

Opinion Piece for Palliative and Respiratory Care Tweet Chat 6th January 2015:8pm

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There is a growing awareness of the palliative care, communication (Curtis et al 2001, 2002) and policy (Russell 2008) needs of other disease groups than cancer but little evidenced based recommendations on how to discuss dying, life expectancy and future symptoms for non-cancer palliative care patients (Parker et al 2006, Russell and Knowles 2009). There is a risk to consider a 'one size fits all' approach across all disease groups in end of life care despite the prevalent argument of the different types of physical, psychological, spiritual and social illness trajectories e.g. as described by Lynn and Adamson (2003), Murray et al (2005, 2007, 2008), Kendall et al (2009) and the increasing integration of supportive and palliative care from the point of diagnosis and uncertain curative intent goals (Lynn and Anderson 2003, Murray et al 2005, Hawley 2014).

Skilbeck and Payne (2005) suggest that contemporary palliative care in the UK falls into two client groups; cancer and non-cancer and palliative care has predominately focussed on those with cancer (Boland et al 2013, Gomez-Batiste et al 2014) despite towards the end of life most people acquire other serious progressive diseases such as cardiovascular or respiratory disease (Murray et al 2005, Chadwick et al 2011). In high income countries 75% of deaths are caused by chronic rather than cancer diagnosis (Gomez-Batiste et al 2014). Early palliative care interventions (including advance care planning) has been shown to benefit across all disease groups (Beernaert et al 2014) despite this there is evidence of unmet need in non-cancer care (Gadoud et al 2014, Addington Hall and Higgingson 2003, Claessens et al 2000, Russell and Knowles 2009).

Examining the literature suggests that attention should be paid to the individual's unique circumstances as seen in person and patient centred care (Russell 2012), the context of the disease experience itself (Gadoud et al 2014) and disease trajectories (Murray et al 2005). Examples from non cancer respiratory illustrate the value of understanding the multiple influences on palliative care not only from the patient/person centred perspective but also the context of the disease context and trajectory. They illustrate not only some of the palliative care commonalities (e.g. inequity with cancer palliative care, lack of disease specific research, patient desire to discuss end of life care, health care professional barriers to so do) but also the importance of recognising specific disease trajectory conversation triggers from pulmonary rehabilitation, dialysis, dementia diagnosis to implantable cardiac devices. Although there maybe commonalities in problem prevalence across different diagnostic groups (Moens et al 2014) attention to the individual context of the person, their illness experience and disease trajectory is important to facilitated person centred end of life care. One size does not necessarily fit all.

Chronic Obstructive Pulmonary Disease (COPD) is an incurable illness and the fourth leading cause of death world-wide (Pauwels et al 2001). Prognostication is challenging (Russell 2006) and patients with COPD frequently do not discuss end of life care with physicians (Knauff et al 2005). There are few studies concerning the quality of patient

– physician communication about end of life care specifically for patients with COPD (Curtis et al 2004). Individuals do not receive palliative care in the same way that cancer patients do, despite a similar disease burden (Addington Hall and Higginson 2006, Yohannes 2007). There is a lack of research (Edmonds et al 2001, Gott et al 2009) and little knowledge into the specific needs of end-stage COPD patients with advance care planning studies rarely focused on this patient group (Carmen et al 2014, MacPherson et al 2012, Houben et al 2014). Patients are willing to discuss end of life preferences (Carmen et al 2014) particularly when their COPD is stable (Heffner 1996, Gott et al 2009). COPD patients desire end of life discussions about decision making and the meaning of the disease for them (Russell and Russell 2007). A review of the differences between COPD, Cancer and HIV patients perspectives on end of life care provision identified specific needs from COPD patients of knowing more about the disease processes, treatments, prognosis and what dying might be like (Curtis et al 2004). Shah et al (2006) described difficulty in predicting when non cancer patients will die and fear of causing distress when raising such issues – but in discussion with 40 patients from a teaching hospital and hospice (20 with cancer, 20 with COPD, heart failure or renal disease) revealed patients did not object to questions about end of life care.

Barriers to end of life and advance care planning conversations include inadequate information provision about the likely course of COPD at diagnosis; lack of consensus regarding who should initiate advance care planning and in which setting; connotations of comparing with cancer; discussions conflicting with goals of chronic disease management, and a lack of understanding of the meaning of 'end of life' within the context of COPD (Gott et al 2009, Yohannes 2007, Chadwick and Russell 2012). Patients understanding of prognosis, end of life options (Goeman et al 2012, Seamark et al 2012) and possible medical interventions (Hajizadeh et al 2013) has also been identified as a narrower and often neglected (Seamark et al 2012) part of advance care planning in COPD as well as the logistics of multiple hospital admissions at the end of life and the gaps in discussion and information in the hospital to home transition (Seamark et al 2012). Further barriers have been identified as health care professional anxieties about lack of time, fear of taking away hope and assumptions that the patient is not ready to have such discussions (Knauff et al 2005, Houben et al 2014). There rarely is a clear transition point predicting the timing of the need for initiation of end-of-life care (Patel et al 2012). The challenge of prognostication (discussing how long to live, uncertainty, or identifying the final days or weeks of a patient's life) for patients with COPD is widely reported (Yohanes 2007, Russell and Russell 2007) and has been said to lead to '*prognostic paralysis where clinicians prevaricate when considering end of life issues*' (Murray 2005). We do know that advance care planning can improve outcomes for COPD patients and their relatives in terms of informing and preparing them about their diagnosis, treatment, prognosis, and what dying might be like (Jansen et al 2012). The COPD disease trajectory commonly has multiple admissions or exacerbations particularly in the last year of life (Murray et al 2005). The disease trajectory and experience of the illness means that COPD individuals, families and their health care professional carers potentially have a period of years for advance care planning conversations. These conversations include living with the disease, implications and consequences of treatments, prognosis and preferred place of death, advance decisions, resuscitation, and uncertainty of the timing of death, withholding and withdrawing treatments (e.g. intubations or mechanical ventilation), long term oxygen therapy, symptom control and maintaining base line respiratory function (Russell and Russell 2007).

So here is the challenge. Does one size fit all? What are the commonalities across 'palliative care' (whatever the diagnosis) and what are the unique characteristics to end of life from the individual perspective? As the end of life evidence develops in non-cancer respiratory disease we can see a pattern to other non-cancer experiences in health care professional barriers to it, unmet need and lack of research as well as the disease specific triggers for conversation such as context of disease trajectory (especially length with peaks and troughs), types of interventions and hospital admissions and the importance of incorporating advance care planning into the broader picture of pulmonary rehabilitation (Burge et al 2013, Hill et al 2013). How do we as people, clinicians, carers, researchers, educators, commissioners and policy makers design and implement a service that is both consistent and individualistic enough? How do we '*get around it*', '*live with it*' or '*get over it*' (Cherny 2009:1811).

Full references on request.