

## International Community Palliative Care Interventions for COPD Patients

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Chronic Obstructive Pulmonary Disease (COPD) is a serious long-term condition, in which the flow of air into the lungs is gradually reduced by inflammation of the air passages, and damage to the tissue in the lungs. COPD is a general term for a group of conditions, of which Chronic Bronchitis and Emphysema are most common. The disease is globally under-diagnosed, despite the fact that, for example in Hong Kong, it ranks 5<sup>th</sup> in the list of main causes of death<sup>1</sup>. This results in approximately 10% of all medical beds in public hospitals in Hong Kong being occupied by COPD patients (Yu et al., 2011).

The main cause of COPD is smoking. With an increasingly ageing population, of whom many have smoked for a considerable part of their lives, this means that a great number of people are at risk of developing COPD. The need for quality palliative care for COPD patients will become increasingly important.

In general, palliative care models for non-malignant lung diseases still seem to be sparse, and in their review on palliative care for non-malignant lung disease patients, Boland et al. (2013, p.814) conclude that “the optimal model(s) of service delivery remain unknown.” Despite this, different service models are described and proposed in the literature, all discussing several community intervention strategies for patients with COPD and (in a few cases) their family members. The interventions mainly focus on symptom burden and symptom management, as well as education and competence building, as these aspects prove useful in community palliative care services. We will describe some of these initiatives, as well as their implications, below.

### 1. SPACE for COPD<sup>2</sup>



<sup>1</sup> When not taking external causes of death into account, such as injuries or poisoning. Source: <http://www.chp.gov.hk/en/data/4/10/27/117.html>

<sup>2</sup> For further info, please see <http://www.spaceforcopd.co.uk/>



Image:<http://www.spaceforcopd.co.uk/>

SPACE, short for Self-management Programme of Activity, Coping and Education, is a novel online programme developed for people suffering from COPD, by University of Leicester Hospitals. The programme aims to support COPD patients in managing their disease. For example, it provides support for everyday tasks, seeks to minimize symptom burden, fosters health-enhancing behaviour change and improves emotional well-being of a patient with COPD. SPACE for COPD has been structured around a previously designed manual that was developed, tested and described in a pilot study conducted by Apps et al. (2013). Important outcomes of this pilot study were the positive effects of proper self-management on the increase in exercise tolerance, and improvement in dyspnoea. In a randomized control-trial conducted by Mitchell et al. (2014), the researchers conclude that SPACE for COPD, besides minimal professional healthcare support, showed clinical advantages in disease knowledge, exercise performance, symptom burden and anxiety. Some of these advantages were even maintained at 6 months. The authors discuss that COPD patients at an earlier stage, before exacerbation, may benefit more from the intervention compared to those patients post-exacerbation.

## 2. “INSPIRED”

‘INSPIRED’ (“Implementing a Novel and Supportive Program of Individualized care for patients and families living with REspiratory Disease”) is a Canadian evidence-based outreach program that provides hospital-to-home care through dedicated case management. Over a period of approximately four months, pro-active home care is managed and coordinated by a skilled respiratory specialist, and supported by a respirologist, other respiratory therapists, and a spiritual care practitioner who focusses on advance care planning issues. Rocker & Cook (2013) report that preliminary analysis of the initial cohort of INSPIRE participants shows that the program was associated with a 70% decrease in subsequent emergency room visits, hospital admissions and the length of hospital stay. Many of the patients were able to sustain this improvement for more than 6 months after they completed the program. Furthermore, post-INSPIRED interviews with 18 patients reveal that these patients felt “less anxious, more confident of their ability to manage their symptoms and more willing to discuss goals of care, including advance care planning (ACP)” (Rocker & Verna, 2014, p.E312

## 3. COPD-Home model

The last palliative care approach for patients with COPD that will be discussed is the COPD-Home model, an integrated care model developed in Norway (Sunde et al., 2014). This model is based on guidelines defined in the GOLD report <sup>3</sup>, and focuses on severe and very severe COPD

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<sup>3</sup> The GOLD report, Global Strategy for the Diagnosis, Management, and Prevention of COPD, emanates from the most current information and evidence related to COPD. According to their report, an effective COPD management plan should include 1) assessing and monitoring COPD, 2) reducing risk factors, such as smoking cessation 3)

patients that have been hospitalized for COPD exacerbation. The HOME-Model seeks to improve a patient's quality of life by supporting patient and/or home-care nurse in monitoring the disease, and reinforcing self-management strategies both during stable stages of COPD, and during exacerbations. Besides education and support for patients and nurses, the HOME-Model intervention also includes visits to the patients' home, a call center where the patient and nurse can phone in to talk about the condition, or to get back-up for medical interventions, and the intervention includes an individualized self-management plan.

The impact of an integrated care intervention in accordance with the HOME-Model was documented by Titova et al. (2015). The researchers focused on hospital utilization of COPD patients that were hospitalized for acute exacerbation, who received either integrated care after hospitalization, or usual care, during a two-year follow-up. While the researchers conclude that hospital utilization reduced for the patients receiving integrated care, they stress that the relatively small number of patients that were included in the study (after 2 years, 51 participants were left in the integrated care group, and 49 in the usual care group), who also suffered from a broad variety of co-morbidities and medical needs, may not make the results generalizable. Furthermore, the researchers noticed an inexplicable increase in mortality in the intervention group. Conclusively, the researchers emphasize the need for individually designed self-management programs, and determining carefully which COPD patients would benefit most from such programs.

To conclude, although the "optimal model of service delivery" for severe COPD patients may not exist yet as Boland et al. stated, interventions like the ones discussed above look hopeful and their outcomes offer useful insights for further development. While integrative care and self-management programs like these seem generally applicable and effective, we must not forget, however, that, as Titova et al. (2015) suggest, the COPD-patient is an individual, with individual needs. Strategies will likely be most successful when they combine widely-accepted 'best practices' with individually-tailored measures to help patients gain a sense of ownership over their treatment.

#### References:

Apps, L.D., Mitchell, K.E., Harrison, S.L., Sewell, L., Williams., J.E. et al. (2013). The Developments and Pilot Testing of the Self-management Programme of Acitivity, Coping and Education for Chronic Obstructive Pulmonary Disease (SPACE for COPD). *International Journal of COPD*, 8,317-327.

Boland, J., Martin, J., Wells, A.U., Ross, J.R. (2013). Palliative care for people with non-malignant lung disease: Summary of current evidence and future direction. *Palliative Medicine*, 27(9), 811-816

Kaplan, A. (2009). The COPD Action Plan. *Canadian Family Physician*, 55(1), 58-59.

Mitchell, K.E., Johnsons-Warrington, V., Apps, L.D., Bankart, J., Sewell, L. et al. (2014). A Self-management Programme for COPD: A Randomized Controlled Trial. *European Respiratory Journal*, 44, 1538-1547.

Rocker, G.M. & Cook, D. (2013). 'INSPIRED' Approaches to Better Care for Patients with Advanced COPD. *Clinical and Investigative Medicine*, 36(3), E114-E120.

Titova E, Steinshamn S, Indredavik B, Henriksen AH. (2015). Long Term Effects of an Integrated Care Intervention on Hospital Utilization in Patients with Severe COPD: a Single Centre Controlled Study. *Respiratory Research*, 16:8, DOI 10.1186/s12931-015-0170-1

Rocker, G.M. & Verma, J.Y. (2014). 'INSPIRED' COPD Outreach Program™: Doing the Right Things Right. *Clinical and Investigative Medicine*, 37(5), E311-E319.

Yu, W.C., Tai, E.L.B., Fu, S.N., Kwong, K.C., Yeung, Y.C. et al. (2011). Treatment of patients with chronic obstructive pulmonary disease as practiced in a defined Hong Kong community: a cross-sectional pilot survey, *Hong Kong Med J*, 306-314.