

Signs of End of life in COPD: the value of collaborative care

Chronic Obstructive Pulmonary Disease is the most common respiratory condition in the UK. In a survey by the British Lung Foundation (2019) statistics show that 1.2 million people live with the condition. The symptom burden in COPD has been described as greater than that of Lung Cancer although comparatively the quality and amount of care that patients with COPD receive compares poorly (Crawford 2010; Diaz-Lobato et al 2015; White et al 2011).

End of life care (EOL) is used to describe care for people whose condition is in the terminal phase of illness (Russell 2015; WHO 2017). Commencing EOL care early has been shown to be beneficial to those diagnosed with COPD (Higginson et al 2014). It is the heterogeneous nature of COPD which often makes it difficult to determine the stage a person has reached in the condition. Some people with COPD present with a gradual decline, others remain stable for years. Whilst a sub group presents with a volatile form of COPD which requires hospital admission or respiratory support of some kind (Almagro et al 2017). It is the lack of clarity in some cases which means that end of life care is often restricted to the latter stages of the condition by which time the condition may have become terminal. (Duenk et al 2016).

In order to implement EOL care requires a health care professional (HCP) to make forward planning with the patient in a conducive setting not a respiratory ward or urgent care centre where important issues may not be included within the conversation. To establish satisfactory dialogue includes the frequency and quality of what topics are raised, and what are important to the patient, recognising this as a two way process and there can be barriers to commencing this form of discussion. A patient may not want to talk about the deteriorating level of their condition which can present a dilemma for the HCP when to commence these discussions. However communication is but one component of holistic care management. COPD has a multi system impact and to provide appropriate and timely care can incur the services of a range of health care professionals, utilising their observational skills to recognise care needs in order to enhance a person's quality of life and address symptom changes. Multi disciplinary care was a target of the 2011 Department of Health COPD strategy. (DOH 2011; Taveres et al 2017). This is a complex subject as managing EOL care can be challenging especially when COPD is advanced, and this paper will explore some of the physical indicators of decline in a person with COPD..

Exacerbations

One of the indicators of the last year of life is considered to be characterised by a gradual dependence on others for activities of daily living that worsens with each COPD exacerbation. COPD is often unpredictable in nature and does not necessarily follow a specific course, differing from person to person (Gill et al 2010) The disease trajectory is characterised by a decline in function with acute respiratory exacerbations. The uncertainties of the nature and progression of COPD makes decisions for EOL challenging as these entry and re entry trajectories involve episodic, acute exacerbations, which may require re hospitalisation and can 'mask' the steady decline of a patient's condition (Choudhuri et al 2012). Some people deteriorate slowly over a period of years, others may remain stable whilst a sub type will have acute COPD exacerbations. It is the variability of the condition which acts as a hindrance for the health care professional to know when to initiate EOL care. This is coupled with a lack of prognostic tools specific to COPD that would guide a clinician when deciding on end of life care (Choudhuri et al 2012). The variability of COPD symptoms supports the concept of multi disciplinary working. In recognition that a range of HCP and subsequent services are required to identify and support symptom changes to provide the right care accordingly. Also to address the variability of the condition multi disciplinary working was included as one of the key concepts of the Department of Health COPD strategy in 2011.

The definition for a COPD exacerbation is a worsening of a person's condition from a stable state and beyond normal day to day variations to one that is acute in nature and that requires a change in medications (GOLD 2019; Wedzicha 2013) The characteristics of COPD is of progressive, generally irreversible airflow limitation, due to an inflammatory response within the lungs with increased incidence of exacerbations. (Wedzicha et al 2013). Exacerbations characterise the worsening of a person's condition and present with a range of respiratory symptoms which can include an increase in breathlessness,

mucous production and cough. Also other symptoms may be more general and include fatigue and loss of appetite, all of which have an effect on a person's quality of life, and in older people with COPD has a greater influence on their mortality.(Suissa et al 2012:Wedzicha et al 2007) The provision of care that reduces the rate of exacerbations has been shown to have a direct effect on improvement of quality of life. However, there is no set consensus to define an exacerbation. Also a patient may struggle to determine an imminent exacerbation therefore not all exacerbations are recognised by the patient or reported and are therefore untreated(Pavord 2016).

Exacerbation history and those in a person's recent past provide an indication whether end of life has been reached, these include clustering of exacerbations which are significant events in the patients overall prognosis: (Suissa 2012).. It is the severity of the exacerbation and need for hospitalisation which are considered signs that a person is entering the final phase of the condition and contribute to the assessment for end of life care (Hurst 2009:Wedzicha et al 2007). Research has identified in some patients a 60% probability of mortality the year after hospitalisation due to an exacerbation(Suissa et al 2012:Esteban et al 2018).

Depression and anxiety

symptoms such as depression and dyspnoea have been described as having an effect on the quality of life in those people with COPD. Anxiety and depression have been related to worse health outcomes and this was raised as another barrier with regard to initiating palliative care (Almagro et al 2017).

The current focus of COPD tends to be related more on the physical symptom management with often limited attention to the psychological symptoms of the condition despite the prevalence of psychological dysfunction (Yohannes et al 2014). Research has suggested that underdiagnosis and undertreatment of psychological disorders in COPD affects the overall quality of life of the person, and also are factors for readmission to hospital. As these untreated symptoms can have an influence on day to day living (Salerno et al 2011:Cully 2006). Also post traumatic stress was identified in a study by Jones et al (2009). With 8% of the sample used in the study showing symptoms. This was in people with COPD whose disease was stable, although the figure may be greater after an acute exacerbation and did not form part of the research. However, the psychological status of a person with COPD is not routinely measured although distress and fear are often reinforced by the reactions of others during an acute episode. Also the changeability of the condition can induce a constant state of hypervigilance to body changes and symptoms in the individual, and therefore induce greater stress (Almagro et al 2017).

Sarcopenia and COPD

The main symptom of COPD is characterised by breathlessness. The added work of breathing coupled with a chronic inflammatory condition has the effect of increasing the bodies metabolic rate and raising the resting expenditure when compared to a healthy person. Therefore nutritional support is an important aspect of palliative care in this group of people and poor nutritional status is considered common amongst those with COPD. (Sergei et al 2006).

Various studies have identified that weight loss and reduced skeletal muscle mass are strong predictors of mortality risk in COPD exacerbations. (Marquis et al 2002:Gronberg et al 2005:Sergei et al 2006). The reduction in body mass affects exercise tolerance and capacity, which can lead to a downward spiral of a person limiting their activities of daily living and in turn increasing the possibility of exacerbations(Franssen et al 2008)

COPD alone is considered a disease of accelerated ageing, whilst Sarcopenia and poor nutritional status adds to the complexity. The wasting effects of sarcopenia which involves the decline of lean and muscle mass is recognised as an age related condition and contributory factors which include physical inactivity, malnutrition and long term disease. These people often present with greater airflow obstruction, other symptoms include reduced quadriceps strength, loss of bone mineral density and exercise capacity as opposed to those people without sarcopenia. (Jones et al 2014). The issue of frailty due to the multi system dysfunction in the person with COPD which do not relate to age also makes the person with COPD more at risk of a range of conditions include falls, and higher risk of

infection (Gale et al 2017). Although various research has supported the issue that those people with the better prognosis had a lower incidence of sarcopenia as opposed to those with the worst prognosis (Jones et al 2014). Supporting the view that muscle dysfunction and low functional performance have been related to adverse outcomes in COPD (Rossi et al 2014; Schols et al 2005)

Cognitive dysfunction

The nature of COPD is associated with pulmonary and systemic inflammation, and brain function can be vulnerable to changes in pathology. A growing volume of evidence has demonstrated an association between cognitive impairment which has been identified as being more prevalent in the person with COPD, indicating lung dysfunction as a specific risk factor for poor cognition (Dodd 2015).

Various study's have researched cognitive impairment in those with COPD. Villeneuve demonstrated that 36% of those within a study sample presented with aspects of cognitive deficits. In comparison to 12% of individuals without COPD amongst the general population but with cognitive deficits (Villeneuve et al 2012;Dodd 2015). It has been suggested there may be a pattern of cognitive dysfunction caused by the effects of the condition coupled with the person in the older age range, factors that can severely impact on managing COPD (Dodd 2010).

Although the definitive reason for cognitive decline is not fully clear, the very nature of COPD may include co morbidities such as cardio vascular disease, and include hypertension which can affect cerebral circulation (Vanfleteren 2015). Also cognitive dysfunction can affect personality and psychological profile, altering a persons level of conscientiousness, and their ability to adhere to medication regimes. Poor medication adherence may be deliberate or accidental, due to forgetfulness or poor technique, but it has an association with executive dysfunction affecting a person's overall quality of life (Brown et al 2017). It is estimated that only 1 in 10 patients with a metered-dose inhaler perform all of the steps correctly. The changes caused by cognitive dysfunction are another factor affecting medication delivery, and therapeutic management of COPD (Chang et al 2012;Restrepo 2008: Lareau et al 2010). Also communication difficulties during respiratory assessments may affect the person's ability to perform instructions, causing inaccurate estimations of the disease staging and severity . Poor cognitive function affects a person's ability to plan and sequence, and is a contributory factor leading to increased rates of morbidity (Bourbeau et al 2008: Villeneuve et al 2012).

Conclusion

This paper has identified some of the physical indicators of end stage COPD although these can be variable. Those symptoms that have been mentioned require a specialised approach, and a range of skills that the individual HCP may not possess. COPD does not always follow a predictable course differing from person to person which can cause problems for an HCP in determining the staging of the condition in order to implement EOL care.(Gill et al 2010). There is also a lack of accurate prognostic tools in COPD which again adds to the difficulty of knowing when is the 'right time' to discuss EOL care(Taveres et al 2017). Multi disciplinary (MDT)working can assist when determining the condition stage that the patient has reached, in order to improve quality of life and end of life care.(2011:Duenck et al 2017).

However the provision of MDT services for COPD has been described as 'patchy' in the UK. This is despite the high prevalence and health care burden of the disease (Chew et al 2018) The Continuity of care that can be provided by MDT's can have a favourable influence on a person's respiratory health. This was noted in patients who received care from respiratory teams in acute care , with follow up in the community. (Esteban et al 2018.;DOH 2011).

Therefore the collective knowledge base and observational skills of an MDT can assist with care implementation with regard to EOL planning in recognition that not all patients want to discuss EOL. Also, some clinicians consider EOL conversations difficult to commence, regarding this as potentially destroying hope in a person(Reinke et al 2011). However, when discussion does occur there is evidence of real benefit for the patient which includes higher

health status and a higher quality of dying and death, in a life limiting condition (Reinke et al 2011:Taveres et al 2017).

Almagro P, Yun S, Sangil A, Rodriguez-Carballeria M, Marine M, Landete P, Soler-Cataluna J J, Soriano JB, Miravitlles M. (2017) Palliative care and prognosis in COPD: a systematic review with a validation cohort. *International Journal of COPD* 2017;12 1721-1729.

Brown J, Lansdall C, Wiggins J, Rowe J, Parker R. (2017) The Test your memory for MCI (TYM-MCI). *Journal neurology neuro surg Psychiatry*. BMJ pp 1045-1051.

Bourbeau J, Bartlett SJ. (2008) Patient adherence in COPD. *Thorax* 2008; 63: 831-838.

British Lung Foundation 2019 Chronic Obstructive pulmonary disease (COPD) statistics. *British Lung Foundation 2019*

Chang S, Chen MS, McAvay G, Tinetti M. (2012) Effect of Coexisting Chronic Obstructive Pulmonary Disease and Cognitive Impairment on Health Outcomes in Older Adults. *Journal of the American Geriatrics Society*. Vol 60, Issue 10.

Chew J, Mahadeva R (2018) The role of a Multi disciplinary severe chronic obstructive disease hyperinflation service in patient selection for lung volume reduction *Journal of Thoracic disease* Vol 10. Suppl 27.

Choudhuri A. (2012) Palliative Care for Patients with Chronic Obstructive Pulmonary Disease: Current Perspectives *Indian J Palliativ Care*. 2012 Jan-Apr; 18 (1): 6-11

Crawford A (2010) Respiratory Practitioners' experience of end-of life discussions in COPD. *Br J Nurs* 2010;19: 1164-1169.

Cully JA, Graham DP, Stanley MA, Ferguson CJ, Sharafkeneh A, Soucek J, Kunek ME (2006) Quality of Life in patients with COPD and comorbid anxiety or depression. *Psychosomatics* Vol 47, issue 4, July-August 2006. p 312-319

Department of Health (2011) Outcomes strategy for COPD and Asthma.

Diaz-Lobato s, Smyth D, Curtis JR, (2015) Improving palliative care for patients with COPD. *Eur Respir J* 2015; 46:596-598

Dodd J W, Getev S V, Jones P W. (2010) Cognitive function in COPD. *Eur Respir J*. 2010. 35:

Dodd J W, (2015) Lung disease as a determinant of cognitive decline and dementia. *Alzheimer Res Ther* 2015; 7: 32 .

Duenk RG, Heijdra Y, Verhagen SC, Dekhuizen RP, Vissers KC, Engels Y. (2014) PROLONG: a cluster controlled trial to examine identification of patients with COPD with poor prognosis and implementation of proactive palliative care. *BMC Palm Med*. 2014;14:54.

Esteban C, Castro Acosta A, Alvarez-Martinez C J, Capelastegui A, Lopez-Campos J L, Pozo Rodriguez F (2018) Predictors of one-year mortality after hospitalization for an exacerbation of COPD. *BMC Pulmonary Medicine* (2018) 18:18 DOI 10.1186/s12890-018-0574-z

Franssen FM, Sauerwein HP, Wouters EF, Schols AM. (2008) Whole-body resting and exercise-induced lipolysis in sarcopenic patients with COPD. *Eur Respir J* 2008. 32(6): 1466-71, *Erratum in Eur Respir J*. 2009.3314.947.

Gale N, Albarrati A, Munnery M, Hubbard R, Tal- Singer R, Cockroft J, Shale D (2017) Frailty: A global measure of the multisystem impact of COPD

Gill TM, Gahbauer EA, Han L, Allore HG (2010) Trajectories of disability in the last year of life. *N Engl J Med*. 2010;362(13):1173-1180.

Global Initiative for Obstructive Lung Disease (2019) GOLD

Gronberg A M, Slinde F, Engstrom CP, Hulthen L, Larsson S. (2005) Dietary problems in patients with severe chronic obstructive pulmonary disease. *J Hum Nutr Diet*, 2005;18:445-52

Higginson IJ, Bausewin C, Reilly CC et al (2014) An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised control trial. *Lancet Respir Med* 2014; 2 (12): 979-987

Salerno F, M Cerone (2011) Anxiety and depression in COPD *Multi discip Resp Med* 2011;6(40 212-213

Hurst JR, Donaldson Q C, Quint JK et al (2009) Temporal Clustering of exacerbations in chronic pulmonary disease. *Am J Respir Crit Care Med* 2009; 179:369-74

Jones R C, Harding S A, Chung M C et al (2009) The prevalence of post traumatic stress disorder in patients undergoing pulmonary rehabilitation and changes in PTSD symptoms following rehabilitation. *J Cardiopulm Rehabil Prev*: 2009;29: 49-56.

Jones S, Maddocks M, Kon S, Canavan J, Nolan C, Clark A, Polkey M, Man W. (2014) Sarcopenia in COPD: prevalence clinical correlates and response to pulmonary rehabilitation. *BMJ Journals* Vol 70, Issue 3.

Lareau S, Yawn B (2010) Improving adherence with inhaler therapy. *Int J Chronic Obstruct Pulmon Dis*. 2010;5; 540-406

Lynn J. (2001) Perspectives on care at the close of life. Serving patients who may die soon and their families: The role of hospices and other services. *JAMA*. 2001;285:925-32.

Marquis K, Debigare R, Lacasse Y, LeBlanc P, Jobin J, Carrier G et al. (2002) Mid thigh muscle cross-sectional area is a much better predictor of mortality than body mass index in patients with chronic obstructive pulmonary disease. *Am J Respir Crit Care Med* 2002;166:809-13

Wedzicha JA, Seemungal TA (2007) COPD exacerbations: defining their cause and prevention. *Lancet* 2007;370:786-96.

Pavord I, Jones P, Pierre-Regis B, Rabe K (2016) Exacerbations of COPD. *Int.J.Chron. Obstruct. Pulmon.Dis* (2016); 11 21-30.

Reinke LF, Slatore CG, Uman J et al (2011) Patient-Clinician Communication about End-of-Life Care topics: Is anyone talking to patients with Chronic Obstructive Pulmonary Disease? *J Palliat Med* 2011;14:923-928.

Restrepo R D, Alvarez M T, Wittnebel LD et al (2008) Medication adherence issues in patients treated for COPD. *Int J Chron Pulmon Dis* 2008; 3: 37-384.

Rossi AP, Gantin F, Miccioli, et al. (2014) Identifying sarcopenia in acute care setting patients. *J Am Med Dir Assoc* 2014; 15: 303 e&-12

Russell S (2015) Do definitions matter in palliative care? *International Journal of Palliative Nursing*. 21,4, 160-161.

Sergei G, Coin A, Marin S, Vianella A, Manzan A, Peruzzi S, Inelmen E, Busetto L, Moline S, Enzi G. (2006) Body composition and resting energy expenditure in elderly male patients with chronic obstructive pulmonary disease. *Respiratory Medicine* (2006) 100,1918-1924.

Schols AM, Broekhuizen R, Wellin- Scheepers CA et al. (2005) Body composition and mortality in chronic obstructive pulmonary disease. *Am J Clin Nutr* 2005: 82:53-9

Suissa S, Dell-Aniello S, Ernst P (2012) Long term patient history of Chronic obstructive pulmonary disease severe exacerbations and mortality. *Thorax* 67: (11) 957-63

Tavares N, Jarrett N, Hunt K et al (2017) Palliative and end-of-life care conversations in COPD: a systematic literature review. *ERJ Open Res* 2017; 3:00068-2016 [<http://doi.org/10.1183/23120541.00068-2016>]

Villeneuve S, Pepin V, Rahayel S. et al (2012) Mild cognitive impairment in moderate to severe COPD: a preliminary study. *Chest* 2012; 142: 1516-1523.

Vanfleteren L E. (2015) Does COPD stand for “Comorbidity with Pulmonary Disease”? *Eur Respir J* 2015; 45: 14-17.

Wedzicha JA, Brill SE, Allinson JP, Donaldson (2013) Mechanisms and impact of frequent exacerbator phenotype in chronic obstructive pulmonary disease. *BMC Med.* 2013;11:181.

White P, White S, Edmonds P, et al (2011) Palliative care or end of life care in advanced chronic pulmonary disease: a prospective community survey. *Br. J Gen Pract* 2011; 61: e 362-e370.

Yohannes A, Alexopoulos G (2012) Depression and Anxiety in patients with COPD. Vol 67:23(133) 345-349 *European Respiratory Review*

World Health Organisation (2017) Definition of Palliative Care www.int/cancer/palliative/definition/en/.