From reactive to proactive: implementing palliative care for patients with COPD

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Chapter 1

General introduction

COPD

Chronic Obstructive Pulmonary Disease (COPD) is a progressive disabling lung disease that affects millions of people worldwide.[1] It is mainly caused by tobacco smoking, but also non-smokers can develop COPD due to air pollution, occupational exposure, or genetic factors.[1] Patients with COPD experience many symptoms such as breathlessness and fatigue.[2] The disease course is typically characterized by a gradual decline with episodes of acute worsening of the disease – acute exacerbations – for which up to 20% of patients require at least one hospital admission per year for treatment.[3] The management of COPD is mainly disease-oriented and aims to preserve optimal lung function, decrease symptoms, and prevent recurrent exacerbations.[1] It includes smoking cessation, bronchodilators, pulmonary rehabilitation, and in advanced stages it may include oxygen therapy. In a very small number of patients non-invasive mechanical ventilation, surgery, or bronchoscopic interventions may be beneficial.[1] No curative treatment for COPD is available, except for lung transplantation for which there is an enormous donor shortage, and which is very costly.[4]

COPD and mortality

COPD is a life-threatening disease, with many patients dying prematurely from it. It is one of the top three causes of death worldwide.[5] In the Netherlands, it is the number five cause of death, with yearly more than 6000 people dying from COPD.[6] The mortality risk increases with the frequency of acute exacerbations and is higher than with heart attacks.[7, 8] Therefore the term 'lung attack' has been introduced to illustrate the severe consequences of acute exacerbations of COPD and to put emphasis on the urgent need for action for patients and healthcare providers.[9]

Symptom burden and quality of life

Patients with COPD have a high symptom burden leading to poor quality of life, similar or even higher than patients with incurable lung cancer.[10, 11] Comorbidities are frequently present, often related to the common pathways of smoke-induced diseases, and increase the symptom burden and physical limitations even further.[1] Breathlessness is the most prevalent symptom, but other debilitating symptoms such as fatigue, cough, pain, insomnia, anxiety and depression are often present.[12] Many patients have fear of becoming breathless or suffocating, resulting in avoidance of activities and physical deconditioning.[13] The physical limitations reduce participation in family and social life, resulting in feelings of social isolation[14, 15] and increasingly experiencing being 'a burden to family'.[16, 17] COPD is stigmatized in our society as people view it as a self-inflicted disease due to the patient's smoking history, leaving patients feeling ashamed or guilty, or thinking they do not deserve proper care.[18] Moreover, the prolonged disease course with decreasing functional status negatively affects their informal caregivers. Also, with increasing dependency, their relationship changes, which can be grieving for both patient and informal caregiver.[19] As COPD affects many aspects of quality of life and limits the life-expectancy, patients with advanced COPD may benefit from a palliative care approach.

Palliative care

Palliative care is 'care improving the quality of life of patients and their families, who are facing a life-threatening condition or frailty, through prevention and relief of suffering by means of early identification and careful assessment, and treatment of physical, psychological, social and spiritual problems. Over the course of the illness or frailty, palliative care aims to preserve autonomy, access to information and the opportunity to make choices.'[20] The phrase 'through prevention and relief of suffering' emphasizes the need for a proactive rather than a reactive attitude. Palliative care includes advance care planning (ACP). ACP is a continuous and dynamic process of discussing patient goals and preferences.[21] Doing so, care becomes aligned with the patient's wishes and preferences. It aims to improve the relationship with the patient, enable patients to prepare themselves for the end-of-life, and avoid overtreatment and unwanted hospital admissions, preventing patients from dying in an acute care setting.[22] Emerging evidence indicates that palliative care has a positive impact on enhancing the quality of life and reducing symptom burden for patients with life-limiting illnesses. Also, it has the potential to increase patient and informal caregiver satisfaction with care and reduce healthcare utilization.[23]

The publication of the Quality Framework Palliative Care in 2017 aimed to encourage implementation of palliative care in the Netherlands.[20] The framework describes the essential elements to deliver high-quality palliative care. In the Netherlands, palliative care is considered not a separate specialism, but all healthcare providers should include 'generalist' palliative care when caring for and treating palliative patients. Thus, a palliative care approach should be integrated into routine COPD care, starting early in the disease trajectory.[24, 25] Only in the case of complex needs, specialist palliative care should be involved.

Palliative care provision in COPD

Although guidelines recommend palliative care for patients with COPD,[26, 27] palliative care still is no daily practice for patients with COPD and their informal caregivers. Communication about palliative and end-of-life care topics is unlikely. A systematic review found that the proportion of patients with whom palliative and end-of-life care were discussed, varied between 0 and 56% across 17 studies, of which the majority found a proportion less than 30%.[28] In a study among Dutch pulmonologists and pulmonologists in training, participants reported to have discussed life-sustaining treatment preferences in 20% of their patients with GOLD stadium 3-4, and life expectancy 16%.[29] Also, patients with COPD are less likely to be referred to palliative care services than those with cancer. And when they are referred, it is mostly at the very end of life, with a median of 10 days before death in patients with COPD.[30] In 2011, a national guideline 'Palliative care for people with COPD' was developed by the Lung Alliance Netherlands (LAN).[31] However, a survey among Dutch pulmonologists in 2015 showed that the guideline was used by only half of the pulmonologists.[32]

Palliative care is hampered by several barriers related to the disease course, patients and their family, and healthcare providers. One of the main barriers is the unpredictable disease trajectory of COPD, making it difficult to determine when to start palliative care and discuss ACP.[28] Whereas cancer is directly associated with death ("how long do I still have, doctor?"), and often has a clear moment when life-prolonging treatment is not available anymore, most people are unaware that they could die of COPD.[33] Moreover, symptoms and limitations worsen gradually over the years, making patients to view them as a normal part of aging and struggle with accepting support.[34] Half of the patients with COPD have a low education level and low health literacy, limiting their understanding of their disease and prognosis.[35] Many healthcare providers avoid ACP conversations because of a lack of such communication skills, a fear to take away the patient's hope or increase feelings of anxiety, the assumption that palliative care is restricted to the terminal and dying phase, or time constraints. Furthermore, there is a lack of care continuity and collaboration between healthcare providers.[36]

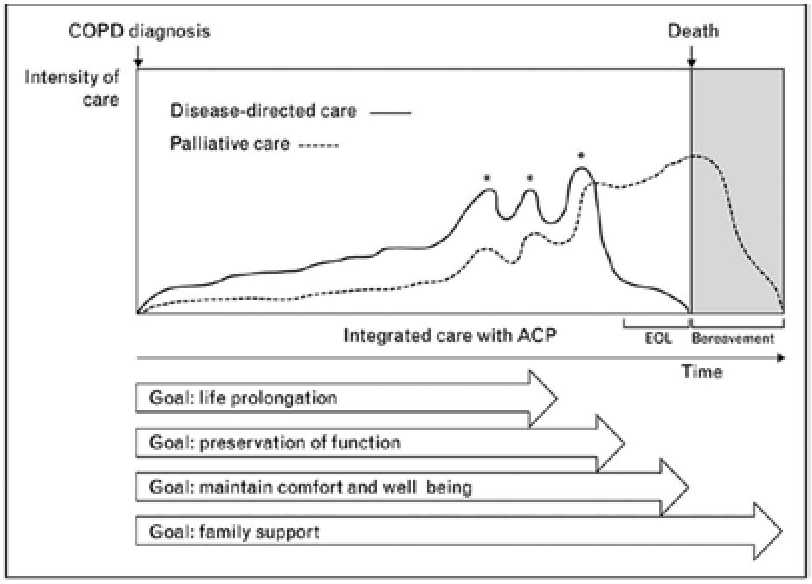

Figure 1. Care model of the integration of disease-oriented and palliative care, as proposed by Harrington et al. (2017)[24]

Although barriers and facilitators to palliative care provision have been studied, insufficient knowledge existed on how to overcome these barriers and successfully implement palliative care for patients with COPD. Researchers and policy makers have gradually become aware of the significant unrealized potential of effective interventions, due to the fact that they are not actively implemented after development.[37] In recent decades, implementation research has been a developing field. It entails the understanding of implementation barriers and facilitators and generates evidence for implementation strategies, how to translate knowledge into practice and improve healthcare.[38] Also, elements of both clinical effectiveness and implementation research can be combined using so-called 'effectiveness-implementation hybrid designs', to achieve more rapid translational gains and more effective implementation strategies.[39]

The COMPASSION project

To improve and implement palliative care provision in COPD, a national 4-year project was initiated by the Lung Alliance Netherlands, the Leiden University Medical Center, and Radboudumc in 2017, with financial support from The Netherlands Organization for Health Research and Development (ZonMw). The project was called COMPASSION, as it is an acronym for COPD Palliative and Supportive care Implementation and should be a central element in providing COPD-care.

In collaboration with representatives of relevant patient, family and professional organizations, we developed an integrated palliative COPD care intervention that integrates existing scientific and practical knowledge. From the immense enthusiasm with which healthcare providers collaborated in this project, it became clear that it was a topic with high potential for improvement. As identifying patients for palliative care was considered the most important aspect for improvement by pulmonologists,[32] an important first step was to determine to whom palliative care should be provided. Earlier research, focused on general practitioners, showed that identification of palliative patients with organ failure in general practice was not succesful.[40] Instead, hospital admission for an acute exacerbation of COPD appeared more feasible, as care is concentrated in this setting, allowing healthcare providers to make it a routine. Also, it is associated with increased mortality and it aligned the successful national transmural care pathway for patients hospitalized with an exacerbation of COPD.[41] The ProPal-COPD tool, combining the Surprise Question ("Would I be surprised if this patient were to die within the next 12 months?") with six clinical indicators was chosen as screening instrument. It had previously been developed by Duenk et al. and appeared a promising tool to identify patients in the palliative phase, with a high sensitivity to predict death within 12 months in an internal validation study.[42]

To enhance the adoption of the intervention by healthcare providers, a multifaceted implementation strategy was developed comprising a training, an online toolbox with information and practical tools, and support with planning and monitoring of implementation. As palliative care is not a standard part of medical training, doctors and nurses lack skills to communicate about palliative and end-of-life topics. Communication training using role play was found successful in previous research of Tilburgs et al,[43] and was also included in the COMPASSION training. Within a cluster randomized controlled trial, the strategy was tested in hospital regions spread over the Netherlands. Alongside the study and after the study had ended, we continued to develop the online toolbox into its current form. The training has been transformed into a blended learning program. Scan the QR-code to view the online toolbox or click the following link: https://palliatievezorgcopd.nl

Aims and outline of this thesis

This thesis aims to study how to improve and implement the provision of palliative care for patients with COPD and their informal caregivers. More specifically, the aim was to broaden the knowledge on the effectiveness and process of integrating palliative care into COPD care. To achieve this goal, several studies using different designs have been conducted. First, we explored current palliative care practice in COPD and available literature by addressing the following two research questions:

1. **To what degree is palliative care for patients with COPD currently implemented and formalized in primary and secondary care in the Netherlands?**

2. **Have palliative care interventions been developed for patients with COPD and what evidence is available on the effectiveness and implementation outcomes?**

Chapter 2 describes a national survey among pulmonologists and general practitioners to explore the current content and organization of palliative care for patients with COPD. **Chapter 3** provides an overview of the literature to date on palliative care interventions for patients with COPD. We assessed the characteristics of such interventions, reviewed the available evidence on effect outcomes, and identified barriers and facilitators to successful implementation.

Next, we performed a cluster randomized controlled trial – the COMPASSION study – in which the clinical effectiveness and implementation process of palliative care in COPD were studied using mixed-methods. The research questions were:

3. **What is the effect of the implementation of integrated palliative care on patient, informal caregiver and healthcare provider outcomes?**

4. **What is the effect of a multifaceted implementation strategy on implementation outcomes and what barriers hamper the implementation of integrated palliative care in routine COPD care?**

Chapter 4 describes the study protocol of the COMPASSION study in detail. In Chapter 5 and 6 the results of the COMPASSION study are presented. **Chapter 5** reports on the effects of the integrated palliative care intervention on quality of life and other patient outcomes. **Chapter 6** describes a comprehensive evaluation of the implementation strategy and process of implementing palliative care into regular COPD care.

Within the COMPASSION study, hospitalized patients were screened for palliative care needs using the ProPal-COPD tool. The trial data were used to address the last research question of this thesis:

5. **What is the accuracy of the ProPal-COPD tool in predicting 1-year mortality, and what are user experiences of healthcare providers?**

In **Chapter 7,** we externally validated the ProPal-COPD tool and we explored user experiences of healthcare providers.

In **Chapter 8**, the main research findings of the studies and their implications are discussed. Finally, recommendations for clinical practice, education, policy and future research are provided.

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