Palliative care needs of patients with advanced COPD: an exploration of illness experiences
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Summary

Chronic Obstructive Pulmonary Disease (COPD) is a chronic, potentially fatal progressive condition of the lungs. According to the World Health Organisation, COPD ranked fourth in leading causes of death globally in 2004 and is predicted to be the third leading cause of death globally in the year 2030. While it is recognised that COPD patients have a shorter life expectancy than their healthy counterparts, accurate prognosis for individual patients remains problematic due to the highly unpredictable disease trajectory of COPD at the end of life. Little is known about the problems and demands for care in patients with end-stage COPD. This makes the provision of high quality palliative care problematic. The central aim of this study was therefore to explore and better understand the problems, needs and preferences of patients with end-stage COPD.

In the general introduction, as described in chapter 1, a brief overview of background information is provided. It describes how palliative care has developed from an initial focus on cancer patients towards a holistic type of care which should be applied as early as possible in the course of any chronic, ultimately fatal illness, including COPD. An overview of three distinct illness trajectories at the end of life is also presented, as well as information about characteristics and epidemiology of COPD. The chapter ends with stating the research questions of the study: What is known about health care needs in end-stage COPD? What are specific areas where knowledge about needs is still lacking? How does the quality of life of end-stage COPD patients compare to that of end-stage lung cancer patients? How does the quality of life and functional status change over time in end-stage COPD patients? How do patients with end-stage COPD express their health care needs? To what extent can a better understanding of the end-stage in COPD be used to improve palliative care provision?

In chapter 2, a structured literature review is presented. Our aim was to provide an overview of relevant literature regarding health care needs in end-stage COPD and to identify specific areas where knowledge about needs was still lacking. In order to structure our results, we used Bradshaw's classification of social need. Bradshaw distinguishes four types of need that are all valid components of the concept of need: normative need, felt need, expressed need and comparative need. Seventy-seven publications were found and ten publications were included in the review. The reported results covered a wide range of
subjects, all regarded as health care needs. Most reported on ‘felt need’, i.e. needs that are mentioned by patients themselves. Results on ‘normative need’ (based on expert judgement) were lacking. We conclude that the literature about the health care needs of patients in the end-stage of COPD is sparse, and there is no commonly accepted definition of health care needs. Looking at the increasing demand for end-of-life care for COPD patients, there is a clear need for further research on this subject.

As a first step towards further knowledge on the subject, we examined the health-related quality of life (HRQOL) of end-stage COPD patients. To examine whether COPD patients experience similar or worse disease burden in comparison with non-small cell lung cancer patients, we compared HRQOL scores of severe COPD patients with those of advanced lung cancer patients. This is described in chapter 3. Eighty-two COPD patients and nineteen lung cancer patients completed generic and disease-specific HRQOL questionnaires. Besides comparing the HRQOL of these patients, we performed an individual patient data meta-analysis in which we used data provided by a landmark study published by Gore et al. in 2000. We also performed a sensitivity analysis using a subgroup of patients with a similar degree of “terminality,” namely those who had died within one year after study entry. Considerable differences in HRQOL between COPD and lung cancer patients were found for physical functioning, social functioning, mental health, general health perceptions, dyspnea, activities of daily living, and depression. All differences favored the lung cancer patients. The sensitivity analysis, using only terminal COPD and lung cancer patients, confirmed these findings. We conclude that end-stage COPD patients experience poor HRQOL comparable to or worse than that of advanced lung cancer patients. This is an indication that COPD patients have a similar need for palliative care.

These eighty-two COPD patients were asked to continue to complete HRQOL questionnaires (SGRQ and GARS) every three months, during one year. We set out to explore changes in HRQOL and functional status over time. These results are presented in chapter 4. Data were analysed by stratifying the study population in severity subgroups according to the lowest, intermediate and highest tertile of SGRQ and GARS at baseline. Mixed models using random intercepts and slopes were used to investigate the development of SGRQ and GARS over time. Survival was explored by using Kaplan-Meier curves and univariate Cox proportional hazards models. The course of HRQOL and functional status showed a gradual decline over time. The predicted one-year increase in
SGRQ and GARS scores (indicating deterioration in health status) was largest in the low severity subgroups. We conclude that patients in end-stage COPD have low HRQOL and functional status which deteriorates steadily over time. Even in patients who died during the study period, there is no sudden deterioration in health status visible. This means that clinicians do not gain much additional support on differentiating the end-stage of COPD by looking at HRQOL and functional status using the SGRQ and GARS; both widely used HRQOL and functional status measurements.

Chapter 5 presents results from sixteen interviews with eleven COPD patients; a subsample of the group of patients described in chapters 3 and 4. Patients were interviewed about their illness experiences. During the interviews, it became clear that patients were reluctant to express a wish for help, despite the severe problems they encountered in their daily lives. We wanted to gain further insight into this phenomenon. We found that in order to express a wish for help, patients should regard their limitations as abnormal and should realise that there are possibilities to improve their situation. However, this was not the case with the patients interviewed. They appeared to consider themselves ill at a time of acute exacerbation, but regarded their everyday life as normal. In addition, patients lived with the assumption that, as their lungs were damaged beyond repair, they could not get help. These results suggest that care in this stage should focus on improving daily life instead of just aiming to improve the functioning of the lungs. Professionals in health care should actively explore what kind of practical help these patients might welcome in keeping up their daily activities.

In order to provide health care professionals with more specific tools for improving the care for end-stage COPD patients, we focused more on the work that patients do in order to keep up their daily activities as much as possible. This is described in chapter 6. A primary inductive analysis of the interview material, focusing on situations in which patients did or did not succeed in keeping up their daily activities, lead to the metaphor of athletics which we used as our analytical framework. We found that living with end-stage COPD may be compared to athletes improving their achievements. First, prerequisites have to be met. Second, patients develop skills in technique, tactics and mentality in the same way athletes do. Likewise, health care professionals involved in caring for COPD patients may be compared to coaches. We therefore recommend a supportive coaching
approach in end-stage COPD. The position of the coach – right next to the patient – enables a tailor-made approach.

In chapter 7, the general discussion, a summary of the main findings is given. A reflection on these findings, as well as on research methodology, is provided. The chapter ends with recommendations for future research and implications for clinical practice. The main conclusions are that end-stage COPD patients experience a great symptom burden on physical, psychological and social areas. This deserves attention, especially because the end-stage in COPD may be as long as several years. A useful, new approach for health care providers to obtain an indication of the problems, needs and preferences of end-stage COPD patients may be to focus on daily activities. In obtaining information about daily life and daily activities, specific attention should be paid to patients’ experiences, knowledge and work. In order to implement palliative care approaches in daily practice in such a way, that the focus is on keeping patients as active as possible, but that – at the same time – the palliative vision is not lost, we suggest a coaching approach, similar to sport coaches in athletics. By implementing this coaching approach early in the disease trajectory, problems concerning the timing of the palliative phase and the prognosis of death become less relevant and patients learn proper skills early on in their illness trajectory so that loss of activity level and physical condition can be prevented as much as possible.