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

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Chapter 9

Summary

Chronic Obstructive Pulmonary Disease (COPD) is an incurable, progressive lung disease and is the third leading cause of death globally. Patients suffering from COPD experience debilitating symptoms such as breathlessness, fatigue, anxiety, and depression, resulting in a reduced quality of life. Patients with severe COPD may benefit from a palliative care approach to improve the quality of life and reduce symptom burden. However, palliative care is poorly implemented due to various reasons, including the disease's unpredictable trajectory, patient and family's limited understanding of COPD and palliative care, and healthcare providers' lack of communication skills or time constraints. Therefore, the COMPASSION project, initiated by the Lung Alliance Netherlands, Leiden University Medical Center, and Radboudumc, aimed to improve the implementation of palliative care provision for patients with COPD and their informal caregivers.

First, in **Chapter 2,** we explored the current level of palliative care provision for patients with COPD in the Netherlands. We developed a survey based on previous studies and national guidelines and invited pulmonologists and general practitioners to complete the survey between April and August 2019. Data were analyzed using descriptive statistics. Most physicians reported discussing palliative care topics with COPD patients, and opioid prescription for dyspnea was common. This appeared to have increased compared with numbers from previous research. However, the study also showed that palliative care for patients with COPD remained mainly unstructured, with only a minority of general practices or hospitals having formalized agreements or protocols. Often, discussions took place in an acute care setting. However, there was a positive trend towards improvement, with half of the pulmonologists and one-tenth of general practitioners intending to establish protocols in the future. The most critical barrier for palliative care discussions appeared to be difficulty predicting the disease course. Collaboration between healthcare providers was generally satisfactory, but information exchange between primary and secondary care was identified as an area for improvement. The study highlights the need for clear guidance on the timing of palliative care discussions, specialist palliative care referrals, and improved care continuity.

In **Chapter 3**, we searched the international literature to systematically review the evidence available on palliative care interventions in patients with COPD. Across seven databases, we screened for eligible studies published between January 1990 and June 2020. We identified 31 articles reporting on 20 palliative care interventions, varying from short-term interventions focused on breathlessness to longitudinal coordinated care models. Although qualitative results indicated that the acceptance was high among patients and informal caregivers (with 'having someone to call for support' and 'education about breathlessness' as the most valued characteristics), quantitative results on effectiveness were mixed and inconclusive. We concluded that little high-quality evidence was available since few interventions had been evaluated using a controlled study design. Also, adequate process evaluations using standardized methodologies were still lacking.

To fill this knowledge gap, we designed a hybrid type 2 effectiveness-implementation study in which the integration of palliative care into regular COPD care was studied, the COMPASSION trial. A hybrid type 2 design was chosen because it allows studying both the clinical effectiveness of an intervention and its implementation process simultaneously, with equal importance. In **Chapter 4**, the study protocol of the COMPASSION trial was comprehensively described. We developed an integrated palliative care intervention based on existing guidelines, a literature review, and input from patient and professional organizations. The intervention consisted of 1) identification of palliative patients with COPD admitted to the hospital for an acute exacerbation using the ProPal-COPD tool, 2) palliative care conversations comprising a multidimensional assessment, symptom management, and advance care planning, 3) coordination and continuity of care, and 4) aftercare for the informal caregiver when a patient died. An implementation strategy was developed to facilitate the uptake of the intervention: an online toolbox with practical information and existing tools, two interactive training sessions including roleplay for healthcare providers, a regional action plan, and implementation guidance during monitoring meetings. In the Netherlands, eight hospital regions (pulmonary care departments collaborating with affiliated general practitioners, home care organizations, and palliative care consultation teams) were recruited and randomized into the intervention group or control group. Healthcare providers of the four intervention regions received the implementation strategy, and healthcare providers of the four control regions continued to provide care as usual. Various clinical patient outcomes were measured using questionnaires and medical record data. Additionally, informal caregiver burden and healthcare professionals' self-efficacy to provide palliative care were measured by questionnaires. The implementation process was evaluated using mixed methods. The results of the COMPASSION trial are described in Chapters 5 and 6.

In **Chapter 5**, we examined the effects of palliative care on the clinical outcomes of patients with COPD. A cluster randomized controlled trial was performed across the eight hospital regions. Patients admitted to the hospital with an exacerbation of COPD and a positive ProPal-COPD score were included in the study between May 2019 and August 2020. Quality of life was the primary outcome measure and measured using the FACIT-Pal questionnaire, a 46-item questionnaire consisting of four subscales on physical, social/family, emotional, and functional well-being, and a fifth palliative care subscale. Secondary outcomes were spiritual well-being, anxiety and depression, the number of emergency department visits, the number of unplanned hospital admissions, the number of intensive care unit admissions, and the place of death. Questionnaires were administered at baseline and three and six months after inclusion. Medical record data were assessed twelve months after inclusion. Data were analyzed using generalized linear mixed modeling. In total, 222 patients were included. Quality of life and other secondary outcomes did not differ between patients of the intervention group and those of the control group. However, intensive care unit admissions were lower in the intervention group. Factors hampering the effectiveness evaluation included insufficient power due to the COVID-19 pandemic, not all patients of the intervention group receiving the intervention, and several patients not returning questionnaires.

In **Chapter 6**, the implementation strategy and process were comprehensively evaluated using process data, questionnaires, medical records, and interview data. The training including roleplay was positively evaluated and improved healthcare provider's self-efficacy in providing palliative care, measured by the End-Of-Life Professional Caregiver Survey (EPCS). Less than half of the 98 patients identified received one or more palliative care conversations at the outpatient clinic, on average six weeks after inclusion, and held mainly by the pulmonologist and COPD nurse together. The intervention was highly valued because it gave patients and relatives more peace and clarity and higher provider job satisfaction. The most important barriers to implementation were insufficient time for palliative care conversations, low priority to implementation due to the COVID-19 pandemic, and lack of a communication tool for transmural collaboration. Facilitators were systematic screening of patients, adapting to the patient's readiness, conducting palliative care conversations with a pulmonologist and COPD nurse, and meeting regularly with a small team led by a dedicated project leader. The study highlights the importance of communication training and setting up a small project team led by a dedicated implementation leader. Also, it emphasizes that future research is needed to optimize transmural collaboration and reach consensus on when to involve specialist palliative care.

As identification of the palliative phase was considered a main barrier to palliative care provision, the ProPal-COPD tool was previously developed by Duenk et al. to facilitate healthcare providers to identify palliative patients with COPD during hospital admission for an exacerbation of COPD. The prediction model was based on the Surprise Question and six clinical indicators: MRC dyspnea score, CCQ score, lung function, BMI, specific comorbidities, and previous hospitalizations. Death within one year was used as a proxy for palliative care needs and the tool seemed promising with a high sensitivity. In **Chapter** 7, the ProPal-COPD tool was externally validated and we assessed user experiences of healthcare providers using interview data. We showed that the tool did not predict 1-year mortality with high accuracy, but in the qualitative evaluation, we found that systematically screening patients using its indicators helped healthcare providers to become aware of the palliative phase and to timely initiate appropriate care in COPD patients with palliative care needs.

To conclude, in **Chapter 8**, the main research findings are summarized and critically discussed in light of the methodologies used and previous literature. The chapter also reflects on the implications of the results of this thesis on clinical practice and future research. First, methodological challenges must be considered when designing a hybrid effectiveness-implementation study. I recommend testing the feasibility and study procedures before the trial and providing a more extended implementation period before collecting clinical effectiveness data. Second, a specific outcome measure aligned with the goal and timing of the intervention should be chosen. Indeed, our qualitative data showed that palliative care leads to more clarity and peace of mind in patients with COPD, but the questionnaires did not capture this. It is questionable whether existing questionnaires are appropriate to assess the quality of life in patients with severe COPD and whether a broad outcome such as quality of life is an appropriate measure to assess palliative care intervention effects in this patient group at all. Third, this thesis contributes to the ongoing discussion of when palliative care should be initiated. Although a clear tipping point may not exist within the COPD trajectory, we found that systematic screening of patients is essential to overcome the healthcare provider's reluctance to discuss end-of-life topics. Fourth, I address the uncertainty of the roles and responsibilities of healthcare providers involved in caring for patients with severe COPD and the challenges to provide continuous care. Fifth, I discuss what is needed to successfully implement palliative care into COPD care. Achieving this requires behavior change in individual healthcare providers and organizational changes with appropriate financial structures. Finally, I conclude with recommendations for clinical practice, education, policy, and future research.