

【論文】

END STAGE COPD (chronic obstructive pulmonary disease)

終末期にある慢性閉塞性肺疾患の患者のケア

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Key words: Palliative care, COPD, Quality of care the patient and family

This report is one of assignment from the International Institute of Palliative and Supportive Studies Distance Course in Palliative Care Nursing of Flinders University (Adelaide, AUSTRALIA). Palliative care promotes an interdisciplinary approach to care, yet each professional group has specific learning needs to enable them to provide the care required. This course has been designed to meet the needs of nurses who would like to incorporate the concepts of palliative care into their daily nursing practice. This course explores a range of issues in palliative care and specific nursing approaches and interventions. The emphasis is on quality of care the patient and family.

抄録：

2012年、オーストラリア・フリンダース大学にある緩和ケアに関するコース受講し修了した。そのコースのうち「終末期にある慢性閉塞性肺疾患(COPD)の患者のケア」について模擬事例に関する3つの課題に取り組んだ。その内容は①COPDの一般的に現れる病状や経過を説明する。②模擬事例であるMyer氏の呼吸困難に関して状態評価する。③呼吸困難の急性憎悪に対するケア、特に薬物を使用するケアと薬物を使用しないケアの両方についてそれらに関する理論と方法を考察する。以上の3つの課題について下記に述べる。

Case2:End Stage COPD

Mrs Norma Myers is a 79 year old lady. She has had three recent admissions to hospital for acute infective exacerbations of her chronic obstructive pulmonary disease. She has returned home to the care of her daughter on home oxygen. She sits up in a chair most of the day and also sleeps there. She still has severe episodes of breathlessness, mainly at night. Her daughter is at a loss about what to do. In particular she does not want to have to call an ambulance every time her mother experiences acute dyspnoea.

Question: 1. Describe the common illness trajectory for COPD

2. How would you assess Mrs Myer's breathlessness?
3. What strategies could you put in place to help with the acute episodes of breathlessness? Consider both pharmacological and non-pharmacological management strategies

Introduction

In this paper I will begin by describing the common illness trajectory for COPD and then, specific to a case study (Case2: End Stage COPD), will examine the methods for assessment of the patients breathlessness and recommend a series of management strategies to cope with the acute episodes suffered by the patient. (Jolanda,MH.*et al.*2008). Finally I will conclude with a general overview of the future requirements for providing better care including a brief look at education and the importance of collaboration (Chassens,MT.*et al.*2000,Elkington,H.*et al.*2004).

In this case, Mrs Norman Myers has chronic obstructive pulmonary disease (COPD) and she uses Home Oxygen Therapy (HOT) where she is cared for by her daughter. She has two main problems. Firstly, she has severe episodes of breathlessness, mainly at night. (Murray,SA.*et al.*2005, Viegi,G.*et al.*2007) This problem could be addressed in 2 ways; Assessment of the medical/pharmacological methods currently being used by the patient would need to be clarified and adjusted to best suit the patients' needs in a non-clinical environment, as would the non-pharmacological methods including the emotional condition of both patient and daughter (Elkington, H. *et al.*2004, Jones, I.*et al.*2004). Mrs Norman Myers is sitting in a chair for most of the day and she sleeps there. We would need

to examine her daily routine (Exercise, movement, position, diet and nutrition, etc). Certain antagonists such as house dust, air conditioning, positioning, nutrition, stress, etc, can compound the problem and these factors should be taken into consideration.

The other problem is that her daughter, who is acting as the primary caregiver, does not want call an ambulance every time her mother has an acute dyspnoea. She would appear to be somewhat uncomfortable with the idea but due to her lack of knowledge and understanding about the disease she has little option but to call an ambulance. Both she and her mother lack the skills required to manage the episodes without third party intervention, creating additional anxiety which in itself can further complicate the situation (Blyth, A. *et al.*1990). In order to provide the best quality of care, it is essential that we consider the patients' medical and emotional condition, the daughters' physical and emotional condition, the environmental factors and the ongoing professional support options that are available (Fordham, S. *et al.*1999, Addington-Hall, J. *et al.*1994).

The common illness trajectory for COPD

People who suffer from one or more of the main contributing phenotypes e.g. chronic bronchitis, asthma, emphysema are more likely to go on to develop COPD (Marsh, S.E. *et al.*2008). Cigarette smoking is the most important cause of COPD (Fletcher, C. *et al.*1977, Burrows, B. *et al.*1977). There is close relationship between the amounts of tobacco smoked and the rate of decline in forced expiratory flow per second (FEV1), although individuals vary greatly in susceptibility (Fletcher, C. *et al.*1977). Around half of all smokers develop some airflow limitation, and 15%-20% will develop clinically significant disabilities (Fletcher, C. *et al.*1977). In susceptible smokers cigarette smoking results in a steady decline in lung function (Fletcher, C. *et al.*1977), with a decrease in FEV1 of 25-100ml/year (Fletcher, C. *et al.*1977). This increases as the disease progresses may not be recognised because of the slow pace of the disease. As the disease progresses, breathing becomes more difficult. COPD develops slowly. Symptoms worsen over time and limit the patients' ability to carry out routine tasks regardless of the diseases aetiology.

End Stage COPD severely restricts movement and patients are prevented from performing even the most basic tasks such as walking, going to the bathroom,

taking care of personal hygiene, etc. There is currently no cure for COPD and doctors do not yet know how to reverse the damage to the airways. However, treatment and lifestyle changes can help the patient to feel better, manage the symptoms more effectively and slow the progress of the disease (Gore, J.M. *et al.*2000).

Assessment Mrs Myer's breathlessness

Breathlessness remains an enigma (Sara, B. *et al.*1986). It is a dominant symptom in the advanced stages of many disorders including cancer, cardio-respiratory and neurological disease Clinicians are often unable to control breathlessness effectively (Higginson, I. *et al.*1989) in contrast with malignant pain management where it is now possible to offer relief for most patients with oral pharmacological therapy alone even in advanced disease. COPD uses reduction of breathlessness as an outcome measure. Recommendations are made on the basis of the evidence available and expert opinion such as the Royal College of Physicians report on the use of domiciliary oxygen. Oxygen is to be tailored to the individual and a formal assessment made of its efficacy for reducing breathlessness and improving quality of life for that person (Sara, B. *et al.*2004). Spirometry is the most reproducible, standardised and objective way of measuring airflow limitation, and FEV1 is the variable most closely associated with prognosis (Peto *et al.*1983). The grades of severity to FEV1 and the likely symptoms and complication are shown in classification of severity of chronic obstructive pulmonary disease (COPD). However, it should be noted that patients with an FEV1 >80% predicted, although within the normal range, may have airflow limitation (FEV1 /FEC ratio <70%) (NHLB/WHO Workshop Report, 2001).

Mrs Norman Myers left the hospital and returned home under the care of her daughter but daily monitoring may not have been carried out. It is possible that neither she nor her daughter had the required information to be able to conduct basic daily monitoring. Also her daughter may not have been made aware of the professional support options available to her leaving her to understand that calling an ambulance was the only option. We need to educate both patient and daughter about COPD and easy methods for monitoring and controlling the acute episodes.

Mrs Norman Myers and her daughter need to be helped to understand a range of factors such as

monitoring of the patient's physical condition (e.g. breathing, sputum and cough, face, lip and nail colors, edema, blood pressure, body temperature, plus, SpO₂, nutrition, exercise or body stretching and moving, rest and sleeping condition, personal hygiene, oxygen therapy) and psychological condition (e.g. anxiety, depression, panic, nerves, pain, feelings all effect daily living and individual quality of life), environment factors (e.g. room temperature, humidity, sunshine, air flow, cleaning the living room and bed room), social support (e.g. relationship with her daughter, other family, friends, neighbors, volunteers, primary caregivers, specialist caregivers, medical workers, psychologists, social workers). Assessing all of these areas and understanding [for patient and daughter] the impact they have on COPD can lead to effective coping strategies and greatly improved QOL for both patient and daughter.

What does the COPD patient need? Quality of life is important. There is a balance of physical factors, psychological factors, the environment and social support. It is essential that health care professionals help both patient and daughter to improve overall motivation levels, confidence and optimism (The Australian Lung Foundation 2011).

Management strategies to help cope with the acute episodes

Mrs Norman Myers has acute episodes of breathlessness. Every day, all day she is sitting in her chair. They need help from health care professionals and should be given a greater understanding of COPD and the mother's daily condition, how to best take care of her at home. Breathlessness is a frightening symptom that is frequently associated with life-limiting illnesses. Refractory breathlessness refers to continuing dyspnoea even when the underlying reversible components of breathlessness have been optimally treated. Unlike many other symptoms, breathlessness tends to worsen as death approaches. Breathlessness has a significant impact on the patient with the life-limiting illness and her family and caregiver (David, C.2007, Allen, S.2005).

Pharmacological management would include her use of volume oxygen and medicines to help with the physical symptoms. Much research has shown that the use of Opioid's can be very effective, rating of breathlessness using the transitional dyspnoea index was significantly better compared with the end of the first week (approximately 5.3 points on a 19-point scale,

$P < 0.05$), also the dyspnoea subscale of the Chronic Respiratory Diseases Questionnaire improved (to 4.6 from a mean of 2.4 on a 0-10 scale, $P < 0.05$) in the month of observation treatment (Juan, G. *et al.* 2005).

The actual benefits of Benzodiazepines are, despite widespread use, still unclear. The role of benzodiazepines in helping to ameliorate refractory dyspnoea is poorly defined in the patient accessing supportive or palliative care (Juan, G. *et al.* 2005). Severe dyspnoea patients (average 7/10 on a Borg scale where 10 = worst possible dyspnoea) were taking regular 4 hourly midazolam with morphine breakthrough doses had the highest levels of unrelieved dyspnoea at 48h. Cognition, level of interaction and anxiety were not observed symptoms. The fact that regular benzodiazepine alone had the poorest levels of dyspnoea relief, lead researchers to the assumption that adding an anxiolytic may be of benefit. These were given in relatively large doses and the results are limited in their ability to be generalised widely into clinical practice (Navigante, A.H. *et al.* 2006).

The role of frusemide has continued to attract broad interest in respiratory medicine over the past two decades (Robuschi, M. *et al.* 1989). The distinction between changing the underlying pathophysiology of breathlessness and treating an established symptom is important (Nishino, T. *et al.* 2000).

Selective serotonin reuptake inhibitors (SSRI) may have some demonstrable benefit and would fit with the broader indications for this class of medications. There are two brief case studies of people with mild - severe COPD in the literature (Pepp, L.A. *et al.* 1995) (Smoller, J.W. *et al.* 1998), one with people who meet mood disorder or anxiety criteria, and another with a sub-cohort who do not meet such criteria when assessed by a psychiatrist. At a mechanistic level, serotonergic modulation of breathing and its sensation may be a target for such therapy. This may be modulated by CO₂ sensitivity. Although these are open-label case studies, both report people whom dyspnoea was reduced weeks to months after sertraline was started and other factors appeared stable.

Anxiety is an understandable component of breathlessness, in both the acute and chronic setting. Treating diagnosed anxiety appears to have a place in the care of people with refractory dyspnoea (Brenes, G.A. 2003), using agents such as buspirone and nortriptyline.

Cognitive-behavioural strategies are part of non-pharmacological methods including a range of therapies (e.g. meditation, biofeedback, relaxing), designed to change the patient's central perception of dyspnoea. If the symptom is relatively brief, acute distraction is more effective for alleviating distress and increasing tolerance than attention to the stressor. However, as in chronic illness, is beneficial when the individual may be more able to actively and successfully confront the situation (Suls, J. *et al.*1985).

Cognitive-behavioural strategies for helping patients cope with symptoms in advanced disease are based on the belief that there is an interaction between mind and body and more importantly those individuals can be taught new patterns of thinking, feeling and behaving to cope with symptoms. Cognition is the mental process, by which knowledge is acquired, manipulated, and changed and is made up of thoughts, knowledge and assigned meaning. Cognitive strategies are attempts to modify thought processes, including thinking, feeling, and knowledge in order to modulate an unpleasant symptom (Bandura, A.1982).

A major tenet of the cognitive-behavioural approach is that symptoms occur in a social context and that there is a reciprocal relationship between cognition, behaviours, and the environment. Behavioural strategies are defined as performance, activities or responses and are believed to change the person's environmental conditions. Both cognitive behavioural strategies provide mastery experiences, increase confidence in skills to control the symptom, and subsequently affect the magnitude of physiological responses to the symptom (Bandura, A. *et al.*1991).

Self-care strategies to managing dyspnoea reported by patients in selected studies include Physiological aspects such as breathing strategies, pursed-lip breathing, diaphragmatic breathing, drink fluids, nutrition, daily activities, body stretching or moving. Also, environmental/social aspects such as activity modification/energy, conservation, are moving slowly. Cognitive/behavioural aspects would include stress education e.g. meditation, prayer, music, relaxation, self-talk etc (Virginia, CK.2005). Acute episodes happen almost every night and her daughter just calls an ambulance,

Mrs Norman Myers and her daughter need to know how to reduce acute episodes, breathing difficulty, continuous observation and monitoring. It is useful to receive stress education and information from health

care professionals.

Biofeedback today, including e-Health, has seen great technological advances in monitoring body systems and is a rapidly growing area of research with findings translated into clinical practice (Gustafson, DH. *et al.*1999) (Gustafson, DH. *et al.*2001). Patients are monitoring physiological data, such as peak rates and heart rate, which are often rapidly transferred to the provider. It is therefore, conceivable that in future it will be much easier for patients to use their own respiratory pattern as feedback to change their breathing pattern, Over the paradoxical breathing, increase tidal volume, increase airway diameter, and decrease weaning time (Sitzman, J. *et al.*1987)(Holliday, JE. *et al.*1990).

Conclusion

Care of end stage COPD patients, in terms of education, management strategies, etc, has to consider individual differences. There are a variety of symptoms, breathlessness, weight loss, co-morbidities and burden of disease. The patient and family benefit from information given by other caregivers, specialists, social support, etc. The patient and family need optimal care and education (e.g. control of symptoms, structure and system of lungs, airway, effect of embalmment, medicine, rehabilitation of breathing, nutrition, oxygen therapy, mental and emotional control, social network, care of acute episode) and information. As they need to modify their lifestyle, methods designed to modify thinking and behaviors are required in order to improve the quality of their daily life. When the patient has an acute episode, they control their physical condition and psychological condition. They access social support, especially specialist caregivers or medical workers. We should work towards giving the patient and primary care giver a greater sense of control which will lead to reduced feelings of stress and anxiety or panic. It is important that there is collaboration with other specialist.

Mrs Norman Myers and her daughter need to cope with lifestyle limitations, patients appeared to adopt one of two strategies: to continue doing daily activities by modifying them, if possible to avoid activities altogether, instead of finding new ways to continue doing the activities they were used to. Conditions for asking for help (Jalanda, M. *et al.*,2008). Poor symptom control remains an important area. The low number of expressed needs may reflect patients' unwillingness to

appear ungrateful, but the variability of information needs to emphasize the importance of an individual approach to patients with an apparently homogenous disease (Jones, I. *et al.*, 2004).

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Reference

Introduction

Jolanda, M.H. Jeannette, P. Patrick, J.E. Bindels, Dick, L.W. 2008, 'The silence of patients with end-stage COPD: *British Journal of General Practice*, December, pp.884-849.

Chassens, M.T. Lynn, J. Zhong, Z. 2000, 'Dying with lung cancer or chronic obstructive pulmonary disease: insights from SUPPORT, Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments.' *Journal of Am Geriatr Soc*, vol.48 (5suppl), pp.146-153.

Elkington, H. White, R. Addington-Hall, J. 2004, 'The last year of life of COPD: a qualitative study of symptoms and services' *Respir Med*, vol.98, no.3, pp.439-445.

Murray, S.A. Kendall, M. Boyd, K. Sheikh, A. 2005, 'Illness trajectories and palliative care' *BMJ*, vol.330, no.798, pp.1007-1011.

Viegi, G., Pistelli, F. Sherrill, D.L. 2007, 'Definition, epidemiology and natural history of COPD' *Eur Respir J*, vol.30, no.5, pp.993-1013.

Jones, I. Kirby, A. Ormiston, R. 2004, 'The need of patients of obstructive pulmonary disease in the community' *Family Practice*, vol.21, pp.310-313.

Blyth, A. 1990, 'Audit of terminal care in a general practice' *Br Med J*, vol.300, pp.983-986.

Fordham, S. Dowrick, C. 1999, 'Is care of the dying improving? The contribution of specialist and non-specialists Palliative care' *Fam Pract*, vol.16, pp.573-579.

Addington-Hall, J. Fakhoury, W. McCarthy, M. 1998, 'Specialist Palliative care in nonmalignant disease', *Palliative Med*, vol.12, pp.417-427.

The common illness trajectory for COPD

Marsh, S.E. Travers, J. Watherall, M. 2008, 'Proportional classifications of COPD pulmonary', *Thorax*, vol.63, pp761-767.

Fletcher, C. Peto, R. 1977, 'The natural history of chronic airflow obstruction', *Br Med*, vol.1, pp.1645-1646.

Burrows, B. Knudson, R. Cline, M. Lebowitz, M. 1977, 'Quantitative relationship between cigarette smoking and ventilatory function', *American Rev Respir Dis*, vol.115, pp.195-205.

Gore, J.M. Brophy, C.J. Greenstone, M.A. 2000, 'How well do we care for patients with end stage chronic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and lung cancer', *Thorax*, vol.55, no.12, pp.1000-1006.

Assessment Mrs Myer's breathlessness

Sara, B. Heather, A. Maelie, S. Rosemary, W. Suzanne, K. Miriam, J. 1986, 'The enigma of breathlessness', *Lancet*, vol.1.1, no.8486, pp.891-892.

Higginson, I. McCarthy, M. 1989, 'measuring symptoms in terminal cancer: and pain and dyspnoea controlled?' *J R Soc Med*, vol.82, no.5, pp.264-267.

Sara, B. Heather, A. Maelie, S. Rosemary, W. Suzanne, K. Miriam, J. 2004, 'the use of oxygen in the palliation of breathlessness. A report of the expert working group of the scientific committee of the association of palliative medicine' *Respiratory Medicine*, vol.98, pp.66-77.

Peto, R. Speizer, F.E. Cochran, A.L. Moore, F. Fletcher, C.M. Tinker, C.M. Higging, I.T. Gray, R.G. Richards, S.M. Gilliland, J. Norman-Smith, B. 1983, 'The relevance in adults of air-flow obstruction, but not of mucus hypersecretion, to mortality from chronic lung disease, Results from 20 years of prospective observation.' *Am Rev Respir Dis*, vol.128, pp.491-500.

NHLB/WHO Workshop Report. April 2001, 'Global Initiative for Chronic Obstructive Pulmonary Disease (GOLD): Global strategy for the diagnosis, management

and prevention of chronic obstructive pulmonary disease.' Bethesda,MD. National Institutes of Health – National Heart, Lung and Blood Institute.

The Australian Lung Foundation 2011, *The COPD-X Plan Version 2.26*, viewed 18 January 2012, < <http://www.copdx.org.au/the-copd-guidelines>>

Management strategies to help cope with the acute episodes

(The pharmacological strategies)

Currow, PDAbernethy, A.2007,'Pharmacological management of Dyspnoea', *Current Opinion in Supportive and Palliative Care*, vol.1,pp.96-101.

Allen, S.Raut, S.Woollard, J.Vassallo, M.2005,'Low dose diamorphine reduces breathlessness without causing a fall in oxygen saturation in elderly patients with end-stage idiopathic pulmonary fibrosis', *Palliate Med*, vol.19, pp.128-130.

Juan,G. Ramon,M. Valia,JC.2005,'Palliative treatment of dyspnoea with epidural methadone in advanced emphysema',*Chest*,vol.39,pp.1088-1092.

Navigante, A H. Cerchiotti, L C. Castro,MA.2006,'Midazolam and adjunct therapy to morphine in the alleviation of severe dyspnoea perception in patients with advanced cancer' *J Pain Symptom Manage*,vol.31,pp.38-47.

Robuschi,M. Gambaro,G. Spagnotto,S. et al.1989,'Inhaled frusemide is highly effective in preventing ultrasonically nebulised water bronchoconstriction', *Pulm Phamacol*,vol.1,pp.187-191

Nishino,T.Ide,T.Sudo,T,Sato,J. 2000,'Inhaled frusemide greatly alleviates the sensation of experimentally induced dyspnea'*Am JRespir Crit Care Med*, vol.161,pp.1963-1967.

Pepp,LA.Weusss,JR.Greenberg,HE.1995,'Sertraline for chronic obstructive plumonary disease and comorbid anxiety and mood disorders'*Am J Psychiatry*,vol.152,pp.1531.

Smoller,JW.Pollack MH.Systrom D.Kradin RL. 1998,'Sertraline effects on dyspnea in patients with obstructive airways disease'*Psychosomatics*,

vol.39,pp.24-29.

Brenes, GA.2003,'Anxiety and chronic obstructive pulmonary disease: prevalence,impact and, treatment' *Psychosom Med*,vol.60,pp.216-220.

(The non-pharmacological strategies)

Suls,J.Flectcher,B. 1985,'The relative efficacy of avoidant and nonavoidant coping strategies: a meta-analysis' *Health Psychology*,vol.4, no.3,pp136-146.

Bandura, A.1982,'Self-efficacy for mechanism in human agency' *American Psychologist*, vol.37, no.2,pp.122-47.

Bandura, A.1997,'Self-efficacy: The Exercise of Control,' New York:WH. Freeman and Co.

Ripamonti,C. Fusco,F. 2002,'Respiratory problems in advanced cancer' *Supportive Care in Cancer*, vol.10,pp.204-216.

Carrieri-Kohlman, V.2005,'Non-pharmacological approaches' in *Dyspnoea in advances disease: A guide to clinical management* ,(eds.)Booth,S. Dudgeon, D.Oxford University Press, Oxford.

Gustafson,DH.Robinson,TN.Ansley,D.Adler,L. Brenman,PE. 1999'Consumers andevaluation of interactive health communication applications,The Science Panel onInteractive Communication and Health' *American Jurnal of Preventive Medicine*,vol.16,no.1,pp.23-29.

Gustafson,DH.Hawkins,R.Pingree,S.McTavish,F. Arora,NK.Mendenhall,J.2001,'Effect of computer support on younger women with breast cancer' *J Gen Intern Med t*,vol.16,no.7,pp.435-445.

Sitzman,J. Kamiya,J.Johnson,J.1987,'Biofeedback training for reduced respiratory rate in chronic obstructive disease: A preliminary study' *Nurs Research*, vol.32,pp.218-223.

Holliday,JE.Hyers,TM.1990, 'The reduction of weaning time from mechanical ventilation using tidal volume and relaxation biofrddback'*American Review of Respiratory Disease*,vol.141,no.5 pt 1,pp.1214-1220.

Booth,S.Anderson,H.Swannick,M.Wade,R.Kite,S.

Johnson,M.2004,'The use of oxygen in the palliation of breathlessness' *Respiratory Medicine*, vol.98, pp.66-71.

The Australian Lung Foundation 2011, *The COPD-X Plan Version 2.26*, viewed 18 January 2012,

< <http://www.copdx.org.au/the-copd-guidelines>>

The Australian Lung Foundation 2012, *The COPD-X Plan Version 2.30*, viewed 30 March 2012,

< <http://www.copdx.org.au/the-copd-guidelines>>

Conclusion

Jolanda, M.H. Jeannette, P., Patrick, J.E. Bindels, Dick, L.W. 2008,'The silence of patients with end-stage COPD:*British Journal of General Practice*, December, pp.884-849.

Jones, I. Kirby, A. Ormiston, P. Loomba, Y. Chan, K. Rout, J. Nagle, J. Wardman, L. Hamilton, S. 2004,'The need of patients of obstructive pulmonary disease in the community' *Family Practice*, vol.21, pp.310-313.