Palliative care needs of patients with advanced COPD: an exploration of illness experiences
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Chapter 7

*General discussion*
The central aim of this study was to explore and better understand the problems, needs and preferences of patients with end-stage COPD. To do so, the literature was searched systematically on publications about health care needs in end-stage COPD. Empirically, we obtained health-related quality of life data from end-stage COPD patients. A subgroup of these patients was interviewed about their illness experiences. Information resulting from these different methods of data collection was used to formulate recommendations for improving palliative care provision in end-stage COPD. In this final chapter, the main findings of the study are summarised. Also, reflections are given on the methods that were used in this study, and on the main findings that resulted from it. The chapter ends with recommendations for future research and implications for clinical practice.

**Main findings and reflections**

**Literature study**

When we searched the literature on health care needs in end-stage COPD, remarkably few publications were found. The publications that were included in the review, described in chapter 2, however did report considerable unmet care needs in end-stage COPD patients. These were mainly that patients perceive their quality of life as low and that they suffer from uncontrolled symptoms such as breathlessness and anxiety and depression. Further, it was reported that patients felt the need for more or better information regarding the nature and management of their illness, such as information about prognosis and timing of death. Unexpectedly, patients mostly reported that they were satisfied with the care they received. Another remarkable finding was that patients with end-stage COPD received little support from health or social services, especially when compared to lung cancer patients. From the literature, we identified a specific lack of knowledge about health care needs in end-stage COPD when looking for agreement between professionals or experts. This lack of knowledge was confirmed by specifically studying three important guidelines on the management of COPD. In these guidelines knowledge on needs in end-stage COPD was not presented, but a firm recommendation for further research on this aspect was considered a necessity in all three.

Fortunately, palliative care in COPD has become a higher priority area in many countries since the time of our initial literature search (2007). When we look at the three major guidelines we studied during our literature study, we can see that NICE is momentarily updating its guideline on COPD. To what extent this new update will pay specific attention
to health care needs in the end-stage of COPD is unclear. The Global Initiative for Chronic Obstructive Lung Disease (GOLD) has updated its COPD guideline in 2008. Although there is still no specific attention being paid to palliative care in COPD, it is emphasized throughout the document that the overall approach to managing stable COPD should be individualized to address symptoms and improve quality of life. In the Netherlands, the Dutch Institute for Healthcare Improvement (CBO) is currently working on a special issue of a COPD guideline that solely focuses on palliative care. Furthermore, the American Thoracic Society (ATS) has recently published an official statement on the palliative care for patients with respiratory diseases and critical illnesses (including COPD).

**Health-related quality of life**

In chapter 3, we studied health-related quality of life in patients with end-stage COPD patients, and compared these scores with scores of end-stage lung cancer patients. In comparing these two groups of patients, we based our study on the landmark study performed by Gore et al. We not only replicated this study to determine whether the same results would be found in the Netherlands, we also formally updated the evidence by using an individual patient data meta-analysis to integrate the new and existing evidence. Considerable differences in health-related quality of life between end-stage COPD and lung cancer patients were found for physical functioning, social functioning, mental health, general health perceptions, dyspnoea, activities of daily living, and depression. All differences were in favour of the lung cancer patients. This means that end-stage COPD patients experience poor health-related quality of life comparable to or worse than that of advanced lung cancer patients. They may therefore have at least a similar need for palliative care services, and possibly a greater need.

Other authors have previously compared these two patient groups with the motivation that the palliative care needs of lung cancer patients have been well documented whereas those of COPD patients have not. The underlying assumption in making this comparison is that lung cancer patients are, in a sense, comparable to COPD patients. This assumption is valid in three ways: COPD and lung cancer may be considered comparable in the sense that both illnesses are life-threatening conditions of the lungs, they are both among the commonest causes of death, and they are both related to smoking. There are however also differences between these two patient groups. First, the illness trajectory for COPD patients is different from that of lung cancer patients. Second, lung cancer
patients have traditionally been the recipients of specialised palliative care provision – unlike COPD patients. Comparing two groups of patients is a way to determine health care needs, following the classification of needs by Bradshaw\textsuperscript{10}. According to Bradshaw, when two groups of patients with similar characteristics are compared, and only one of those two groups is in receipt of a service, then the other group is considered to be in need. The results of our study and that of other authors comparing end-stage COPD and lung cancer patients show that COPD patients experience a symptom burden that is comparable to – or even worse than – that experienced by lung cancer patients. This may indicate that their need for palliative care is also similar to that of lung cancer patients. However, since the course of illness at the end of life is so different in COPD than it is in cancer, it is unlikely that specialised palliative care services that are developed for lung cancer patients are suitable for end-stage COPD patients, despite their similar symptom burden. The results from this comparison can however be used for equity purposes. Whenever end-stage COPD patients experience uncontrolled symptoms in the same magnitude as end-stage cancer patients do, this is an indication that the care for end-stage COPD patients is not optimal and should be re-examined carefully.

The COPD patients continued to fill in the health-related quality of life questionnaires every three months for a period of one year in total whenever possible. The results from this longitudinal study are described in chapter 4. When we look at the changes in quality of life and functional status over time, we can see that the scores continue to be very low, and even deteriorate slightly over time. This deterioration is mostly seen in the group of patients who entered the study with a more favourable health status. It is however expected that also the patients who already had a less favourable health status when entering the study experience a slight deterioration, even though this could not be measured accurately due to ceiling effects in the questionnaires.

It is already recognised that COPD patients follow a distinct illness trajectory at the end of life (Fig 1.c. from the general introduction). Our data confirm that also in the perspective of patients themselves, the last phase of COPD is long and indistinct. There is no indication (or at least not measurable with the present health-related quality of life questionnaires) of a particular sudden decrease in health-related quality of life towards the end of life, such as can be seen in the illness trajectory of cancer patients\textsuperscript{11}. This means that the end-stage in COPD is best described by a low but gradually declining health-related quality of
life in some, and in others a very low but fairly stable health-related quality of life during the last months of life. In many of these patients, death comes unannounced for both patients and health care professionals. This relates to the discussions about how to define the palliative phase or end-stage of COPD. Looking at our data about health-related quality of life, COPD patients may be considered to be in the end-stage of their illness for as long as they are in GOLD stage IV. Their perceived health-related quality of life in this stage (measured by SGRQ and GARS) does not provide clinicians with any additional tools in predicting mortality, nor in adjusting their course of treatment accordingly. Does this mean that end-stage COPD patients should have access to specialised palliative care services throughout this entire period? This question will be addressed in the paragraph about implications for clinical practice.

Illness experiences
During the interviews, patients were asked to tell about their life with COPD. The results from these interviews are presented in chapter 5. Patients spoke freely about the problems they encountered in conducting activities of daily life. However, despite the limitations they experience, patients were reluctant to express a wish for help. Patients regarded their limitations as normal part of their life, instead of something to seek help for. They only considered themselves ill at a time of acute exacerbation of their illness, but regarded their everyday life as normal. Also, patients did not realise that there were possibilities to improve their situation. They lived with the assumption that, as their lungs were damaged beyond repair, they could not get any help. Analysing patients’ experiences further led to the metaphor of athletics, as described in chapter 6. Living with end-stage COPD may be compared to athletes improving their achievements. In athletics, sports(wo)men are keen to improve their skills in order to reach some kind of achievement. For patients with end-stage COPD, the goal they are trying to achieve is mostly to maintain a certain level of daily activities. First, prerequisites have to be met by means of accessibility of public places and the availability of appropriate aids and appliances. When these prerequisites are met, patients develop skills in technique, tactics and mentality in the same way athletes do in order to improve their achievements. Patients are able to develop many of these skills by themselves. However, just like athletes will never win a gold medal without the support of a coach – despite their own talent and ambition – COPD patients in the end-stage will never be able to reach their own goals and set other goals for themselves without proper guidance and support. A coaching
approach would therefore be beneficial for end-stage COPD patients. This approach should be supportive in nature and tailor-made.

The image of the end-stage COPD patient that resulted from these interviews was a complex one: on the one hand, it was an image of a passive, disabled, dejected patient. This patient knew little about his or her illness or about possible treatments or aids and appliances that might be of help, and expressed little desire to actively improve his or her situation, mostly due to a total lack of perspective. We were able to analyse this passive attitude and to understand how it is possible for these severely ill patients to express so little wishes for help and improvement. This however was only part of the picture. On the other hand, it was an image of a patient busy with all sorts of activities to be able to get through a ‘normal’ day while balancing inevitable breathlessness and achievements. To do justice to this other picture of the end-stage COPD patient, we focussed our analysis on the work that patients do in order to live with their illness. This concept of ‘patient work’\textsuperscript{12} proved to be a valuable one to grasp the illness experience of these patients in terms of empowering characteristics such as creativity, perseverance and a positive attitude. This other part of the picture of end-stage COPD patients provided opportunities for improvement, like we have shown in chapter 6. Taking positive aspects in chronic illnesses such as empowerment and experiential knowledge as a starting point for improvement is also found in mental health, where the vision of recovery has gained importance over the last years\textsuperscript{13,14}. The process of recovery in mental illness refers to living life in a meaningful way despite limitations caused by the illness. This constitutes a hopeful outlook for patients, which end-stage COPD patients are lacking at the moment. That the experience of hope in severely ill patients is important, is also illustrated by a study assessing hope in patients with cystic fibrosis\textsuperscript{15}. This study shows that despite the fact that patients with the lowest FEV1 values reported the lowest level of hope, these patients still scored higher on ‘deep inner strength’ compared to the general population.

*Integrating findings from quantitative and qualitative research methods*

We used different methods of data collection to answer different research questions. But the findings originating from these distinct methods also complete each other. The health-related quality of life scores indicated that patients scored low on all domains studied (physical, psychological and social). During the interviews, these findings were confirmed by what patients told about their daily lives and the problems they encountered. These
problems were experienced in each of the three domains. From patients’ stories, it became clear that they saw no options for improvement of their situation. This was fostered by their own experiences (“compared to a year ago, things have gotten a little bit worse”) and by what they were told by their lung physician (“your lungs will never get any better”). This lack of perspective is supported by the longitudinal health-related quality of life scores. These describe a constant, slightly decreasing course over time. The interviews enabled us to get a deeper understanding of this lack of perspective (described in chapter 5) and to formulate recommendations for improving care (described in chapter 6) by closely relating to patients’ own experiences and perceptions. Another example of the integration of qualitative and quantitative methods is the qualitative validation of the SGRQ, as will be described below in the next paragraph about reflection on research methodology.

Reflection on research methodology
Several methods have been used to answer the research questions. The strengths and limitations of these methods have been discussed in the previous chapters. Yet, several aspects of the research process warrant some further reflection.

Definition of the end-stage in COPD
As stated in the general introduction, there is no widely accepted definition of the end-stage in COPD. Prognosis in individual patients is difficult and described to be inaccurate. The forced expiratory volume in one second (FEV\textsubscript{1}) is most often used as an indicator for disease severity and for predicting mortality. Therefore, we have used the GOLD classification based on FEV1 values in our study to define the end-stage. However, new insights have emerged since the onset of this study (2003). In 2004, Celli and colleagues have published the BODE index; a multidimensional grading system for COPD. The BODE index consists of four factors: body-mass index (B), the degree of airflow obstruction (O) and functional dyspnea (D), and exercise capacity (E). This multidimensional index captures the degree of pulmonary impairment (FEV1) as one of the domains, but also captures the patient’s perception of symptoms (dyspnea scale) and systemic consequences of COPD (distance walked in 6 minutes and body-mass index). The BODE index has been shown to predict mortality, exacerbations and health-related quality of life better than FEV1 alone. The BODE index may prove to be a useful tool for better predicting the end-stage in COPD in the future. If we would have had the
opportunity to work with the BODE index to select our patient population, it is possible that we would have selected an even more severe population than the one described in this thesis. However, in our study population, 23% of the patients died within the first year after completing the first questionnaire. It seems therefore that also this population based on FEV1 alone may be considered to contain very severe COPD patients.

**Health-related quality of life measurements**

The World Health Organisation (WHO) states that: ‘Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity’\(^{22}\). Following this definition, health status, or health-related quality of life, can be divided into three domains: physical, psychological and social. To assess health-related quality of life in this study, we included measurements for all three domains, using multiple validated generic and disease specific questionnaires. Both COPD and lung cancer patients completed the Short Form-36 Health Survey (SF-36)\(^{23}\). This generic tool, validated in a variety of conditions, contains questions on physical, psychological, and psychosocial domains. For disease-specific measurements, the COPD patients filled in the St George’s Respiratory Questionnaire (SGRQ)\(^{24}\). Although each of the questionnaires we used were validated and standardised, it is questionable whether these instruments were appropriate for our population of end-stage COPD patients. The SF-36 has been used intensively to study health-related quality of life in various populations, including end-stage COPD\(^{3,25}\). The SGRQ has been developed for assessing health-related quality of life specifically in COPD patients\(^ {26}\) and is now the most commonly used tool for this purpose. The developer of the SGRQ published a review in 2001 evaluating health-related quality of life measurements for COPD patients, including the SGRQ. In this review he states that the application of these instruments in the most severe patients remains an unresolved issue. The questionnaires were developed in patients who were largely not housebound, so indeed they may not be appropriate for patients with end-stage disease. To have an indication of the appropriateness of the SGRQ in end-stage COPD patients, a small sub study (n=6) was conducted in our cohort of severe COPD patients (data not published) in order to qualitatively validate the SGRQ in these patients. The think aloud method\(^ {27}\) was used for this purpose, which has previously been used in a similar study to qualitatively validate the Minnesota Living with Heart Failure Questionnaire\(^ {28}\). Using this method, information can be obtained about the interpretation of the questions by the respondents, and about their motivation for choosing a particular answer. There were
indications that patients’ answers were more extreme than the most extreme answer the questionnaire allowed them to choose from. For example, the SGRQ contains a question about the duration of a shortage of breath period. While most patients in our study experience shortage of breath all the time, the most extreme option patients could answer was ‘most days of the week’. Also, when asked about the duration of the worst attack (answering categories ‘a week or more’, 3 or more days’, 1 or 2 days’, ‘less than a day’), patients explained that they were breathless all the time, but that an attack of extreme breathlessness only lasted for a few minutes. These examples indicate that some questions and answering categories may need to be adjusted to better suit the experience of end-stage COPD patients.

**Generalisability**

This study was conducted in the Netherlands, in a limited number of patients. It is important to recognise the possibility of selection bias in recruiting our patient population. It is possible that patients with a very poor health status were more reluctant to participate in this study. However, we did manage to include patients who reported very low health-related quality of life and functional status scores. Another point of attention is the relatively small sample of this study, especially the qualitative part. However, the group of patients we selected for the qualitative part of our study was purposefully sampled to ensure a wide variety in patient characteristics, such a mix of male and female patients, patients living alone and living with their partner, and patients with and without long-term oxygen therapy. The sample of patients provided rich enough data to discover and analyse issues that are important for end-stage COPD patients, such as their reluctance to actively express a wish for help, and their efforts to maintain a certain level of daily activities. Most importantly, we have no reason to assume that the patients we included in our sample are in any way deviant from other end-stage COPD patients. There is a slight possibility though, that the situation in other countries concerning the care for these patients is different from that in the Netherlands, to the extent that these differences in care cause different outcomes. This is however not confirmed by looking at the international literature about illness experiences in end-stage COPD. Other studies also report a high symptom burden such as severe physical symptoms (mostly breathlessness), anxiety, depression and social isolation, similar to the results we found in our study.
Patient perspective
We focused on the patient’s perspective in order to study health care needs in end-stage COPD. We gathered data about health-related quality of life and we interviewed patients about their illness experiences. We thus focused solely on the patient, and not on the informal carers of the patients. This is a limitation in our research, since it is becoming more and more clear that informal carers of end-stage COPD patients (usually spouses) are also very much affected by the illness\textsuperscript{34}. This is confirmed by what some patients in our study said during the interviews: They were not the only ones who suffered from their illness, but it affected their loved ones as well.

Recommendations for future research
This study has answered the research questions we posed in the general introduction, but it has also raised some new questions. As mentioned in the reflection on research methodology, there is some doubt about the appropriateness of the health-related quality of life measurements we used in our study. Repeated measurements of the SGRQ in this patient population do not provide any prospective tools for individual patients to predict deteriorations in health status. Further research should be directed towards adjusting existing instruments for this specific group of patients. Qualitative research using in-depth interviews should be used to identify how patients perceive small deteriorations in health status. Progress in this area has already been made by the recent development of new HRQOL and ADL measures for use in this severe patient group, such as the LCADL\textsuperscript{35} and MRF-28\textsuperscript{36}. At the start of our study, there was insufficient information about these new questionnaires. Up until now, these questionnaires are not available in the Dutch language. Further research should be directed towards studying whether these – or other – new questionnaires would enable health care professionals to detect deteriorations in this group of patients in an earlier stage.

Another new research question that has risen during the course of our study is related to the recommendations for improving care provision as described in chapter 6. We recommend a coaching approach in the care for (end-stage) COPD patients. This recommendation is based on information gathered from interviews with patients. Further research should test our hypothesis that a coaching approach can improve health care provision for these patients.
As mentioned before, our study has focussed on the patient’s perspective. It would be interesting to direct further research towards different perspectives. We have already mentioned that our study lacks the perspective of informal carers. We would certainly recommend further research from this perspective. Also, research using the (professional) health care provider’s perspective would provide an interesting and important addition to the body of knowledge concerning the care for end-stage COPD.

Besides different perspectives, we would also recommend further research into different patient groups with a chronic, life-limiting illness such as heart and renal failure. Some results from our study will be specific for COPD (for example, the central role of breathlessness), but it is to be expected that much of the problems also play a role in other illnesses (for example, the problems associated with the lack of perspective). Otherwise, knowledge obtained from other disciplines may be applicable to the care for end-stage COPD patients. For example, the vision of recovery in mental health care contains characteristics that may be useful for improving COPD care, such as providing patients with a hopeful perspective on life.

**Implications for clinical practice**

The results from our study may be used to reconsider palliative care provision in end-stage COPD. Health-related quality of life scores revealed 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. We specifically asked patients to talk about their everyday life, in order to get an understanding of their problems, needs and preferences. This proved to be a successful method. Patients said that they did not talk about their problems in daily life with their treating physician. And, according to the patients, the physicians did not ask them about their daily life either. A focus on daily activities may therefore be a useful, new approach for health care providers to obtain an indication of the problems, needs and preferences of end-stage COPD patients. In obtaining information about daily life and daily activities, specific attention should be paid to patients’ experiences, knowledge and work.

**Implementation of palliative care approaches in (end-stage) COPD**

Our results suggest that patients spend a relatively long period of time in the end-stage of their illness, with minimal change in their overall health status. It is stated by the WHO
that the principles of palliative care should be applied as early as possible in the course of any chronic, ultimately fatal illness. This however is not yet routinely practiced. In practice, palliative care is mostly associated with terminal care at the end of life, despite the fact that the formal definition of palliative care states the opposite. Palliative care is also associated with stopping active treatment and preparing the patient for death. In this group of patients, staying as active as possible however is of key importance. Patients tend to (unconsciously) reduce their activities to reduce breathlessness. This reduction in physical activity leads to deconditioning, which further increases breathlessness. The challenge in caring for (end-stage) COPD patients is therefore to prevent them from becoming inactive. This may seem counterintuitive to what is generally considered to be palliative care, but is in fact another argument to start palliative care approaches as early as possible in the course of COPD. Discussions about how to define the end-stage in COPD will no longer be relevant when health care providers are focussed from the early onset of the illness in keeping patients as active as possible, and – at the same time – pay attention to psychosocial and spiritual needs. The statement on palliative care by the American Thoracic Society (ATS) also states that the concept of palliative care should be available to patients at all stages of illness and should be individualised based on the needs and preferences of the patient and the patients’ family. So, theoretically, it is clear how to implement palliative care approaches in COPD. The results from our study provide concrete tools on how 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 (described in detail in chapter 6). This coaching approach is a holistic, multidisciplinary type of care. The coaching approach is a way to implement palliative approaches early in the disease trajectory so that 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.
References


