.
- Gregory, P., Morgan, K. & Lynall, A. (2012). Improving sleep management in people with Parkinson's. *British Journal of Community Nursing*, 17 (1), 14-20.
- Hand, A. & Martin, A. (2015). Assessing quality of life in Parkinson's: the nurse specialist's role. *British Journal of Neuroscience Nursing*, 11(4), 166-169.
- Harding, V., Stewart, I. & Knight, C. (2012). Health-care workers' perceptions of contributors to quality of life for people with Huntington's disease. *British Journal of Neuroscience Nursing*, 8(4), 191-197.
- Heisters, D. (2011). Parkinson's: symptoms, treatments and research. *British Journal of Nursing*, 20(9), 548-554.
- Hellqvist, C. & Bertero, C. (2015). Support supplied by Parkinson's disease specialist nurses to Parkinson's disease patients and their spouses. *Applied Nursing Research*, 28, 86–91.
- Hines, S. et al. (2011). Identification and nursing management of dysphagia in individuals with acute neurological impairment (update). *International Journal of Evidence-Based Healthcare*, 9, 148-150.
- Hoeman, P. S. (2011) *Enfermagem de reabilitação: Prevenção, intervenção e resultados esperados*. 4ª Edição. Rio de Janeiro: Lusodidacta.
- Holmes, T. (2005). Motor Neurone Disease and the NSF for long-term neurological conditions. *Primary health care*, 15(91), 27-31.
- Jani, M. P. & Gore, G. B. (2014). Ocurrence of communication and swallowing problems in neurological disordes: analysis of forty patients. *NeuroRehabilitation*, 35, 719-727.
- Januário, C. (2011). *Doença de Huntington: onde estamos agora?* Tese de Doutoramento. Faculdade de Medicina da Universidade de Coimbra. Disponível em: <https://eg.sib.uc.pt/handle/10316/18242>
- Jarrett, L. (2015). Being and becoming a spasticity nurse specialist: a reflexive narrative study. *British Journal of Neuroscience Nursing*, 11(3), 129-136.
- Jawahar, R., Oh, U., Yang, S. & Lapane, K. L. (2013). A Systematic Review of Pharmacological Pain Management in Multiple Sclerosis. *Adis*, 73, 1711-1722.
- Kirton, J. A., Jacj, B. A., O'Brien, M. R. & Roe, B. (2011). Care of patients with neurological conditions: the impact of a generic neurology nursing service development on patients and their carers. *Journal of Clinical Nursing*, 21, 207-215.
- Klager, J., Duckett, A., Sandler, S. & Moskowitz, C. (2008). Huntington's Disease: a Caring Approach to the End of Life. *Care Management Journals*, 9(2), 75-81.
- Lesmes, I. B., Peláez, R. B., de la Cuerda Compés, C., Alvarez, M. C., & García-Peris, P. (2014). Manejo nutricional

- en las enfermedades neurológicas crónicas. *Nutricion Hospitalar*, 29(2), 38-46.
- Lindahl, A. J. & MachMahon, D. (2011). Parkinson's: treating the symptoms. *British Journal of Nursing*, 20(14), 852-857.
- Lindop, F. (2012). A multidisciplinary approach to Parkinson's disease. *British Journal of Neuroscience Nursing*, 8(2), 61-64.
- Litchfield, J. & Thomas, S. (2010). Promoting self-management of multiple sclerosis in primary care. *Primary Health Care*, 20(2), 32-39.
- Magennis, B., Lynch, T. & Corry, M. (2014). Current trends in the medical management of Parkinson's disease: implications for nursing practice. *British Journal of Neuroscience Nursing*, 10(2), 67-74.
- MDN Association (2015). *Homepage MND Association*. Northampton. Disponível em <http://www.mndassociation.org>.
- Mangnall, J. (2011). Continence during progressive neurological disease. *Nursing & Residential Care*, 13 (12), 582-586.
- Marsden, R. (2011). Motor neurone disease: An overview. *Primary Health Care*, 21(10), 31-36.
- Mendes, A. (2014). Patients with long-term neurological conditions: delivering best practice in the community. *British Journal of Community Nursing*, 19(12), 616-618.
- Oliver, D. (2010). The assessment and management of pain in neurological disease. *British Journal of Neuroscience Nursing*, 6(2), 70-72.
- Ordem dos Enfermeiros (2011). *Atribuição do Título de Enfermeiro Especialista: Processos formativos*. Documento de Trabalho.
- Organização Mundial da Saúde (2007) *Neurological Disorders: Public Health Challenges*. World Health Organisation. Geneva.
- Parnham, J. & MacMahon, D. (2008). Diagnosis and management of Parkinson's disease: what the NICE guidelines say, and why. *Primary health care*, 18 (3), 31-35.
- Parkinson UK (2015). *What is Parkinson*. Disponível em <http://www.parkinsons.org.uk>.
- Quarrell, O. (2008). *Huntington's disease: The facts*. 2ª Edição. Oxford University Press. Oxford.
- Rae-Grant, A., Turner, A., Sloan, A., Miller, D., Hunziker, J. & Haselkorn, J. (2011). Self-management in neurological disorders: systematic review of the literature and potential interventions in multiple sclerosis care. *Journal of Rehabilitation Research & Development*, 48(9), 1087-1100.
- Rawlins, M. (2010). Huntington's Disease out of the closet?. *Lancet*, 376, 1372-1373.
- Ross, C., Pantelyat, A., Kogan, J. & Brandt, J. (2014). Determinants of functional disability in Huntington's Disease: Role of cognitive and motor dysfunction. *Movement Disorders*, 29(11), 1351-1358.
- Rubin, R. (2005). Communication about sexual problems in male patients with multiple sclerosis. *Nursing Standard*, 19 (24), 33-37.
- Squires, N. (2006). Dysphagia management for progressive neurological conditions. *Nursing Standard*, 20 (29), 53-57.
- Skelton, J. (2005). Nursing role in the multidisciplinary management of motor neurone disease. *British journal of nursing*, 14(1) 20-24.
- Skirton, H. (2005). Huntington disease: A nursing perspective. *Medsurg Nursing*, 14(3), 167-173.
- Skirton, H., Williams, J. K., Jackson Barnette, J., & Paulsen, J. S. (2010). Huntington disease: families' experiences of healthcare services. *Journal of advanced nursing*, 66(3), 500-510.
- Sleeman, K., Ho, Y., Verne, J., Glickman, M., Silber, E., Gao, W. & Higginson, I. (2013). Place of death, and its relation with underlying cause of death, in Parkinson's disease, motor neurone disease, and multiple sclerosis: A population-based study. *Palliative Medicine*, 27(9), 840-846.
- Swann, J. (2005). Moving with a purpose in Parkinson's disease. *Nursing & Residential Care*, 7(7), 316-318.
- Swann, J. (2008). Multiple sclerosis part 3: Affects on daily life. *British Journal of Healthcare Assistants*, 2(6), 275-278.

- Swann, J. (2011). Assisting people diagnosed with motor neurone disease. *British Journal of Healthcare Assistants*, 5(4), 174-178.
- Talbot, K. (2009). Motor Neurone Disease: the bare essentials. *Practical Neurology*, 9, 303-309.
- Tan, S., Williams, A. & Kelly, D. (2013). Effectiveness of multidisciplinary interventions to improve the quality of life for people with Parkinson's disease: A systematic review. *International Journal of Nursing Studies*, 51, 166-174.
- Taylor, B. (2014). Sexuality, intimacy and motor neurone disease: matters of concern. *British Journal of Neuroscience nursing*, 10(5), 242-251.
- Veenhuizen, R., Kootstra, B., Vink, W., Posthumus, J., van Bekkum, P., Zijlstra, M., & Dokter, J. (2011). Coordinated multidisciplinary care for ambulatory Huntington's disease patients. Evaluation of 18 months of implementation. *Orphanet Journal of Rare Diseases*, 6(1), 1-6.
- Walker, F. (2007). Huntington Disease. *Lancet*, 369, 218-228.
- Walton, K. (2011). A practical approach to spasticity management in patients with multiple sclerosis. *British Journal of Neuroscience Nursing*, 7(4), 586-592.
- Ward, N. & Winters, S. (2003). Results of a fatigue management programme in multiple sclerosis. *British Journal of Nursing*, 12(18), 1075-1080.
- Ward-Abel, N. & Hall, J. (2007). Sexual dysfunction and multiple sclerosis: part 2. *British Journal of Neuroscience Nursing*, 8(2), 80-86.
- Wilkinson, H. & Nair, R. (2013). The psychological impact of the unpredictability of multiple sclerosis: a qualitative literature meta-synthesis. *British Journal of Neuroscience Nursing*, 9(4), 172-178.
- Williams, J., Skirton, H., Barnette, J., & Paulsen, J. (2012). Family carer personal concerns in Huntington disease. *Journal of advanced nursing*, 68(1), 137-146.
- Wilson, E., Elkan, R., Seymour, J. & Almack, K. (2008). A UK literature review of progressive long-term neurological conditions. *British Journal of Community Nursing*, 13(5), 206-212.
- Wilson, E., Aubeeluck, A. & Pollock, K. (2014). Applying a healthcare model to Huntington's disease: the key worker approach. *British Journal of Neuroscience Nursing*, 10(5), 214-218.
- Wilson, E., Pollock, K. & Aubeeluck, A. (2014). Providing care services to people affected by huntingons disease: An overview of the challenges. *British Journal of Neuroscience Nursing*, 10(3), 139-143.
- Woodward, S. (2013). Managing urinary incontinence in people with neurological disorders. Part 1: assessment. *British Journal of Neuroscience Nursing*, 9(1), 30-34.
- Woodward, S. (2013). Managing urinary incontinence in people with neurological disorders. Part 2: interventions. *British Journal of Neuroscience Nursing*, 9(2), 63-70.
- Woodward, S. (2014). Managing urinary incontinence in people with neurological disorders. *Nursing and Residential Care*, 16(6), 319-324.