

Bibliografia

- 1) Dubowitz V. *Muscle Disorders in Childhood*. London: Ed WB Saunders 1995.
- 2) Walton J, Rowland LP. *Clinical Examination, Differential Diagnosis and Classification*. In: NJ Walton, G Karpati, D Hilton-Jones (eds), *Disorders of Voluntary Muscle*. New York: Churchill Livingstone 1994; pp. 499-552.
- 3) Bertorini TE. *Overview and Classification of Neuromuscular Disorders*. In: TE Bertorini (ed.), *Clinical Evaluation and Diagnostic Tests for Neuromuscular Disorders*. Boston: Butterworth Heinemann 2002; pp. 1-13.
- 4) Turconi AC, Bianchi C, Boccardi S, Felisari G, Gussoni C, Lissoni A, Lodesani M, Pizzi A. *Linee guida per la riabilitazione delle malattie neuromuscolari infantili di origine genetica*. Commissione della Società Italiana di Medicina Fisica e Riabilitazione: MR Giornale Italiano di Medicina Fisica e Riabilitazione, 2003; 17(1):25-45.
- 5) Felisari G, Bianchi C. *Guida alla riabilitazione delle malattie neuromuscolari*. In F Cornelio, L Gallostei (eds): *La terapia delle malattie muscolari*. Padova: CLEUP 2002, pp. 167-203.
- 6) Bird TD, Follet C, Griep E. *Cognitive and personality function in myotonic muscular dystrophy*. *Neurol Neurosurg Psychiatry* 1983; 46:971-980.
- 7) Fitzpatrick C, Barry C, Garvey C. *Psychiatric disorders among boys with Duchenne muscular dystrophy*. *Dev Med Child Neurol* 1986; 28: 589-595.
- 8) Fitzpatrick C, Barry C. *Communication within families about Duchenne muscular dystrophy*. *Dev Med Child Neurol* 1986; 28:589-599.
- 9) Steyaert C, De Die-Smulders, Fryns JP. *Behavioral Phenotype in Childhood Type of Distrophia Myotonica*. *Am J Med Genetics* 2000; 96:888-889.
- 10) Berard C. *Objectifs et place de la rééducation dans la prise en charge globale de l'enfant atteint de maladie neuromusculaire*. *Med Phys* 2001; 44 supp 1: 242-247.
- 11) ATS/ERS Statement on respiratory muscle testing. *Am J Crit Care Med* 2002; 166:518-624.
- 12) Bach JR, Saporito LR. *Criteria for extubation and tracheotomy tube removal for patients with ventilatory failure. A different approach to weaning*. *Chest* 1996; 110:1566-71.
- 13) Bourke SC, Gibson GJ. *Sleep and breathing in neuromuscular disease*. *Eur Respir J* 2002; 19:1194-1201.
- 14) Phillips MF, Smith PEM, Carroll N, Edwards RHT, Calverly PMA. *Nocturnal oxygenation and prognosis in Duchenne Muscular Dystrophy*. *Am J Respir Crit Care Med* 1999; 160:198-202.
- 15) Perrin C, D'Ambrosi C, White A, Hill NS. *Sleep in restrictive and neuromuscular respiratory disorders*. *Semin Respir Crit Care* 2005; 26:117-130.
- 16) Ragette R, Mellies U, Schawake C, Voit T, Teschler H. *Patterns and predictors of sleep disordered breathing in primary myopathies*. *Thorax* 2002; 57:724-728.
- 17) Evans J, Shaw PJ. *Motor neurone disease: management of the condition*. *The Pharmaceutical Journal* 2001; 267:714-717.
- 18) Winkel LPF, Van den Hout JMP, Kamphoven JJJH, Disseldorp JAM, Remmerswaal M, Arts WFM, Loonen MCB, Vuloo AG, Van Doorn PA, De Jong G, Hop W, Smit GPA, Shapira SK, Boer MA, van Diggelen OP, Reuser AJJ, Van der Ploeg AT. *Enzyme Replacement Therapy in late-onset Pompe's disease: a three-year follow-up*. *Ann Neurol* 2004; 55:495-502.
- 19) Bensimon G, Lacomblez L, Meininger V. *A controlled trial of riluzole in amyotrophic lateral sclerosis*. ALS/Riluzole Study Group. *N Engl J Med* 1994; 330:585-591.
- 20) Bensimon G, Lacomblez L, Delumeau JC, Bejuit B, Truffinet P, Meininger V and for the Riluzole/ALS Study Group III. *A study of riluzole in the treatment of advanced stage or elderly patients with amyotrophic lateral sclerosis*. *J Neurol* 2002; 249:609-615.
- 21) Wagner ML, Landis BE. *Riluzole: a new agent for amyotrophic lateral sclerosis*. *Ann Pharmacother* 1997; 31:738-744.
- 22) Manzur AY, Kuntzer T, Pike M, Swan A. *Glucocorticoid corticosteroids for Duchenne muscular dystrophy*. Cochrane Database of Systematic Reviews 2004, Issue 2.
- 23) Simmons Z. *Management strategies for patients with amyotrophic lateral sclerosis from diagnosis through death*. *Neurologist* 2005; 11:257-270.
- 24) Hardiman O. *Symptomatic treatment of respiratory and nutritional failure in amyotrophic lateral sclerosis*. *J Neurol* 2000; 247:245-251.
- 25) Ashworth NL, Satkunam LE, Deforge D. *Treatment for spasticity in amyotrophic lateral sclerosis/motor neuron disease*. Cochrane Database Systematic Reviews 2006; (1): CD004156.
- 26) Forshaw DA, Bromberg MB. *A survey of clinicians' practice in the symptomatic treatment of ALS*. *Amyotroph Lateral Scler Other Motor Neuron Disord* 2003; 4:258-263.
- 27) Jost WH. *Botulinum toxin in multiple sclerosis*. *J Neurol* 2006; 253(suppl 1):I16-I20.
- 28) Yelnik AP, Colle FM, Bonan IV, Vicaut E. *Treatment of shoulder pain in spastic hemiplegia by reducing spasticity of the subscapular muscle: a randomized, double-blind, placebo-controlled study of botulinum toxin A*. *J Neurol Neurosurg Psychiatry* 2007; 78:845-8.
- 29) Newall AR, Orser R, Hunt M. *The control of oral secretions in bulbar ALS/MND*. *J Neurol Sci* 1996; 139(suppl):43-44.
- 30) Andersen PM, Gronberg H, Franzen L, Funegard U. *External radiation of the parotid glands significantly reduces drooling in patients with motor neurone disease with bulbar paresis*. *J Neurol Sci* 2001; 191:111-114.
- 31) Verma A, Steele J. *Botulinum toxin improves sialorrhea and quality of living in bulbar amyotrophic lateral sclerosis*. *Muscle Nerve* 2006; 34:235-237.
- 32) Nahas Z, Arlinghaus KA, Kotrla KJ, Clearman RR, George MS. *Rapid response of emotional incontinence to selective serotonin reuptake inhibitors*. *J Neuropsychiatry Clin Neurosci* 1998; 10:453-455.
- 33) Schiffer RB, Herndon RM, Rudick RA. *Treatment of pathologic laughing and weeping with amitriptyline*. *N Engl J Med* 1985; 312:1480-1482.
- 34) Brooks BR, Thisted RA, Appel SH, Bradley WG, Onley RK, Berg JE, Pope LE, Smith RA for the AVP-923 ALS Study Group. *Treatment of pseudobulbar affect in ALS with dextromethorphan/quinidine: a randomized trial*. *Neurology* 2004; 63:1364-1370.
- 35) Hillemacher T, Grassel E, Tigges S, Bleich S, Neundorfer B, Kurnhuber J, Hecht MJ. *Depression and bulbar involvement in amyotrophic lateral sclerosis*. *Amyotroph Lateral Scler Other Motor Neuron Disord* 2004; 5:245-249.
- 36) Chiò A, Gauthier A, Montuschi A, Calvo A, Di Vito N, Ghiglione P, Mutani R. *A cross sectional study on determinants of quality of life in ALS*. *J Neurol Neurosurg Psychiatry* 2004; 75:1597-1601.
- 37) Goldstein LH, Atkins L, Landau S, Brown RG, Leigh PN. *Longitudinal predictors of psychological distress and self-esteem in people with ALS*. *Neurology* 2006; 67:1652-1685.
- 38) Lou JS, Reeves A, Benice T, Sexton G. *Fatigue and depression are associated with poor quality of life in ALS*. *Neurology* 2003; 60:122-123.
- 39) Hill NS, Liesching T, Kwok H. *Indications for non invasive ventilation*. In: AS Slutsky, L Brochard Mechanical Ventilation eds. Update in intensive care medicine. Berlin: Springer 2004.
- 40) Shneerson JN, Simonds AK. *Noninvasive ventilation for chest wall and neuromuscular disorders*. *Eur Respir J* 2002; 20:480-487.
- 41) Annane D, Chevrolet JC, Chevret S, Raphaël JC. *Nocturnal mechanical ventilation for chronic hypoventilation in patients with neuromuscular and chest wall disorders (Review)*. The Cochrane Library 2007, Issue 1.
- 42) Vianello A, Bevilacqua M, Salvador V, Cardatoli C, Vincenti E. *Long-term nasal intermittent positive pressure ventilation in advanced Duchenne's muscular dystrophy*. *Chest* 1994; 105; 445-448.

Valutazione e trattamento delle malattie neuromuscolari e malattia del motoneurone in ambito pneumologico

- 43) Bourke SC, Tomlinson M, Williams TL, Bullock RE, Shaw PJ, Gibson GJ. *Effects of non-invasive ventilation on survival and quality of life in patients with amyotrophic lateral sclerosis: a randomised controlled trial.* Lancet Neurology 2006; 5(2):140-147.
- 44) ENMC (39th Workshop Report). *Respiratory insufficiency and ventilatory support.* Neuromusc Disord 1996; 6:431-435.
- 45) Schultz MJ, Veelo DP, Spronk PE. *Timing of tracheostomy in adult patients: conclusions may be premature (letter).* BMJ 2005; 331(7513):404.
- 46) ACCP Consensus conference: *Clinical indications for noninvasive positive pressure ventilation in chronic respiratory failure due to restrictive lung disease, COPD, and nocturnal hypoventilation - A consensus conference report.* Chest 1999; 116:521-534.
- 47) American Thoracic Society Documents. *Respiratory Care of the Patient with Duchenne Muscular Dystrophy. ATS Consensus Statement.* Am J Respir Crit Care Med 2004; 170:456-465.
- 48) Bach JR. *Conventional approaches to managing neuromuscular ventilatory failure.* In: JR Bach eds. Pulmonary Rehabilitation: the obstructive and restrictive-paralitic syndromes. Philadelphia: Henley &Belfus 1996.
- 49) Hill NS. *Ventilator management for neuromuscular disease.* Sem Respir Crit Care Med 2002; 23(3):293-305.
- 50) Navalesi P, Fanfulla F, Frigerio P, Gregoretti C, Nava S. *Physiologic evaluation of noninvasive mechanical ventilation delivered by three types of masks in patients with chronic hypercapnic respiratory failure.* Crit Care Med 2000; 28:1785-1790.
- 51) Schonhofer B, Sortor-Leger S. *Equipment needs for non invasive mechanical ventilation.* Eur Respir J 2002; 20:1029-1036.
- 52) Kacmarek RM, Hill NS. *Ventilators for noninvasive positive pressure ventilation: technical aspects.* Eur Respir Mon 2001; 16:76-102.
- 53) Bach JR. *Guide to the evaluation and management of neuromuscular disease.* Philadelphia: Hanley &Belfus Inc. 1999; pag. 80-87.
- 54) Recommandations: modalités pratiques de la ventilation noninvasive en pression positive, au long cours à domicile, dans les maladies neuromusculaires. Rev Mal Respir 2006, 23: 13S145-13S152.
- 55) Soudon P, Steens M, Toussaint M. *Disostruzione tracheobronchiale nei portatori di grave deficit restrittivo secondario a patologia neuromuscolare.* Rivista Italiana di Fisioterapia e Riabilitazione Respiratoria 2003; 1: 22-34 (parte I) 2003; 2:15-27 (parte II).
- 56) Bach JR. *Mechanical Insufflation-Exsufflation. Comparison of peak expiratory flows with manually assisted and unassisted coughing techniques.* Chest 1993; 104(5):1553-1562.
- 57) Vianello A, Corrado A, Arcaro G, Gallan F, Ori C, Minuzzo M, Bevilacqua M. *Mechanical Insufflation-Exsufflation Improves Outcomes for Neuromuscular Disease Patients with Respiratory Tract Infections.* Am J Phys Med Rehabil 2005; 84:83-88.
- 58) Miske L, Hickey E, Kolb S, Weiner D, Panitch H. *Use of the mechanical in-exsufflator in pediatric patients with neuromuscular disease and impaired cough.* Chest 2004; 125:1406-1412.
- 59) Sancho J. *Efficacy of mechanical insufflation-exsufflation in medically stable patients with amyotrophic lateral sclerosis.* Chest 2004; 125(4):1400-1405.
- 60) Conference de Consensus en Kinésithérapie Respiratoire, Lyon 1994.
- 61) Toussaint M, De Win H, Steens M, Soudon P. *Effect of intrapulmonary percussive ventilation on mucus clearance in Duchenne muscular dystrophy patients: a preliminary report.* Respir Care 2003; 48(10):940-7.
- 62) Higo R, Tayama N, Nito T. *Longitudinal analysis of progression of dysphagia in amyotrophic lateral sclerosis.* Auris Nasus Larynx 2004; 31:247-254.
- 63) Heffernan C, Jenkinson C, Holmes T, Feder G, Kupfer R, Leigh NP, McGowan S, Rio A, Sidhu P. *Nutritional management in MND/ALS patients: an evidence based review.* Amyotroph Lateral Scler Other Motor Neuron Disord 2004; 5:72-83.
- 64) Kasarskis EJ, Neville H. *Management of ALS: nutritional care.* Neurology 1996; 47:S118-120.
- 65) Mazzini L, Corra T, Zaccala M, Mora G, Del Piano M, Galante M. *Percutaneous endoscopic gastrostomy and enteral nutrition in amyotrophic lateral sclerosis.* J Neurol 1995; 242:695-8.
- 66) Kasarskis EJ, Scarlata D, Hill R, Fuller C, Stambler N, Ceterbaum J. *A retrospective study of PEG in patients during the bone and cone trials.* J Neurol Sci 1999; 169: 118-125 .
- 67) Desport JC, Preux PM, Truong TC, Vattat JM, Sautereau D, Couratier P. *Nutritional status is a prognostic factor for survival in ALS patients.* Neurology 1999; 53:1059-1063.
- 68) Shaw AS, Ampong MA, Rio A, Al-Chalabi A, Sellars ME, Ellis C, Shaw CE, Leigh NP, Sidhu PS. *Survival of patients with ALS following institution of enteral feeding is related to pre-procedure oximetry: a retrospective review of 98 patients in a single centre.* Amyotroph Lateral Scler 2006; 7:16-21.
- 69) Strong MJ, Rowe A, Rankin RN. *Percutaneous gastrojejunostomy in amyotrophic lateral sclerosis.* J Neurol Sci 1999; 169:128-132.
- 70) Mitsumoto H, Davidson M, Moore D, Gad N, Brandis M, Ringel S, Rosenfeld J, Shefner JN, Strong MJ, Sufit R, Anderson FA. *Percutaneous endoscopic gastrostomy (PEG) in patients with ALS and bulbar dysfunction.* Amyotroph Lateral Scler Other Motor Neuron Disord 2003; 4:177-185.
- 71) Hassett JM, Sunby C, Flint LM. *No elimination of aspiration pneumonia in neurologically disabled patients with feeding gastrostomy.* Surg Gynecol Obstet 1988; 167:383-388.
- 72) Cogen R, Weinryb J. *Aspiration pneumonia in nursing home patients fed via gastrostomy tubes.* Am J Gastroenterol 1989; 84:1509-1512.
- 73) Patel PH, Thomas E. *Risk factors for pneumonia after percutaneous endoscopic gastrostomy.* J Clin Gastroenterol 1990; 12:389-392.
- 74) Jarnagin WR, Duh Q, Mulvihill SJ, Ridge JA, Schrock TR, Way LW. *The efficacy and limitations of percutaneous endoscopic gastrostomy.* Arch Surg 1992; 127:261-264.
- 75) Kadakia SC, Sullivan HO, Starnes E. *Percutaneous endoscopic gastrostomy or jejunostomy and the incidence of aspiration in 79 patients.* Am J Surg 1992; 164:114-8.
- 76) Light VL, Slezak FA, Porter JA, Gerson LW, McCord G. *Predictive factors for early mortality after percutaneous endoscopic gastrostomy.* Gastrointest Endosc 1995; 42:330-5.
- 77) Shailesh LTC, Kadakia C, Sullivan HO, Starnes E. *PEG or jejunostomy and the incidence of aspiration in 79 patients.* Am J Surg 1992;164:115-118.
- 78) Hawthorne M, Gray R, Cottam C. *Conservative laryngectomy (an effective treatment for severe aspiration in motor neuron disease).* J Laryngol Otol 1987; 10:283-285.
- 79) Carter GT, Johnson ER, Bonekat HW, Lieberman JS. *Laryngeal diversion in the treatment of intractable aspiration in motor neuron disease.* Arch Phys Med Rehabil 1992; 73:680-2.
- 80) Gagie NM. *Cricopharyngeal myotomy.* Can J Surg 1983; 26:47-9.
- 81) Chatwin M, Ross E, Hart N, Nickol AH, Polkey MI, Simonds AK. *Cough augmentation with mechanical insufflation/exsufflation in patients with neuromuscular weakness.* Eur Respir J 2003; 21:502-508.
- 82) Bach JR, Ishikawa Y, Kim I. *Prevention of pulmonary morbidity for patients with Duchenne muscular Dystrophy.* Chest 1997; 112:1024-28.
- 83) Leger P, Paulus J. *Modalités pratiques de la ventilation non invasive en pression positive, au long cours dans les maladies neuromusculaires. Recommandations pour la pratique clinique.* Rev Mal Respir 2006; 23:13s 141-13s 143.
- 84) American Academy of Pediatrics Committee on Children with disabilities. *Guidelines for home care of infants, children, and adolescents with chronic disease.* An Pediatr (Barc) 1995; 96:161-164.
- 85) Chiò A, Bottacchi E, Buffa C, Mutani R, Mora G. *Positive effects of tertiary centres for amyotrophic lateral sclerosis on outcome and use of hospital facilities.* J Neurol Neurosurg Psychiatry 2006; 77:948-50.

- 86) ATS Documents. *Statement on Home care for patients with respiratory disorders*. Am J Respir Crit Care Med 2005; 171:1443-1464.
- 87) Pierson DJ. *Controversies in home respiratory care: conference summary*. Respiratory Care 1994; 39(4):294-308.
- 88) Davis J, Goldman M, Loh L, Casson M. *Diaphragm function and alveolar hypoventilation*. Q J Med 1976; 45:87-100.
- 89) De Troyer A, Borenstein S, Cordier R. *Analysis of lung volume restriction in patients with respiratory muscle weakness*. Thorax 1980; 35:603.
- 90) Laroche CM, Moxham J, Green M. *Respiratory muscle weakness and fatigue*. Q J Med 1989; 71:373-397.
- 91) Polkey MI, Green M, Moxham J. *Measurement of respiratory muscle strength*. Thorax 1995; 50:1131-1135.
- 92) Yanagihara N, Von Leden H, Werner-Kukuk E. *The physical parameters of cough: the larynx in a normal single cough*. Acta Otolaryngol 1966; 61:495-510.
- 93) Lechtzin N, Wiener CM, Shade DM, Clawson L, Diente GB. *Spirometry in the supine position improves the detection of diaphragmatic weakness in patients with amyotrophic lateral sclerosis*. Chest 2002; 121:436-442.
- 94) Perrin C, Unterborn JN, D'Ambrosio C, Hill NS. *Pulmonary complications of neuromuscular diseases and their management*. Muscle Nerve 2004; 29:5-27.
- 95) Bach JR, Rogers B, King A. *Non invasive respiratory muscle aids: intervention goals and mechanisms of action*. In: Management of patients with neuromuscular disease. Bach JR (ed). Hanley and Belfus, Philadelphia 2004, pp. 211-269.
- 96) Heritier F, Rahm F, Pasche P, Fitting JW. *Sniff nasal pressure: a non-invasive assessment of inspiratory muscle strength*. Am J Respir Crit Care Med 1994; 150:1678-1683.
- 97) Uldry C, Fitting JW. *Maximal values of sniff nasal inspiratory pressure in healthy subjects*. Thorax 1995; 50:371-375.
- 98) Chetta A, Harris ML, Lyall RA, Rafferty GF, Polkey MI, Olivieri D, Moxham J. *Whistle mouth pressure as test of expiratory muscle strength*. Eur Respir J 2001; 17:688-695.
- 99) Laroche CM, Mier AK, Moxham J, Green M. *The value of sniff oesophageal pressure in the assessment of global inspiratory muscle strength*. Am Rev Respir Dis 1988; 138:598-603.
- 100) Man WD, Kyrouissis D, Fleming TA, Chetta A, Harraf F, Mustafa N, Rafferty GF, Polkey MI, Moxham J. *Cough gastric pressure and maximum expiratory mouth pressure in humans*. Am J Respir Crit Care Med 2003; 168:714-717.
- 101) Mier A, Brophy C, Moxham J, Green M. *Phrenic nerve stimulation in normal subjects and in patients with diaphragmatic weakness*. Thorax 1987; 42:885-888.
- 102) Miller J, Moxham J, Green M. *Sniff as a test of diaphragm function*. Clin Sci 1985; 69:91-96.
- 103) Vitacca M, Scalvini S, Spanevello A, Balbi B. *Telemedicine and home care: controversies and opportunities*. Breathe 2006; 3(2): 149-158.
- 104) Wootton R, Dimmick SL, Kvedar JC. *Home telehealth: connecting care within the Community*. London: The Royal Society Medicine Press Ltd 2006.
- 105) Scalvini S, Vitacca M, Paletta L, Giordano A, Balbi B. *Telemedicine: a new frontier for effective healthcare services*. Monaldi Arch Chest Disease 2004; 61(4): 226-233.
- 106) Mair F, Whitten P. *Systematic review of studies of patients satisfaction with telemedicine*. BMJ 2000; 320:1517-1520.
- 107) Vitacca M, Pizzocaro P, Assoni G, Scalvini S, Glisenti F, Bianchi L, Barbano L, Giordano A, Balbi B. *A pilot study of nurse-led, home based telepneumology for patients with chronic respiratory insufficiency with mechanical ventilation assistance*. J Telemed Telecare 2006; 12(7): 337-342.
- 108) Vitacca M, Assoni G, Guerra A, Pizzocaro P, Marchina L, Baratti D, Martinelli G, Scalvini S, Balbi B. *Telesorveglianza durante un episodio di riacutizzazione di BPCO*. Rass Patol App Respir 2006; 21:46-54.
- 109) Vitacca M, Guerra A, Assoni G, Pizzocaro P, Marchina L, Scalvini S, Balbi B. *Weaning from mechanical ventilation followed at home with the aid of a telemedicine programme*. Telemedicine and e-Health Journal 2007; 13 (4):445-9.
- 110) Whitten SP, Mair SF, Haycox A, May RC, Williams TL, Hellmich S. *Systematic review of cost effectiveness studies on telemedicine interventions*. BMJ 2002; 324: 1434.
- 111) Vitacca M, Bianchi L, Guerra A, Barbano L, Porta R, Fiorenza D, Gilè S, Fracchia C, Spanevello A, Balbi B, Scalvini S. *Tele-assistance in Chronic Respiratory Failure Patients: a Randomised Clinical Trial*. Eur Respir J 2009; 33:411-418.
- 112) Vitacca M, Escarrabill J, Galavotti V, Vianello A, Prats E, Scala R, Peratoner A, Guffanti E, Maggi L, Barbano L, Balbi B. *Home mechanical ventilation patients: a retrospective survey to identify level of burden in real life*. Monaldi Arch Chest Dis 2007; 67(3):142-147.
- 113) Liv Merete Holm Frich RN. *Nursing interventions for patients with chronic conditions*. Journal of Advanced Nursing 2003; 44(2):137-153.
- 114) Kwok T, Ming Lum C, Shum Chan H, Ming Ma H, Lee D, Woo J. *A Randomized, Controlled Trial of an Intensive Community Nurse-Supported Discharge Program in Preventing Hospital Readmissions of Older Patients with Chronic Lung Disease*. J Am Geriatr Soc 2004; 52:1240-1246.
- 115) Shepperd S, Parkes J, McClaran J, Phillips C. *Discharge planning from hospital to home (Review)*. Cochrane Database of Systematic Reviews 2004, Issue 1.
- 116) Jardine E, Wallis C. *Core guidelines for the discharge home of the child on long term assisted ventilation in the United Kingdom*. Thorax 1998; 53:762-767.
- 117) AACR Clinical Practice Guideline. *Discharge Planning for the Respiratory Care Patient*. Respir Care 1995; 40(12):1308-1312.
- 118) Farrero E, Escarrabill J, Prats E, Maderal M, Manresa F. *Impact of a Hospital-Based Homecare Program on the Management of COPD Patients Receiving Long-term Oxygen Therapy*. Chest 2001; 119:364-369.
- 119) Hernandez C, Casas A, Escarrabill J, Alonso J, Puig-Junoy J, Farrero E, Vilagut G, Collivinent B, Rodriguez-Roisin R, Roca J, and partners of the CHRONIC project. *Home hospitalisation of exacerbated chronic obstructive pulmonary disease patients*. Eur Respir J 2003; 21:58-67.
- 120) Cotton MM, Bucknall CE, Dagg KD, Johnson MK, MacGregor G, Stewart C, Stevenson RD. *Early discharge for patients with exacerbations of chronic obstructive pulmonary disease: a randomised controlled trial*. Thorax 2000; 55:902-906.
- 121) Smith B, Appleton S, Adams R, Southcott A, Rufn R. *Home care by outreach nursing for chronic obstructive pulmonary disease (Review)*. Cochrane Database of Systematic Reviews 2001, Issue 3. 1-12.
- 122) Borohn RJ. *Distal myopathies and dystrophies*. Semin Neurol 1993; 13:247-255.
- 123) Baydure A, Layne E, Aral H, Krishnareddy N, Topacio R, Frederick G, Bodden W. *Long term non-invasive ventilation in the community for patients with muscular disorders: 46 years experience and review*. Thorax 2000; 55:4-11.
- 124) Report of a Consensus Conference of the American College of Chest Physicians. *Mechanical Ventilation Beyond the Intensive Care Unit*. Chest 1998; 113:289s-338s.
- 125) Gilmartin M. *Transition from the intensive care unit to home: patient selection and discharge planning*. Respir Care 1994; 39:456-480.
- 126) Weaver FM, Burdi M. *Developing a model of discharged planning based on the patient characteristics*. J Aging Health 1992; 4:440-452.
- 127) Prescott PA, Soeken KL, Griggs M. *Identification and referral of hospitalized patients in need of home health care*. Res Nurs Health 1995; 18:85-95.
- 128) Simonds AK. *Discharging the ventilator dependent patient*. Eur Respir Mon 2001; 16:137-146.
- 129) Sturani C. *Come prescrivere e monitorare la ventilazione meccanica domiciliare a lungo termine*. Rass Patol App Respir 1995; 10:757-767.
- 130) O'Donohue Jr WJ, Giovannoni RM, Goldberg AI, Keens TG, Make BJ, Plummer AL, Prentice WS. *Long-term mechanical ventilation: guidelines for management in the home and alternate community sites*. Chest 1986; 90(1):1s-37s.
- 131) American Thoracic Society. *Standards of nursing care for adult patients with pulmonary dysfunction*. Am Rev Respir Dis 1991; 144(1):231-236.
- 132) Haddock KS. *Collaborative discharge planning:nursing and social services*. Clin Nurse Spec 1994; 8(5):248-252.
- 133) Thompson CL, Richmond M. *Teaching home care for ventilator-dependent patients:the patients' perceptions*. Hert Lung 1990; 19(1):79-83.
- 134) Holroyd KA, Creer Tr. *In: Self- managment in chronic disease*. Orlando: Academic Press, 1986.

Valutazione e trattamento delle malattie neuromuscolari e malattia del motoneurone in ambito pneumologico

- 135) Srinivasan S. *Frequency, causes, and outcome of home ventilator failure*. Chest 1998; 114:1363-67.
- 136) Leger P. *Infrastructure, funding and follow-up in a program of non invasive ventilation*. Eur Respir J 2002; 20:1573-1578.
- 137) Doyle D, Hanks G, Cherny NI, Calman K. *Oxford Textbook of Palliative Medicine 3th edition*. Oxford University Press, Oxford 2004.
- 138) Santiago-Palma J, Payne R. *Palliative care and rehabilitation*. Cancer 2001; 92(4):1049-105.
- 139) United Kingdom back pain exercise and manipulation (UK BEAM) randomised trial: effectiveness of physical treatments for back pain in primary care. BML 2004; 329(7479):1377.
- 140) Mitsumoto H, Chad DA, Pioro EP. *Amyotrophic Lateral Sclerosis*. Philadelphia: F.A. Davis Co, 1998.
- 141) Chetney R, Waro K. A new home health approach to swallowing disorders. Home Healthcare Nurse 2004; 22(10):703-709.
- 142) Morris ME. *Outcomes of Physical Therapy, Speech Pathology, and Occupational Therapy for People with Motor Neuron Disease: A Systematic Review*. Neurorehabilitation and Neural Repair 2006; 20(3):424-434.
- 143) Trainini D, Saleri M, Paneroni M, Rongioletti C, Fiorenza D, Barbano L, Voltolini D, Berteni M, Chezzi Silva S, Assoni G, Marchina L, Bernocchi P, Scalvini S, Vitacca M. *Feasibility of telesurveillance and home cough assistance for amyotrophic lateral patients (ALS)*. TeleMed & eHealth 2007: Supporting Self care (London, 26-27 November 2007) SA 18 pp. 70-71.
- 144) Sinaki M, Mulder DW. *Rehabilitation techniques for patients with amyotrophic lateral sclerosis*. Mayo Clin Proc 1978; 53: 173-178.
- 145) Chan CW, Sinaki M. *Rehabilitation management of the amyotrophic lateral sclerosis patient*. In: Belsh JM, Schiffmann PL, eds. Amyotrophic lateral sclerosis: diagnosis and management for the clinician. New York: Futura 1996; pp. 315-331.
- 146) Ball LJ, Beukelman DR, Pattee GL. *Acceptance of augmentative and alternative communication technology by persons with amyotrophic lateral sclerosis*. AAC: Augment Altern Commun 2004; 20(2):113-122.
- 147) Tang P, Venables T. "Smart" homes and telecare for independent living. J Telemed Telecare 2000; 6:8-14.
- 148) Lynn J, Teno J, Phillips RS, Wu AW, Desbiens N, Harrold J, Claessens MT, Wenger N, Kreiling B, Connors AF. *Perceptions by family members of the dying experience of older and seriously ill patients*. Ann Intern Med 1997; 126:97-106.
- 149) Teno JM, Clarridge BR, Casey V, Welch LC, Wetle T, Shield R, Mor V. *Family perspectives on end-of-life care at the last place of care*. JAMA 2004; 291:88-93.
- 150) Lloyd-Owen SJ, Donaldson GC, Ambrosino N, Escarrabill J, Farre R, Fauroux B, Robert D, Schoenhofer B, Simonds AK, Wedzicha JA. *Patterns of home mechanical ventilation use in Europe: results from the Euro vent survey*. Eur Respir J 2005; 25:1025-31.
- 151) Vitacca M, Grassi M, Hill N, Barbano L, Galavotti V, Sturani C, Vianello A, Zanotti E, Ballerini L, Potena A, Scala R, Peratoner A, Ceriana P, Di Buono L, Clini E, Ambrosino A, Nava S. *Last 3 months of life in home ventilated patients: the family perception*. 2008 submitted.
- 152) Nava S, Sturani C, Hartl S, Magni G, Ciounti M, Corrado A, Simonds A. *ERS Task-Force. End-of-life decision-making in respiratory intermediate care units: a European survey*. Eur Respir J 2007; 30:156-164.
- 153) Levy M, Tanios MA, Nelson D, Short K, Senechia A, Vespia J, Hill NS. *Outcomes of patients with do-not-intubate orders treated with noninvasive ventilation*. Crit Care Med 2004; 32(10): 2002-2007.
- 154) Abernethy AP, Currow DC, Frith P, Fazekas BS, McHugh A, Bui C. *Randomised, double blind, placebo controlled crossover trial of sustained release morphine for the management of refractory dyspnoea*. BMJ 2003; 327(7414):523-8.
- 155) Fried TR, Bradley EH, Towle MP, Allore H. *Understanding the treatment preferences of seriously ill patients*. N Engl J Med 2002; 346:1061-1066.